# ASSESSING THE NEED FOR SPECIFIC SERVICES FOR HIV/AIDS AFFECTED PEOPLE USING PARTICIPATORY NEEDS ASSESSMENT PROCESSES

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#### Abstract

The purpose of the study undertaken is to develop knowledge to assist service providers in their planning and implementation of community -based programmes and projects. The thesis explores the most appropriate way of conducting a needs assessment, relating to HIV/AIDS services in a particular community; thereafter the needs assessment was carried out.

This qualitative research study is conducted using participatory methods and techniques. The research reviews literature pertaining to HIV/AIDS, specifically in Africa, South Africa and the Eastern Cape and incorporates a discussion on the concept of community, community development and poverty.

The design of the needs assessment tool, implementation and analysis is conducted through focus group discussions and individual semi-structured interviews.

The theory on participatory approaches and community development are central to this study. The study found that HIV/AIDS as an issue is not perceived by the community under study to be an immediate need in light of basic needs being identified as priority. The use of participatory methods in this study highlighted the diversity within communities. Service providers who wish to initiate community - based projects need to take note of diversity and personal interests of individuals or groups who become involved in community- based projects. The study further highlighted the need for service providers to provide training, to their staff in participatory approaches and techniques, before embarking on community development projects.

The study concludes that services relating to the HIV/AIDS epidemic cannot be carried out in isolation, but that an integrated approach is needed in the planning and implementation of services and programmes to address those affected by HIV/AIDS.

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# 1. CHAPTER ONE: INTRODUCTION

#### 1.1 PURPOSE OF RESEARCH:

In 2000 the South African National Council for Child & Family Welfare (SANCCFW) embarked on a HIV/AIDS pilot project in the Eastern Cape. The SANCCFW together with their affiliated societies set up project teams or community committees made up of a broad cross section of people. These committees were set up to mobilize communities around issues relating to children and HIV/AIDS (Halkett 2001:24). Emphasis was placed on community or home-based care and AIDS orphans. As a social worker working at a Child & Family Welfare Society I became involved in the pilot project in having to facilitate a community committee from the Kwa Langa settlement of Uitenhage, which had already been recruited by the SANCCFW to initiate a home-based care project. There had been limited community-based needs assessment undertaken at this time.

My experience in the welfare field has shown that service programmes are often initiated using a top-down approach. As Burkey(1993:134) has pointed out, those planning services must be willing to be influenced by the "group" understanding of reality, perceptions of the people themselves, their immediate needs and problems rather than preconceived theories and dogma. Those developing services and those doing research must follow where the people lead and allow the rate and direction of the expansion of services to be decided by the people rather than by an external agency's need to spend programme money (Burkey 1993:49). It is for all these reasons that I chose to use a participatory research process to determine how to appropriately develop services. The basic tool of participation is dialogue; an interchange and discussion of ideas based on a process of open and frank questioning, and analysis between researchers and people both individually and in small groups (Burkey 1993:62). This research study seeks to do a need assessment in a participatory manner.

The SANCCFW had identified the need for home-based care services as a priority service relating to the impact of HIV/AIDS within the specific community. As the assessment conducted was from a top-down approach, and lacked community participation in the identification of the need. I chose to conduct a research, to identify as to whether home-based care was a priority need in the community and to assess the need for services for HIV/AIDS affected persons, using a bottom-up approach. In order to determine that services that are rendered to the community are appropriate to the needs of the community

#### 1.2 RATIONALE FOR RESEARCH:

According to the literature on community development by (Hasenfled in Rothman, Elrich & Tropman 1995:431), no programme should be initiated unless it is propelled by the existence of a viable need that is defined by the community and for which appropriate interventions and strategies are determined by the community. Lack of clarity on needs and their dimension is likely to result in lack of community support for any new programme and thus result in a programme that may be ineffective and inefficient. Furthermore Kaul (in Rothman, Elrich & Tropman 1995:274) says that community based programmes should only be developed if the accomplished projects are truly community defined and community based. There are thus practical and ethical reasons for ensuring that community development planning and needs assessment are community based. In addition the dependence that is created when the state or donor organization takes full responsibility for initiating and designing services works against the sustainability of the service and can result in hostility if people perceive themselves to be passive subjects (Collins 1999:6; Rahman in Burkey 1993:118,135).

Community-based solutions for the care and support of HIV/AIDS affected persons and children are being promoted by the government in line with its broader strategy of developmental social welfare (Harber 1998:22). However, in my experience there is

little empirical evidence of what it meant by community-based care for HIV/AIDS persons and children in South Africa. It is my intention that this study will provide information on the most appropriate method of conducting a needs assessment in order to plan and develop services and programmes that are identified, initiated and supported by the service recipients. Mbambo(1999:9), argues that programmes are developed for communities without bothering to check whether they are culturally acceptable to the people or whether they enhance the capacities that people have. Programmes should make use of what already exists, what people are already committed to, instead of starting new initiatives that have no connection with what already exists. Furthermore Mbambo (1999:10) mentions three methods of implementing this. Firstly, recognizing that people of all ages; the youth and the elderly, are partners in creating safe communities. Secondly, to reassess community resources and assets. People have skills that they can share as well as beliefs, practices and strategies that they use to address issues that affect their lives. Thirdly, engaging people in a collaborative and meaningful way, forming real partnerships with them at neighborhood and local level to implement sustainable programmes.

#### 1.3 THE GOALS OF THE RESEARCH:

A needs assessment is a research and planning activity designed to determine human service needs and to provide data for the establishment of new programmes (Mark 1996:238).

It is my intention that the research undertaken will be able to answer the following:

- > To explore the most appropriate way of conducting a needs assessment related to HIV/AIDS services in the target community under study.
- > To design a needs assessment tool which could be implemented in the community.
- > To use the analyzed data to describe a process of implementing a sustainable service.

The goals and title link in that, the data obtained by applying the first two goals describes the participatory process used and the needs assessment tool and implementation thereof. The third goal refers to the data obtained from the needs assessment conducted and the describes the findings and relevance for service rendering.

#### 1.4 RESEARCH METHODOLOGY:

# 1.4.1 Research Design:

The research was conducted with participants from a semi-formal community within the Magisterial district of Uitenhage. The research was conducted using focus groups consisting of community members. The focus group members were already known to the researcher and an initial meeting was held with the group where an open discussion took place concerning the purpose of the research and the role of the researcher and community members, as well as the issue of HIV/AIDS. The purpose of such a meeting is to introduce the research idea to the community members and to receive their acceptance of the research idea in order to proceed.

The first phase; determining how best to carry out a needs assessment in the target community, the research was conducted using the qualitative research method of focus group discussions. The focus group members were selected through a purposive, non- probability sampling strategy. The focus group members were selected for their interest in and knowledge of the topic under study.

In order to ensure that they had the necessary knowledge to decide on an appropriate tool for the needs assessment, an initial meeting was held with the focus group to workshop the different types of assessment tools and the method of application. Five focus group sessions were held. The focus group discussions were conducted as an open conversation and notes were taken as method of recording (Marlow 1998:204).

Focus groups are necessary in that they serve to strengthen communication networks in the community and facilitate the research process (Marti-Costa & Serrano Gracia in Rothman, Erlich & Tropman 1995:261).

The objective of the first five focus group discussions was to explore the community members' perceptions of the issue of AIDS and to determine the most appropriate method of conducting a needs assessment within the target community. As stated by De Vos(1998:5), participants in focus group interviews need not reach consensus, instead emphasis is placed on finding out as much as possible about the participants' experiences and feelings about a specific aspect of social reality, such as an issue or service.

The focus group interview enables the researcher to develop inductively from the bottom up rather than from the top down (De Vos 1998:4), thus the focus group discussions is an appropriate method of conducting participatory research.

The focus group participants identified that the needs assessment tool and method of implementation should be interviews with further focus groups of key informants.

A further two focus group discussions were held with purposively selected community members. Van Rooyen (in Gray 1998:44) refers to the implementation phase, which comprises of a host of context- and problem- specific activities decided upon by the community in collaboration with the researcher. As there is a range of data collection techniques from which to choose, this selection will determine the related steps and activities. In participatory research these techniques are usually used in the context of group processes.

#### 1.4.2 Sampling and Recruitment:

The first focus group consisted of an existing community committee of ten members who had an existing working relationship with the researcher. The members were

selected through a purposive, non-probability sampling strategy, which targeted health professionals, civic structure leaders and people living in the community who were directly affected by HIV. The specific group has received training in HIV/AIDS education and counselling.

An additional two focus groups were recruited to compensate for any limitations and to improve the validity of the study. Participants of these two groups were recruited from the same community, through church groups, service organizations and community leaders; members were selected for their interest in the topic under study and their particular skills and positions in the community. An open discussion was held with both groups to explain the purpose of the study and to exchange ideas.

#### 1.4.3 Data Collection:

The carrying out of the needs assessment and the collection of data was facilitated by implementing the participatory techniques of time line, time trend, Venn diagramming and matrix scoring within the sixth and seventh focus group discussions.

The collection of data through the use of the time line, time trend and Venn diagramming was carried out with the first two focus groups, through open discussion facilitated by the researcher. Information was given verbally or by written comments and all feedback was visually displayed on a board for the participants to view, discuss, contradict, change or confirm.

In the final focus group session the three focus groups were combined and feedback from data gathered in previous focus groups was displayed and discussed. The technique of matrix ranking was then carried out, by dividing the large group into subgroups. Each subgroup discussed the needs, which had been identified in the previous sessions and gave feedback, which was once again displayed. An interchange of ideas and open and frank questioning and analysis between researcher and participants took place.

Verification took place through the duplication of the techniques, the visual display of data and the participation of the focus group members in discussion and analysis of the data. Further verification was carried out by selecting three members from the focus groups and to conduct individual semi-structured interviews on the data produced through the matrix ranking technique applied in the final focus group.

All data was constantly referred back to the participants for verification.

These techniques promote sharing of ideas, experiences and knowledge from the participants themselves, and can be visually displayed to allow for clarity and verification. This is in line with the theory of participatory research methods that focuses on facilitating local people to produce and analyze their own information, according to their own priorities (Cornwall 1995:1670).

Three members were chosen from the focus groups and individual semi structured interviews were held with each. These interviews were taped and transcribed. This was done for reasons of validity. The data collected through the participatory techniques within the focus group discussions was confirmed or contradicted by the individuals, for further verification.

#### 1.4.4 Ethical Considerations:

The issue of informed consent was addressed by providing each focus group with a detailed explanation on the purpose of the study and the aspect of voluntary participation was highlighted.

Permission was requested from the participants for discussions to be audiotaped and the participant's decision in this regard was respected.

The ethical issue that arose out of group dynamics and power imbalances was addressed by providing a platform where each individual participant has the opportunity to voice their opinions.

#### 1.5 OUTLINE OF THE REPORT:

# 1.5.1 Chapter 1: Introduction

Chapter 1 outlines the purpose and rationale for conducting the research by providing a discussion on literature pertaining to community development, HIV/AIDS and specifically literature relating to participatory approaches in research. The goals of the research are briefly discussed. The chapter further provides a brief account of the methodology used in the research process and ends with a brief overview of the report.

# 1.5.2 Chapter 2: Literature Review

In this chapter the general aspects of HIV/AIDS are discussed with special focus on the issue of HIV/AIDS in Africa and South Africa and especially pertaining to the Eastern Cape. In considering the literature relating to HIV/AIDS and communities, a discussion will include statistics on the spread of the epidemic and the different communities responses. Special reference is made of the community-based initiatives in South Africa and in the Eastern Cape and the successes and challenges associated with community based initiatives. Included in this chapter is a discussion on the concept of community and the issue of poverty and its relation to the HIV/AIDS issue and to communities' involvement or lack thereof in community-based initiatives.

To further expand, the theory on needs assessment and the participatory research approach will be discussed in relation to the issue of HIV and poverty.

Furthermore the literature will show how the participatory method is used to facilitate local people to produce and analyze their own information according to their priorities through focus group discussions.

# 1.5.3 Chapter 3: Methodology

In this chapter participatory approach as a method of conducting a needs assessment is discussed. The chapter will describe the participatory research process, from recruitment through to data collection and analysis. This will include a discussion on focus group interviews as a method of data collection and individual interviews. The participatory techniques of time line, time trend, Venn diagramming and matrix scoring used to facilitate the research process will be further expanded on, as well as the challenges and limitations of the process. The chapter further examines the ethical considerations involved when conducting participatory research.

# 1.5.4 Chapter 4: Data Analysis and Findings

The chapter describes the data analysis process which includes an in depth description of the focus group discussions and individual interviews. The chapter further explains the findings, facilitated by exploring the participatory method and techniques used, including the limitations and lessons that may be gained by choosing to conduct a needs assessment using participatory methods. This chapter will present an overview of the HIV/AIDS issue and assess the advantages and disadvantages of the participatory approach as a method in conducting a needs assessment. Further discussion in the chapter will cover the issue of community development and participation and will identify learning needs for service providers when implementing the participatory methods within communities.

# 1.5.5 Chapter 5: Conclusion and Recommendations

The chapter will draw conclusions on the findings, taking into account the limitations in the choice of the initial focus group members and the researchers own limitations. The chapter will conclude with a discussion on the strengths and lessons that were gained and which can be useful to service providers when planning services or implementing programmes in disadvantaged communities, as well as a discussion on proposed recommendations.

# 2. CHAPTER 2 : LITERATURE REVIEW

#### 2.1 INTRODUCTION:

In this chapter I have provided an overview of the literature pertaining to my research study. The chapter is introduced by a discussion on the general impact of HIV/AIDS as well as statistics relating to HIV/AIDS in South Africa and specifically the Eastern Cape. Furthermore, the chapter provides a discussion on the concepts of community, definition of community development, poverty and participatory approaches.

The review also includes actual programme or project initiatives on the HIV/AIDS issue, that illustrate the integration of the theory on communities and participation with practice.

HIV/AIDS has been described in the following manner, (The House of Resurrection Haven 2001: 8). HIV infection is when the HIV virus enters the body through the transmission of bodily fluids or blood. There are no signs or symptoms of infection and this period can last from weeks to months. When the antibodies develop in the blood an HIV blood test will detect these bodies and the person's blood count will change from HIV negative to HIV positive. There are however still no signs of illness, although the infection is present. This period may last up to many years, whereafter symptoms of disease increases, but are not as yet severe enough to threaten life. A person with AIDS is one who is suffering from serious infections that invade the body, because the immune system is now very weak, as a result of the HIV infection. The person could die at this stage from an untreatable condition.

There is no overall treatment for AIDS; there are however different treatments for the various infections, which attack a person with HIV/AIDS. The availability of such treatments is dependent upon the social and economic situation of the person and the overall circumstances of his/her home country (The House of Resurrection Haven 2001:10). In addition to direct medical intervention, the person with HIV/AIDS

requires psychological, social and spiritual support. The availability of such care should be present in all communities and is best dispensed by those who are closest to the person living with HIV/AIDS (The House of Resurrection Haven 2001:10).

In the last few years the previously, largely silent, epidemic of HIV has shifted to a visible epidemic of AIDS. The impact on health services, families and communities is emerging at a rapid pace (Russel & Schneider 2000:1).

The impact of HIV/AIDS on families and communities, as discussed in the paper compiled by the members of the Health Economics & HIV/AIDS Research Division (HEARD), is explained as manifesting itself through negative economic, social and developmental aspects. Furthermore, (Desmond, Michael & Gow 2000: 5-6) state that the demand on members of affected households increases as members fall ill. Women are given the added burden of caring for the ill in addition to household duties. If the women in the house become infected and fall ill, children, especially girls, are taken out of school to care for the sick and help with household duties. When a male is infected and falls ill it leaves a gap in the production process which women or children are required to fill. A further impact on the disruption of the family system is that the increase in health care costs and reduction in income can result in a reduction in food security within the home and a danger of malnutrition and sickness occurring in other members of the household.

Further economic impact results from the AIDS deaths in that in most African countries a large funeral is an important statement and the costs involved, that is transportation, feeding guests and the coffin, add to the financial strain on families (Desmond et al 2000:9). A further impact is that of children orphaned by the loss of one or both parents. Orphaned children generally experience measurable declines in nutritional status and reduction in schooling, as well as having to suffer the stigma of having lost their parent/s to HIV/AIDS. The children face further problems of neglect, lack of accommodation and income, theft of property and inheritance, sexual abuse, economic exploitation and decline in health (Desmond et al 2000:16). Those

children not taken in by relatives, end up as child-headed households or street children. The effect on the family has a ripple effect into the community and society at large.

#### 2.2 COPING STRATEGIES

# 2.2.1 Family and Communities

The families and communities have developed three mechanisms of coping with these impacts. Namely, altering the household composition, withdrawing savings or selling assets and receiving assistance from other households (Desmond et al 2).

# 2.2.1.1 Altering the Household Composition:

The research done by the Health Economics & HIV/AIDS Research Division (HEARD), found that although both AIDS deaths and non-AIDS deaths households fell in size, the composition of the household were not the same. The percentage of the elderly in AIDS death households was found to be higher, while that of adult in prime working age appeared lower. Furthermore the number of households where older siblings took over the responsibility of caring for the younger siblings and the running of the home increased in households where AIDS related deaths existed (HEARD 2000:11).

# 2.2.1.2 Withdrawing Savings and Sale of Assets:

Evidence from studies done in Kagera, Rakai and Chiang Mai suggests that households draw out savings or liquidate assets in response to a prime age adult death. Borrowing from micro-finance organizations is also a common means of boosting the coping capacity of households (HEARD 2000:12-13). In Zimbabwe, households were found to be selling land and cattle and taking children out of school to meet increased costs.

#### 2.2.1.3 Assistance from other Households:

Help from neighbours and relatives are an important supplement to the efforts of a household facing an adult death.; especially an adult that was the prime income generator. Households with lower levels of assets will experience greater difficulty in coping with the death of a prime age adult, than households with more assets, as the household has nothing to offer in return for assistance (HEARD 2000:13). Mutual assistance associations of community residents are an important factor in helping families to cope with AIDS deaths.

#### 2.2.2 Private Sector

# 2.2.2.1 Support of Business sector:

Mining company such as Anglo America, launched its HIV/AIDS strategic plan in February 2001. It announced that it would provide HIV employees with free antiretroviral drugs. Transnet has also devised HIV/AIDS programmes for its workers and Eksom has offered its employees the opportunity to be tested for HIV and to receive counselling. They have also allocated R30 million over the next three years to assist in research for the development of HIV/AIDS vaccine (AIDS Bulletin 2001:11).

# 2.2.2.2 Service Providers (NGO's, NPO)

The NGO's have been involved in the marketing of the use of condoms and run preventative programmes and interventions with sex workers. Further work has been to run orphan care programmes and projects and to establish support groups for people living with HIV/AIDS (AIDS Brief 2001:3). Service providers have been responsible for initiating home-based care projects, awareness programmes especially with the youth and establishing income-generating projects.

#### 2.2.3 Public Sectors

# 2.2.3.1 Government strategies

In 1997 President Mbeki, announced the establishment of an Inter-Ministerial Committee on AIDS. The Committee is responsible for the support and networking functions across the national departments as they embark on developing and implementing HIV/AIDS related activities (Hatane 1999:12). The National Government targeted R319 million for HIV/AIDS programmes for 2001/2002. The main thrust of the national government's targeted response to combat the epidemic is the Integrated Plan for Children and Youth Affected by HIV/AIDS, a joint strategy conceptualized and managed by the National Health Department and the Department of Education and Social Development (Hickey 2001:15).

Further strategies to cope with the rising epidemic are to increase government and international assistance, in order to implement sustainable programmes and improve health care. Appropriate legislature needs to be implemented that eliminates discrimination and ensures the rights and dignity of HIV- infected persons in the workplace and reduces the exploitation of women and children. Further government assistance is needed in the form of support grants for families and individuals (Galloway 2001:2).

# 2.3 HIV/AIDS STATISTICS

Anthony Kinghorn and Malcolm Steinberg of HIV Management Services (2000:21) report that projections indicate that within 3 years almost 250 000 South African's will die of AIDS each year. This figure will rise to more than 500 000 by the year 2008. Various projections of the demographic impact of HIV, based on the antenatal

survey results, suggest that the disease will have a considerable impact on mortality in South Africa. While the projections differ somewhat, they suggest that between 2000 and 2010 between four and seven million South Africans will die from AIDS (Medical Research Council of South Africa 2001:7). According to the MRC, registration of deaths has increased from 50% in 1990 to over 90% in 1999, making it easier to keep track of mortality rates, specifically those related to HIV/AIDS. According to MRC HIV/AIDS findings in their annual report, the mortality rates of women between 25 and 29 years are three times higher than what they were a decade ago.

Looking at South Africa per province it is evident that there is a considerable variation in provincial figures ranging from 32.5 % prevalence in KwaZulu Natal to 7.1 % in the Western Cape. The highest rate of increase is in the Free State.

The HIV/AIDS statistics for the Eastern Cape (Western Sub-Province), for the period 1989 to 2000, is reflected below, (http://www.hivaids.co.za/charts2ec.htm:2001);

Year	Number of Reported Cases
1989	30
1990	70
1991	199
1992	430
1993	750
1994	1534
1995	2621
1996	3703
1997	5234
1998	5800
1999	6444
2000	6837

Since 1997 the numbers have stabilized somewhat, showing that education and awareness may have an effect on the spread of the epidemic. Kinghorn and Steinberg 2001:22, further report that the HIV prevalence as indicated from statistics of antenatal attendees in South Africa between the period 1998 to 2000, reflect that the Eastern Cape had no significant increase in numbers. The only provinces that showed significant increases for 2000, were Gauteng and Kwa-Zulu Natal.

Statistical figures (from January 2001 to April 2001) gained from AIDS Training & Information Counseling Centre (ATICC) in Port Elizabeth, show that in P.E and surrounding areas the following is reflected:

- > total cases 2270
- > male cases 756
- > female cases 1363
- > paediatric cases 126
- > total deaths 287

#### 2.4 IMPACT OF HIV/AIDS

In January the South African National AIDS Council (SANAC) was established. This is a multi-sectoral body designed to advise government regarding HIV/AIDS. This body held workshops in May 2001 to plan programmes in-line with the National Integrated Plan for Children and Youth Infected and Affected by HIV/AIDS. The SANAC have held discussion workshops to develop a document reflecting practical and realistic standards and criteria for the practice of Peer Education Strategies.

It is true, however, that the world has limited resources and we must respond to the priority of the day. At the present time, no other disease of which we know, either sexually transmitted or any other terminal disease has the same community penetration or challenges the basic human identity of individuals and communities as

does AIDS (Campbell 1990:22). Social Workers dealing with the problems surrounding HIV/AIDS in South Africa (Woods in Gray 1998:194 & 198), are called upon to deal with a unique mix of people and cultures.

Creativity and innovation become key qualities when seeking to find relevant methods for intervention. Much of the burden of HIV care in developing countries is now falling onto households and communities.

Examples of such was found in a study conducted by Foster in Mutare, where households were headed by grandparents and many of these were caring for more than one family of orphaned children. A further example is the Families, Orphans and Children Under Stress (FOCUS), who based their orphan care programme on existing community support networks (Foster1996:8).

According to Foster(1996:7), there is a growing recognition that strengthening spontaneous community based initiatives, such as caring for the sick and orphans, are as urgent as preventing the further spread of HIV. Furthermore, the extended family continues to remain the predominant caring unit for sick relatives throughout Africa.

Campbell(1990:21) in support of Foster says that in Africa AIDS challenges individuals, families and whole communities to identify the nature of personal responsibility. Communities are challenged into the realization of the indivisible link between personal and public responsibilities.

Because of the long onset of AIDS many people infected by HIV in South Africa as yet remain well; the steep rise in the AIDS orphans will only occur in several years time (Harber 1998:23). AIDS is thus still a hidden problem. The lack of an obvious AIDS orphans problem, however, means that the issue does not have a positive meaning for many people. This then makes it difficult to get communities to give priority to the AIDS need in the face of other more immediate needs such as housing, roads and water (Campbell 1990:22).

The Mail & Guardian quoted that as at November 2001, the worldwide infection rate of HIV/AIDS amounted to 44 076 222 people. According to statistics, South Africa has the highest number of people living with HIV globally. Out of a population of approximately 40 million, an estimated 4,3 million South Africans are HIV positive. UNAIDS forecasts that the South African economy will be 17% smaller in 2010 than it would have been without HIV/AIDS. Metropolitan Life further forecasts that 20 % of the workforce will be HIV positive by 2005 and 22,5 % by 2010 if no interventions are made (AIDS Bulletin 2001: 8-9).

Welfare will face the challenge of dealing with those debilitated by AIDS. The majority of South Africans will be affected by this epidemic as it impacts on family members, friends and colleagues (UNAIDS 2000:5).

Resources are a scarcity in most areas of South Africa. The identification of resources therefore becomes an important aspect in addressing the epidemic. Woods (in Gray 1998:199) says one needs to identify resources other than buildings, services and finances, but needs to look towards informal relationships and the inner strengths of individuals and communities. In community or neighborhood settings where, not policy but informal patterns determine relations among people, strategies of community education, social action and project management need to be considered in influencing the involvement with HIV affected people.

AIDS Brief (2001:1-2), comments that most government's response to the HIV/AIDS epidemic was initially slow and often faced with denial, ignorance or persecution. NGOs helped place HIV/AIDS on the national agenda and pioneered the development of services. As the government's response to the epidemic has changed, the involvement of NGO's in HIV/AIDS has diversified and grown. Links with government and other organizations have been formed to plan and formulate policy and develop programmes. Just when NGO's need increased capacity to meet new threats in the external environment, then reduced government capacity, increased

community care needs and loss of labour availability threaten both the formal and informal sectors, impoverished households, communities and enterprises.

Communities already face the problem of AIDS and bear the costs of declining income, increasing ill health and withdrawal of children from schools. Communities need help in addressing the spread and impact of AIDS in the context of all their other needs. NGO's will have to transform themselves from service providers to community mobilizes, particularly in the rural areas. According to De Vos, the term mobilization refers to simultaneous engagement of groups of people in activities that have a predominantly social or collective objective. The nature of the problem, the availability and the structural features determine whether social support for individuals and families will be mobilized spontaneously. When the social support is insufficient, professional helpers can intentionally mobilize support groups or networks with the particular purpose of providing a new set of ties that could replace, supplement or compensate for deficiencies in the natural support network. The community members under the facilitation of a professional helper, can come together to share their experiences, render mutual aid, identify community resources and provide feedback on coping mechanisms (De Vos 1998:408). Mobilization can then empower community members to understand their own situation and to solve their own problems, as they become aware of their own potential, regain their sense of dignity and take collective action for self-development (Rahman in De Vos 1998:409).

Such transformation will be more difficult in fast urbanizing areas because they generally lack community cohesion. In such settings, direct service provision has a larger role, but promoting informal networks for care and coping skills remains worthwhile (AIDS Brief 2001:2).

Thus, when considering AIDS care and support one must take into consideration the methods of achieving greater community participation, both in minimizing the impact on the formal health sector and in meeting the needs of people infected and affected by HIV.

#### 2.5 CONCEPT OF COMMUNITY

Community mobilization is seen as a key to the sustainability and success of community based responses to HIV. According to Muntungadura in Russel & Schneider 2000:10), 'community' is a term that is often used in a very glib manner with common definition assumed. The concept 'community' has been used in different ways over time. It has been used within the context of alternative sociological approaches and competing political orientations (Mayo 1994: 48). Community, as Bulmer(in Mayo 1994:48) illustrates can be defined in terms of people who live in a common geographical area, or it can be defined in terms of common interests which may be diverse as ethnic origin, religion, politics, occupation, leisure pursuits or sexual propensity. As Bulmer (in Mayo 1994:51), points out, such diverse uses can cover a wide range of meaning.

In classic sociological usage, social development tends to be characterized by social relationships, community ties based upon the family and traditional community ties.

Harvey (1989:265), argues that different classes construct their sense of community in radically different ways. Low-income populations, usually lacking the means to overcome and hence command space, find themselves for the most part trapped in space.

In this space the community can be positive in terms of mutual aid and defense, but conversely, for the poor, the community can be limiting and can lead to mutual predation. These negative aspects of community for those on low income are increasing with the processes of impoverishment.

Cohen and Uphoff (in Taylor 1994:217), assert that the concern with participation came from development practitioners and members of the United States Congress,

rather than from the social scientists. The concern rose from the development practitioner's experience that the success of projects was critically affected by the extent of community participation in development projects.

Community, as defined by the South African Council for Social Work in (Russel & Schneider 2000:10), is described as a collection of people living within a geographical area engaged in social interaction amongst themselves and having psychological ties with one another and the place in which they live. The concept of community is particularly complex in South Africa where communities and families have been systematically disrupted by migrant labour policies, community removals, political conflict and urbanization.

To continue, newly established communities and informal and peri-urban settlements tend often not to have a 'strong sense of community'. Thus in developing or replicating programmes based on the assumptions of the term 'community', it is doubtful whether the programmes will actually fit the community.

Russel and Schneider (2000:13) note that the greatest challenge for service providers in South Africa is the fact that in many areas 'community' is more a notion than a reality.

The researchers of the Participatory Institute for Development Alternatives (PIDA), (Burkey 1997:42) report that practically all rural developments initiatives in Sri Lanka, whether government or nongovernmental, have attempted to work with total village communities without recognizing the basic contradictions or conflicting interests that exist within communities. Agencies intentionally avoid disturbing the status quo have failed to realize that even by intervening in a so-called neutral manner still has an affect on the dynamics of power relations and end up serving the dominant interests.

Burkey (1997:43), argues that community development projects seem to have become trapped in their own nomenclature by treating a village as a whole entity. This assumption has been called more and more into question. The assumptions that individuals and groups in communities have common interests who are sufficient to bind them together proved to be unrealistic. The better off benefited from the programmes thereby increasing disparity and inequality. A way of ensuring that the organized and powerful elements in the community do not appropriate the benefits of development activities is to discriminate in favour of the less powerful and the poor. This can be done by service providers consciously directing efforts to smaller, more homogenous groups.

Oakley and Winder, (in Burkey 1997:44), found a characteristic common to all participatory projects that they studied in India and Latin America. They found that social development work is based upon group development, as opposed to community or village. The formation and development of clearly identified local groups was seen to reflect the issues and the dissatisfaction that the community felt towards developmental projects.

The Community Development Movement in India, established a nationwide programme implicitly accepted the assumptions that individuals, groups and classes in a village community have common interests, which are sufficiently strong to bind them together (Burkey 1997:43). The movement assumptions proved to be unrealistic. In that the better off benefited most from the programmes and a growing disparity and inequality became visible. The agencies assumption that rural communities are harmonious socio-economic entities proved to be incorrect.

That working through the established traditional leaders in the village, generally the better-off, would automatically benefit the whole community, proved not to be the case and that the better-off benefited from the extension work and other projects rather than the majority of less fortunate community members (Burkey 1997:43).

It also showed that the local people were quite able and willing to participate in programmes that are clearly designed to benefit them, rather than the better off.

The impact for HIV affected communities is greater poverty or greater discrepancy between the wealthy and the poor as well as greater isolation and rejection of people living with AIDS. When planning programmes one must thus consider not only making contact with the expressed leadership structures, but always to include people living with AIDS (PLWA), in assessing the need for services or programmes.

Burkey continues that it would be nice if harmonious communities existed, but we are living and working in the real world in which individuals or groups co-operate, compete and exploit when it is to their own advantage. Therefore our policies, programmes and actions must take the real world into consideration

# 2.6 TARGET COMMUNITY:

For the purpose of this study the target group are members from a community within the Uitenhage district, which can be described as follows;

A semi-formal settlement, consisting of mud roads and the occasional tarred road. The homes are constructed of wood and iron. At present brick houses are being constructed as part of a housing development project. Water is provided to the area but not to the individual homes, the 'bucket system' is used and portable toilets are available in certain sections.

There are two formal schools in the neighbouring areas and one crèche. One Day Clinic is available to the community, but is a fair distance away from the target community, making it inconvenient for the elderly or very sickly inhabitants. A mobile clinic visits the area once a month.

The majority of the inhabitants' mother tongue is Xhosa, with a number of them able to converse in English or Afrikaans.

Unemployment, poverty, child neglect, alcohol abuse and inhabitants who are desperate for government grants or material assistance characterize the target community. Three Welfare agencies provide services in the target community, the Department of Health & Welfare, Christelike Maatskaplike Raad (CMR) and Child & Family Welfare Society.

With regard to services relating to HIV/AIDS, the Department of Welfare is involved in awareness and education programmes in conjunction with the Department of Health as well as the training of volunteers to provide home-based care. These programmes are not active in the community under study, but in another community situated in the Uitenhage area.

The CMR is involved in awareness and life skills programmes and AIDS education, particularly in schools and with youth groups, within the broader community of Uitenhage.

Uitenhage Child & Family Welfare Society is involved with the SANCCFW HIV/AIDS pilot project and provides HIV/AIDS training to members of the target community. The Society is also involved in awareness and education programmes in other areas of Uitenhage.

#### 2.7 COMMUNITY PARTICIPATION:

According to Midgley (in Taylor 1994:103), the United Nations Economic and Social Council resolution on participation states that:

"Participation requires the voluntary and democratic involvement of people in contributing to the development effort; sharing equitably in the benefits derived there from and decision-making in respect of goals, policies, planning and implementation of development programmes."

According to Vandervelde (in Taylor 1994:104), participation should be defined as:

"Involvement in, sharing in, and partaking of the group decision-making process; the who, what, when, where and how aspects of involvement."

Paul, in (Taylor 1994:104), defines community participation as an active process by which the beneficiary / client groups influence the direction and execution of a development project with the view to enhancing their well-being in terms of income, personal growth, self reliance and other values of priority. This definition has a number of implications. These being;

- > that the context of community participation is the development programme
- > that the focus of community participation is on the beneficiaries
- > that collaborative involvement is the hallmark of community participation as it occurs when people act in concert to advise, decide or act on issues
- that community participation refers to a process and not a product in the sense of sharing project benefits.

Van Rooyen noted a relationship between participatory research and the more traditional research methodologies. Van Rooyen suggested that participatory research made use of the qualitative and quantitative methodologies of orthodox research, but that it was in essence, the manner in which these approaches were used as part of the research endeavour that afforded them their participatory interpretations and acceptability.

What legitimized these orthodox methodologies as appropriate participatory strategies were their research endeavours, which involved the full participation of the people actually faced with the problem under study (Van Rooyen in Gray 1998:34).

Cohen and Uphoff (in Taylor 1994:105) support the notion that community participation cannot be seen as a clearly definable concept, but should be described by looking at its specific elements or components.

In the context of development, community participation refers to an active process whereby beneficiaries influence the direction and execution of development projects, rather than merely receive a share of the project benefits (Pauls 1988:65). Community participation could lead to greater project efficiency, local resource mobilization, and more equitable distribution of project benefits. Conversely, it could lead to local communities making increased demands for more services (Mayo 1994:65), or to the co-option of the project by certain groups. Community participation should be promoted despite the differing outcomes.

#### 2.8 ASSESSMENT OF NEEDS

Community intervention programmes directed towards communities as undifferentiated wholes, without taking adequate account of the social stratification patterns of those communities, have tended to benefit the more powerful, often to the detriment of the poorer and less powerful (Mayo 1994:63). Sufian (in Van Vugt 1994:61), points out that the experience of AIDS intervention programmes in Puetro Rican communities, suggests that such projects need to take full account of the specific culture present in the group being targeted. The importance here is to ensure that a needs assessment is carried out. The information gathered in the needs assessment process forms a cultural portrait of the targeted community (Van Vugt 1994:190-191).

Burkey refers that culture is how people structure their experience conceptually so that it can be transmitted as knowledge from person to person and from generation to generation (Fuglesang in Bukey 1997:45).

Burkey continues to say that each person is defined by their social relationships and cultural traditions. In Western societies and to an increasing extent in the urban centres of the Third World, the individual functions as a separate member of society.

In isolated rural communities, social relationships are generally rigidly defined and cultural traditions strong and relatively static. Freedom of the individual is clearly subordinated to the interests of the family, the clan and the community (Burkey 1997:45).

Social relationships are established and cultural traditions maintained through ceremonies and social events. They are given intellectual expression through beliefs, legends, myths and tales either written or oral.

The behaviour of individuals and groups and their responses to external impulses cannot be understood completely without an intimate understanding of their social relationships and their cultural traditions. Societies use these relationships and traditions to minimize conflict. They set rules for interaction between individuals and groups and determine how new information will be processed and how decisions are made (Burkey 1997:46).

Development workers must be familiar with the social and cultural systems in which they are working in order to successfully promote change. New ideas and new activities will only be adopted if they do not create more conflict with the accepted beliefs and traditions. If new ideas are presented in terms, which are familiar and recognizable to the existing system, they will be more easily identified as useful and acceptable (Burkey 1997:46). Each social relationship and cultural tradition will to some extent affect the decisions made by interest groups regarding their choice of development activities and how these are implemented. With reference to developmental work in South Africa's communities of diverse cultures, the statements made by Burkey are of utmost importance, when planning and implementing programmes in communities with cultural traditions opposite to that of the service provider.

As Posavac & Carey(1992:103), point out a clear understanding of what is meant by 'needs' must be established. Assessing the need for social services means looking for

potential services needed which bring people up to a satisfactory state, that they are not presently experiencing. Needs will differ depending on the community and the people being studied. Programmes can be effective only when they meet real needs and when the target population agrees that it has those needs.

Posavac et al(1992:113), further states that the findings of a needs assessment can provide a basis on which to build links between needs and services and between services and resolution of the need. However, need assessments can be inadequate because needs may be ignored or incompletely assessed. Needs may be understood, but the capacity of the community may be ignored.

The profile of the target community defines how the members of the community see themselves, what they know about HIV and how they act on what they know. It also describes what the community values and how the people act on these values. The profile of the community should assist in identifying the needs of highest priority and in selecting the most appropriate culturally specific manner of approaching the community to meet these needs (Van Vugt 1994:192).

In determining the effectiveness of funding allocations and service distribution, well-researched knowledge or assessment ought to be a basis (Van Rooyen in Gray 1998:41).

Unless one tests for difference, commonalties or consensus cannot be assumed and those who are younger, very old, female, of low-status groups and/or poor, deprived, disabled or weak will tend to be left out unless care is taken to include them. The techniques used in participatory research include collective research through meetings and socio-dramas, critical recovery of history, valuing and applying folk culture and the production and diffusion of new knowledge, through written, oral and visual forms (Chambers 1997:181,108). As Mbambo (1999:9) states, professionals look at deprived communities and make assumptions about their abilities and capacity to know what they want and need and how to find solutions to meet these needs.

It is quite possible to have an accurate understanding of a community's need, but to fail to assess the community's capacity to support the service or project or the cultural context in which the service would be implemented. One of the tragedies of the relationship between the developed nations and undeveloped nations is the repeated failure of foreign aid initiatives to consider the economic and cultural context of the people in the undeveloped nation (Posavac et al 1992:114).

#### 2.9 DEVELOPMENTAL PROCESS

According to Cohen in (Lombard 1991:253) the definition of the problem is the first and decisive phase in the community developmental process. A problem or need is only really identified when it has been demarcated or defined clearly. The community or community group with the community developer must discuss the nature and extent of the need or problem and this will determine the process of involvement.

Participation of the community is an integral aspect in this process as personal experience is one of the best sources of information about actual needs. After identifying the needs and problems, the community participants should place the identified needs in order of priority. The analysis of the problem or needs places everyone involved in the process in the same frame of reference concerning the nature and extent thereof and it becomes easier to reach consensus on how best to address them. The aim of problem or need analysis or assessment is to determine the most effective approach or strategy for planning efforts to effect change (Lombard 1991: 255-256).

A need is a concept, which has various meanings or interpretations, it does not refer to something in particular, but rather to something which does not exist. Communities should be educated to experience a real need as a felt need, that is to say as a need with which they themselves can identify. Therefore it is important to bear in mind

that the community worker or community developer cannot provide the community with specific criteria by which they can identify their needs. The community identifies its needs according to personal criteria formulated by individuals in the community themselves (Lombard 1991:255-256).

After identifying and defining the needs and problems, the community should put these needs and problems in order of priority. This choice is based on what is of importance to the community as a whole and not what is regarded by specific individuals to be important (Lombard 1991:256). Needs assessment is designed to guide resource allocation decisions, partly through ranking needs in priority order.

Even though some needs identified may have to be addressed on national or provincial level, the development project should also identify short term goals which can be achieved in the shortest possible time, in order that small successes keeps the community motivated and involved (Lombard 1991:257).

Campbell(1990:25), refers that if communities hold the reins of their own responsibility and promote responsibility for care and prevention in families; then the policy makers and the international, national and local organizations will become what they should really be, which is facilitators and appropriate resources for advice and clarification.

Empowerment emerges from a grounded assessment of where people are, including an understanding of their socio-economic conditions, cultural patterns, social organization and inter-group diversity. Empowerment can be described as the process of increasing personal, inter-personal and political power, enabling individuals or collectives to improve their life situations. Empowerment increases the energy, motivation, coping and problem-coping skills, decision-making power, self-esteem, self-sufficiency and self-determination of community members (De Vos 1998:407).

Chambers further expands that the PAR approaches can be empowering for people on lower levels. Empowerment in the PAR context has four angles, these being;

### 2.9.1 Differences within Communities:

Differentiating groups and interests can empower the disadvantaged groups in that it can give them collective awareness and confidence to confront others and argue their case. This can be especially useful with gender-sensitive issues. Whether empowerment is good depends on who are empowered and how their new power is used (Chambers 1997:217).

### 2.9.2 Methods and Process:

People can learn through PAR methods, by expressing and sharing what they know, but before had not expressed and shared. Through diagramming, mapping, investigating they can add to their knowledge. Through their analysis they become more aware and reach new understanding. Those who plan and then implement what they have planned take command and further learn through the experience of action (Chambers 1997:217).

## 2.9.3 Community-level Organization:

Empowerment can be weak and short lived unless it is embodied in institutions. PAR can initiate a process, which leads to, and empower community-based organizations.

# 2.9.4 Conflict and Negotiation:

PAR approaches and methods can change the attitudes of dominant groups. Gender relations provide examples. The PAR methods of diagramming can be used to clarify and resolve conflicts (Chambers 1997:219).

Empowerment, unless abused serves equity and well-being. It is not a static condition. It is a process not a product, it is something that is never finished. It entails enhanced capabilities and wider scope for choice and action and especially requires and implies changes in power relations and behaviour (Chambers 1991:220).

Empowerment education, as developed in Paulo Freire's work (1970, 1973), involves enabling people to join together in group efforts to identify their problems, critically assess the social and historical roots of these problems, envision a healthier society and collectively develop social and educational strategies to overcome obstacles to achieving their goals.

The Freirian approach differs from traditional community education in that the emphasis is on the collective development of knowledge and understanding as a springboard for concerted action, rather than the offering of established information to equip the individual to make healthy decisions (Van Vugt1994: 63).

In Freire's view, rather than impose their own cultural values, educators should enter into an authentic dialogue so people emerge from their cultural silence to redefine their own reality.

Burkey(1997:51) explains that, many but not all poor or disadvantaged people have low opinion of themselves and of their ability to change their situations for the better. Because of this low opinion and also fear, they do not assert themselves. They remain shy, passive and withdrawn. Their dependency relationship with others who are stronger diminishes their self-confidence and initiative. Their lack of knowledge and

information prevents them from competing successfully for their fair share of resources and keeps them from effectively utilizing the few resources they do control. No developmental activity whether initiated by outsiders or by the disadvantaged themselves, can hope to succeed unless it carries a strong element of human development. Human development involves the strengthening of the personality and the acquisition and internalization of knowledge and information (Burkey 1997:51-52).

There is a wide range of facilitation methods for fostering community involvement. These methods range from general techniques for facilitating communication and interaction within focus groups, to self-surveys and more comprehensive methods for conducting community audits, such as Participatory Rural Appraisal (Kelly in Blanche & Durrheim 1999:232).

Kelly (in Blanche et al 1999:233) continues to say that Freire's epistemological framework is dialogical and participatory, meaning that research is conceived of as the joint effort of a facilitator and a group of people aspiring to understand their own circumstances better in order to change them. The first stage of the Freirian intervention begins with researching people's thematic universe, usually together with a group of people from the community, co-opted as co-researchers.

The themes are the ideas, values, hopes and concepts that are important to people in relation to a particular issue. This can be done through interviews or focus group discussions.

Service providers do not always have enough information about the communities to do any more than simply react (Bowser in Van Vugt 1994:94). Investigators who are willing to participate, listen and learn as peers will realize that the community is not only a source of crucial information, but also a source of new ideas about methods and the way research is conducted.

#### 2.10 COMMUNITY BASED INITIATIVES:

This section describes a number of community-based initiatives that have taken place and were initiated and implemented by encouraging and enabling community participation and empowerment.

Development theorists stress the importance of a 'fit' between development initiatives and their context (Harber 1998:23). As quoted in Kotze & Kotze, 1995;

"people will not be steered, influenced or taken with, unless the development initiative has positive meaning within their context."

Russel and Schneider found in their study that much of the literature on community based care and support has emerged out of Botswana, Zimbabwe, Tanzania, Malawi and Uganda. In these countries systematic efforts have been made to implement and evaluate community based activities since the late 1980's and include some well known models such as the Family AIDS Caring Trust in Zimbabwe and the AIDS support organization in Uganda (Russel et al 2000:1).

Family AIDS Caring Trust was started in Zimbabwe in 1987. Its services include education, information and home-based care. Volunteers are recruited through the community churches and provide emotional and pastoral support as well as basic home nursing. Clients are assisted in accessing legal advice and referrals to other medical and social services within their community. Bereavement and orphan support is also provided (Foster 1999:7).

The AIDS support organization in Uganda was started in the late 80's by Ugandans, infected and affected by AIDS. It arranges counseling, social support and medical services to people living with HIV/AIDS (Kaleeba 1997:20). The medical care involves complementary support services in hospitals as well as home-based care. Training is offered to other providers, as well as advocacy, financial and material support, such as food parcels to clients.

The Catholic Diocese of Ndola, in Zambia, has been involved with AIDS work since 1991. The programme trains family health nurses and community health workers. The training covers counseling, nursing and health care for people living with HIV/AIDS and their families (www.christian-aid.org.uk 2001:1). Home-based care is an important part of the Diocese's HIV/AIDS work. The programme also provides material assistance to HIV/AIDS orphans and their extended families and aims to find solutions within the community for these children.

With reference to the South African context, a number of programmes and projects focusing on HIV/AIDS have been established and will be discussed in the following paragraphs.

The Wola Nani project was founded in 1994 under the auspices of the St. George's Cathedral Foundation Trust in Cape Town. The centre provides HIV positive women with a safe environment for their children while they participate in income-generating activities. The centre also offers counseling and emotional support. Community workers provide home-based care for clients, monitoring their health and offering advice and support. Wola Nani works to keep orphaned children within their extended families by providing support services and encouraging income-generating activities for people living with HIV/AIDS (www.christian-aid.org.uk 2001).

Community- or home- based care, is an option that has been initiated in other Provinces such as Kwa Zulu Natal (HST Update 1996:25), where a team of women volunteers were trained to care for and counsel patients diagnosed HIV positive and to educate and provide support to the families. The need for this team arose out of the desperate situation of the local hospital in Ngwelezana where wards were swamped with HIV patients. The community was approached to assist the hospital in relieving the pressure, as the team also visits TB patients, this means that the patient is not automatically labeled HIV by the community, when the team arrives at their home.

The team has also started a support group for HIV positive people who have not yet developed AIDS symptoms.

In response to the growing epidemic the South African National Council for Child & Family Welfare initiated HIV/AIDS pilot projects in the Eastern Cape Province (Halkett 2001 24). Project teams or community committees, made up of a broad cross section of people, were formed to mobilize communities around issues relating to children and HIV/AIDS. Twenty-one committees have been established and more are being established. These projects concentrated on awareness and home-based care.

An example of a home-based care initiative is the Nompilo project in Steytlerville. Five women volunteers (Nompilo's) aged between 41 and 50 years, care for 200 families. They provide care to the family by washing, bathing and treating sores. They also deliver medicine and refer problem cases to the local clinic. They are on call 24 hours 5 to 6 days a week. The group is being supported by the local business sector and is able to buy uniforms, gloves and other necessities. The volunteers are all community people and they thus understand local tradition and culture (SANCCFW 2000: 4).

A similar response of community self-help has occurred in Amambisi, in the Eastern Cape, where communal structures are assisting with the number of AIDS orphans and the outreach programmes have influenced people in the community to adjust their behaviour (Mail & Guardian 2001:2). The communities' response in Amambisi is similar to the response to the Education for life programme established in Uganda to promote behaviour change in order to prevent the spread of HIV. The Amambisi programme confirms the statement made at the Dakar conference on HIV/AIDS in 1991:

"Individuals and communities have the inherent capacity to change attitudes and behaviour. The power to fulfill this capacity is often denied or not recognized, called forth and supported both from within and without. This will enable people to initiate

and sustain behaviours that promote a healthy state of mind, body, spirit and environment. A critical component in the process is a supportive response to those living with HIV in the community. We recognize that behaviour change at individual and community level in the present HIV pandemic is a complex and on-going process, it is inextricably linked to such basic human values as care, love,

faith, family, respect for people, cultures, solidarity and support."

Community solutions are all very well but according to Harber (1998:22), there is little empirical evidence of what it means to set up a community-based project for HIV/AIDS affected children in South Africa. However, community based solutions for the care and support of HIV/AIDS affected children are being promoted by the government in line with its broader strategy of "developmental social welfare", but there are many lessons to be learnt by service providers when establishing community based projects, as is demonstrated by the efforts of the Thandanani Association's efforts to develop a community based AIDS orphan project (Harber 1998:22).

The Thandanani Association is a small NGO based in Pietermaritzburg that was founded in the late 1980's to move abandoned babies out of hospital wards. The AIDS orphan project was a new venture developed during the mid 1990's in response to the rapid rise of HIV infections in Kwa Zulu Natal (Harber 1998:22). The project developed out of research undertaken by Mc Kerrow and Verbeek (1995), which looked at community responses to children separated from their parents, in eight communities around Pietermaritzburg.

The project encountered a number of problems with their choice of method of entering the community. Firstly, the entry was through workshops but this proved to be much slower than anticipated. Secondly, the project had not yet established itself as credible and trustworthy and failed to make good contacts with community leaders. Thirdly, logistical problems such as lack of transportation to reach rural areas. Finally, community leaders lack of interest in the project as they had other priorities to take care of.

Due to these setbacks the NGO decided on the following in order to try to overcome the above problems that were experienced.

The project decided to concentrate on only two of the original eight communities. Childcare committees were established in the two areas where the most progress had been possible. The committees consisted of women who were extremely poor and who had expectations that the project would provide them with material assistance. Their initial interest faded once it became clear there was no assistance.

The benefit of encouraging communities to look for solutions from their own resources (UNICEFF: 1991), had unexpected consequences within the Thandanani project. Rather than encouraging communities, it raised expectations of outside assistance and greater demands for material aid.

The project encountered a number of dilemmas and raised a number of important issues for other NGO's planning community based projects. One being that greater clarity is required on concepts such as building human capacity or promoting self-reliance and strategies to do so (Harber 1998:24-45), another being improved collaboration between organizations and finally, a need for better analysis of what is meant by the term 'the community'.

Lund (in Mayo 1994:10-131), says that in South Africa as elsewhere, Community participation, community development and self-help strategies may have potential relevance in the future, both for communities, government and international agencies, but that none of these purposes are likely to be achieved spontaneously. Community initiatives need to be provided with regular public financing together with education and training.

#### 2.11 THE ISSUE OF POVERTY:

It is important to bear in mind that many communities are very poor, often without the most basic of necessities such as food and water (Russel et al 2000:11). Even though communities may be willing to mobilize they may not have the resources. Marcus (in Russel et al 2000:11), says that mobilization is extremely difficult within the South African context where state welfare responses are being driven by cost efficiency and economic rationality rather than social obligation, and there are few safety nets for poor households and communities.

There are limits as to whether communities can be expected to be 'self-reliant' and to absorb the impacts of AIDS without external assistance.

Poverty as defined in the report for the Inter-Ministerial Committee for Poverty and Inequality (1998), is characterized by the inability of individuals, households or communities to command sufficient resources to satisfy a socially acceptable minimum standard of living. Poverty is perceived by poor South Africans to include alienation from the community, food insecurity, crowded homes, usage of unsafe and inefficient forms of energy, lack of jobs and fragmentation of the family.

In measures of human development such as life expectancy, infant mortality and adult illiteracy, South Africa compares unfavorably with several other middle-income countries (Wilkins 1998:4). These indicators also vary widely by race group, gender and geographical location within the country.

Poverty is distributed unevenly among the nine provinces. Provincial poverty rates are highest for the Eastern Cape (71%) and the lowest in Gauteng (17%), as indicated

in the summary report by Wilkins. Furthermore there is also a correlation between poverty and ill health, although this is more difficult to measure and access to effective health care is specific to particular social and environmental situations.

In areas like the Eastern Cape, where 50 percent of people are unemployed and eight out of ten families experience malnutrition, poverty has been found to accelerate the HIV/AIDS epidemic (Daily Mail & Guardian 2001:1).

In the study conducted by Russel and Schneider (2000) they found that the themes of poverty and hunger kept emerging in that people living with HIV/AIDS experienced deepening poverty, increased isolation, rejection by communities and the inability to satisfy basic needs such as food and shelter. The primary need for money, food and clothing must be satisfied, before people can take on the emotional and medical issues of AIDS.

Russel and Schneider further found that programmes with inadequate or no funding had difficulty in maintaining volunteer commitment. Many people could simply not afford to volunteer their time without incentives or reimbursement.

Further limitations were found in the study of home-based care programmes where families were taught to care for the infected members. Most people could not afford the items, such as gloves and antiseptic solutions. There was found to be a lack of hygiene where no water was available and patients suffered with diarrhea. Patients receiving medication could not take the medication as they had no food, and the medication on an empty stomach would make them ill.

Programmes started by, and within poor communities, seemed to have the most difficulty developing strong and sustainable programmes (Russel et al 2000:28).

The rapid appraisal study of Russel and Schneider highlighted the issues of poverty and the importance that communities place on acquiring these basic needs, and the fact that communities have limited energy to place on broader social issues when their basic necessities have not been met. Communities lack knowledge on the issue of HIV/AIDS and suffer from misconceptions and secrecy that surrounds the issue, this adds to community members inability to move beyond concern for their own individual needs and to become involved in issues that affect them and the broader community.

Maslow, who rose out of a childhood marked by poverty, prejudice and hardship to a position of respect, understood the basic needs concept, but he also believed in the tendency of the self to grow and develop (Schultz1990:317). It is also understandable that coming from a background where food and shelter were important everyday concerns, Maslow would develop a system in which those needs assume a position of primacy until they are satisfied.

In Maslow's hierarchy of needs the needs at the bottom of the rung of the motivational ladder must be satisfied before those at the top can be satisfied. The lower needs are physiological needs, these being food, water, and sex. Maslow noted that a starving person thinks only of food, but that once this need is fulfilled the person can then concentrate on the higher needs. In comparing the HIV/AIDS issue, it can be assumed that, in accordance with Maslow's theory (1954), it may be argued that if basic needs are not satisfied then higher needs cannot emerge. In essence if communities are consumed with the daily struggle to meet their basic needs they will then not be mobilized to place their energies in programmes that tackle the issue of HIV/AIDS. As the issue of HIV is a higher need, that can only be given attention once their lower physiological needs have been met.

### 2.12 PARTICIPATORY PROCESSES

In the past research has been used by the select elite, often situated within specialist and remote structures or bureaucracies. Seldom has the link between research and community-based problem -solving processes been made. Seldom to

has the potential for research as a community-building, empowering, democratically framed process been explored or debated in the traditional research literature (Van Rooyen in Gray 1998:29).

In the apartheid system, participation, empowerment and democracy only applied to certain social sectors. These processes served to restrict true empowerment by hampering people's participation in knowledge creation, but also in a subtle way reflected the very nature of traditional processes of knowledge creation. The issues and problems identified by the reconstruction and development programme (RDP) required an alternative response. As the voices of previously unreached communities become heard, so history is rewritten and our social reality is reconstructed to reflect their perspectives. People need to be active participants in the entire developmental process. Through drawing on natural and long-existing community-based coping strategies and problem-solving processes, researchers and participants become partners, working together to develop creative and innovative ways of developing new knowledge and more appropriate responses to community issues (Van Rooyen in Gray 1998:34).

Participatory research is not the panacea for all research related and community problems. Participatory research is presented as an alternative to the more traditional methods of research, in the light of its apparent compatibility with both social worker ethics and processes and with the sociopolitical mindsets and paradigms of contemporary South Africa (Van Rooyen in Gray 1998:35).

The values and preferences of poor local people typically contrast with those better off, outsiders and professionals. Their values, preferences and criteria are numerous, diverse and dynamic and often differ from those supposed for them by professionals. Participatory approaches and practices enable disadvantaged people to express and analyze their multiple realities (Chambers 1997:162). The principles and practices of participatory appraisal facilitate this analysis and expression. The realities that are expressed differ, as do the environment, resources, experiences, values, cultures and livelihood strategies of individuals and groups. The differences can be illustrated through the use of participatory mapping, seasonal calendars, causal and linkage diagramming, matrix scoring, ranking, Venn diagramming, time line and other participatory techniques.

Chambers (1997:182), comments that again and again outside professionals treat communities as homogeneous. Policy documents and project proposals advocate "community participation" and go no further. Visitors to villages and settlements assume that those whom they meet represent 'the community'. Within communities though, there are many obvious differences. The use of participatory approaches and methods has repeatedly confirmed that the different groups, households and individuals within a community have a variety of criteria, preferences and priorities. This has been demonstrated through participatory techniques of mapping, seasonal calendars, causal and linkage diagramming, matrix scoring and ranking, Venn Diagramming, time line and time trend.

Participatory development is not a patchwork quilt of different coloured cloth, but a finely woven textile of many coloured threads. These threads are woven together by the people and the pattern is determined by their own needs and priorities (Burkey 1993:49). The poor will generally attempt to first solve those problems which they consider to be the most urgent and within the limits of their own resources and capabilities.

That poor and vulnerable people can have the ability to undertake their own research has been known for decades, as demonstrated by Paulo Freire and his followers in Latin America (Chambers 1997:206).

Participatory Rural Appraisal (PRA) has been described (Chambers 1995: 1), as a 'growing family of approaches and methods to enable local people to share, enhance and analyze their knowledge of life and conditions and to plan and act'. Further, PRA has not been deduced from theory, in this respect it differs somewhat from the Freirean tradition. PRA has been induced from practice, from methods and approaches that have been found to work.

The approach is more than a simple collection of innovative techniques. It involves self-critical awareness of the attitude and behaviour on the part of the investigators towards the people with whom they work. Moreover, beyond their value for learning and analysis, some of the methods are also means of sustaining the participatory process of which they are part (Chambers 1995:5-6). Chambers further explains the contrasts between Participatory rural appraisal and Rapid rural appraisal.

PRA emphasizes people's empowerment, in theory and practice, whereas RRA is extractive with outsiders controlling, analysing and acting on the information. PRA is participatory, with the control, analysis and actions coming more from the people themselves.

The essence of PAR is change and reversals of role, behaviour, relationships and learning. Outsiders do not dominate and lecture, they facilitate, sit down, listen and learn. Outsiders do not transfer technology; they share methods that local people can use for their own appraisal, analysis, planning, action, monitoring and evaluation. Outsiders do not impose their reality; they encourage and enable local people to express their own (Chambers 1997:103).

For the purpose of this study the term Participatory Action Research (PAR) will be referred to. The PAR term is used for any kind of research with an action and or participatory orientation. Bhana (in Blanche et al 1999:230), states that PAR researchers argue that authentic knowledge of the human and social world can only be gained in the process of attempting to change that world, and that authentic change can only occur when it is accompanied by shifts in the knowledge base of those involved.

Thus PAR attempts to contribute both to the practical concerns people have in an immediate problematic situation and to the larger goals of social science research by emphasizing both rigour and relevance.

Furthermore, PAR attempts to mediate between individuals and collective needs. Traditional research operates from a purely instrumental perspective that is it aims to find the most efficient solutions to applied problems (Bhana in Blanche et al 1999: 230). In a society dominated by capitalist ideologies of individual success this most often translates into the development of social technologies for individual betterment or the optimal management of capitalist enterprises. In contrast, PAR insists on communal participation in the process of knowledge creation, so that knowledge can never become the property of individuals or small interest groups.

PAR researchers try to know with others, rather than about them, and to reconceptualize and foster knowledge as something that exists among people, rather than as some sort of barrier between them.

Participatory approaches or methods have led to a 'paradigm shift' in development. The shift is from top-down, blue print approach towards a bottom up, people-centered process oriented approach. This mean institutions (public sector, NGO's, international bodies), no longer view themselves as 'implementators', who are responsible for planning, implementing, managing and evaluating projects for local

people (Chambers 1995:24), but 'enablers', who help local people to plan, implement and manage their own project.

#### 2.13 CONCLUSION:

The most important instrument in the self-reliant participatory development process is the small group of men or women who have a common interest in working together to individually and collectively improve their lives (Burkey 1993:130).

The integration of community care, support and prevention strategies can have a positive impact on mitigating and decreasing the spread of HIV/AIDS. Providing care and support systems within communities can also result in greater community acceptance and a normalizing of the disease thus enabling people to talk about it openly (Russel et al 2000:13). However, community-based care and support should not be seen as an alternative to care and support through formal structures, but rather as one element in a coordinated and integrated continuum of care.

Russel and Schneider (2000:13) argue in their study, that to be effective, community-based care requires the investment of resources, community ownership and appropriate partnerships with formal service providers.

What needs to be remembered is that a virus which is transferred from person to person unknowingly and whose symptoms may not show up for five to ten years, simply does not have the a crisis driven immediacy for people who are consumed with day to day survival and the meeting of basic needs.

Burkey (1993:70), states that developmental workers need to first analyse the causes of poverty in each particular circumstance; become familiar with various theories of development; understand what development is from the point of view of the poor;

understand communities and the meaning of self-reliance and genuine participation; understand the processes involved in human development and participatory action research and finally, need to appreciate that development requires social transformations that can only take place slowly over time.

Capacity building in families and communities will enable them to identify, analyze and address problems such as the prevention of, and care for; HIV/AIDS affected people in their own communities, and enable them to be accountable for the management of their own resources.

Participatory action research makes use of qualitative and quantitative research designs, data gathering and data analysis, (De Vos 1998:114), however, the actual research takes second place to the emergent processes of collaboration, mobilization, empowerment, self-realization and the establishment of community solidarity.

# 3. CHAPTER 3: METHODOLOGY

#### 3.1 INTRODUCTION:

This chapter describes the research methods used, from recruitment/selection through to data collection and analysis. The chapter further examines the ethical considerations, limitations and challenges experienced in the study.

The goals of the research study directed the choice of research methods used. Community members participated in focus group discussions. The participatory methods and techniques were implemented to enable the focus group to express and analyze their individual and shared realties.

The goals of the research study are as follows:

- To explore the most appropriate way of conducting a needs assessment, relating to HIV/AIDS services in a particular community.
- To design a needs assessment tool, which could be implemented in the community.
- > To use the analyzed data to describe a process of implementing a sustainable service.

A needs assessment is a research and planning activity designed to determine human service needs and to provide data for the establishment of new programmes (Mark 1996:238).

According to Marti-Costa & Serrano-Garcia (in Rothman, Erlich & Tropman 1995:260), needs assessment methodology must not only generate information, but must respond to a commitment to the powerless and to the fostering of social change. It must also emphasize techniques that singly or in combination facilitate grouping and mobilizing people; foster collective activities; facilitate leadership development and involve community members in the entire process.

I chose to conduct my research study by using participatory approaches and techniques, in order that the needs assessment would be conducted in a manner that encouraged community members to share their knowledge and ideas and to learn from the community what they perceive to be their needs and priorities.

#### 3.2 RESEARCH METHODS:

Participatory action research (PAR), aims at responding to concrete needs of a group, social section or a community (Lammerink 1998:344). In PAR certain members of the community under study participate actively with the researcher throughout the research process, from the initial design, through data gathering to analysis.

Community members are therefore actively engaged in the gathering of information and ideas to guide future actions. Dialogue between researcher and community members is an important feature of this method.

PAR can be used within both quantitative and qualitative research methods. Qualitative research methods are more descriptive, subjective and refer to participant's feelings and attitudes whereas quantitative methods are more concerned with percentages and numbers and are less focused on the person's opinion. As I chose to conduct this study in a participatory manner, I believe that qualitative methods suited the approach better in that it is a less structured method and I sought to gather information on participant's feelings, ideas and opinions and had less interest in the numbers.

For the purpose of this study qualitative research method of focus group discussions and semi-structured interviews were used to facilitate community members to produce and analyze their own information according to their own priorities (Cornwall & Jewkes 1995 1670).

The focus group interview is described by De Vos(1998:314), as a purposive discussion of a specific topic or related topics taking place between six to ten individuals with similar background and common interests. Focus group interviews generate data regarding people's perceptions of phenomena and services. Participants in focus group interviews need not reach consensus. Instead emphasis is placed on finding out as much as possible about the participant's experiences and feelings about a specific aspect of social reality, issue, event or a service (De Vos 1998:315).

To further verify the data, the triangulation method was used by selecting three members from the focus groups and conducting semi-structured interviews. Triangulation involves the use of different research approaches to the same question in order collect data, this can be done by using different methods to collect data, such as questionnaires and interviews or approaching different people. The data gathered through different sources can be compared to gain a better understanding and consistency (Marlow 1988:217). The data collected in the focus group discussions was presented to each individually and each member was asked to comment on the appropriateness of the data. The interviews were tape- recorded and these recordings were transcribed.

### 3.3 SAMPLING PROCEDURES:

According to Dunbar and Morris (in Cox, Erlich, Rothman & Tropman 1984:176), the selection and involvement of community members is the first step in the participatory process.

I used the qualitative research method of focus group discussions. The focus group members were selected through a purposive, non-probability sampling strategy. The sampling strategy was selected as it best suited the purpose of the study.



The non-probability sampling strategy was chosen as I intentionally chose the participants for the study as they where involved with and had an interest in the topic under study (Marlow 1988:142).

My reasons for selecting this sampling method are that I consider this strategy to be the most ethically appropriate for this study. As the group selected already exist and has legitimacy and an existing relationship with the welfare organization concerned and had indicated a willingness to participate in the process, it would therefore not be appropriate to set up another group simply for the purpose of conducting this research. As Collins(1999:22), states, all these conditions are necessary for respectful research that uses "insider" perspectives.

The topic under study is sensitive and related to proposed service needs, therefore approaching the broader community could lead to raised expectations.

The sample chosen had knowledge and interest in the topic under study and was considered to be representative of the target community.

As Krueger and Casey(2000:4), explain; the purpose of focus group discussions is to listen and gather information and to understand how people feel and think about an issue (HIV/AIDS) or service.

Participants were selected because they had certain characteristics in common that related to the topic of study.

The members of the initial focus group selected, consisted of an existing community committee of ten members that have an existing relationship with me. They are part of Uitenhage Child & Family Welfare Society's pilot project of home-based care for HIV/AIDS infected and affected people and have received training in HIV/AIDS education and counseling.

The advantage of selecting the existing committee as the initial focus group is that I as researcher had already established a relationship with the group and thus access to the

group was convenient. The members of the group had knowledge of the topic under study and knowledge of their community. The pilot project cannot be said to have complimented the research study, but it did provide a basis from which to initiate the research in that home based care was being stated as a need within the community and that the group members had an understanding of the issue of HIV/AIDS.

The problems experienced as a result of this choice, are as follows;

The group used the focus group discussions to promote the pilot project that they were engaged in, they thus had their own personal agendas that influenced the type of data given.

The group was willing to participate as they possibly viewed the study as an extension of the project with which they were already involved and had expectations of their own. When these expectations were not met, in that the study did not help the progress of the project, the members lost motivation and attendance of meetings dropped significantly. The project overlapped with the research study in that the group members saw the research as an extension of the project. They thought that the research would confirm that the home-based care initiative was a necessity in the community.

# 3.4 DATA COLLECTION TOOLS:

### 3.4.1 Focus group discussions

Focus groups are used to gain understanding about a topic so that decision makers can make more informed choices with regard to programme implementation (Krueger et al 2000:12).

The objectives of the focus group discussions were to explore what the most appropriate needs assessment tool would be and thereafter design and implement the chosen tool, in order to gather data.

A group workshop was held to explain the reasons for the study and to describe the different types of needs assessment tools and the method of application of each. My purpose as researcher in this process was to provide information that would sensitize the community members to the issue at hand, in order to enable them to become research partners (De Vos 1998:117).

The outcome of this workshop was positive in that the members were eager to participate and where enthusiastic about the proposed process. The members had an understanding of the concept of participatory approaches, which was encouraging to me as researcher, as I felt the process would progress well.

After discussion at the workshop, the group decided that the meetings could be conducted in English as all members understood and could converse in English and English was the language medium used in previous meetings with the members.

Time would also be allowed for feedback and clarification in order to eliminate any distortion in communication.

The group members also decided on the dates, times and venue of further focus group meetings. The decision was reached that the focus group meetings would be held at two-week intervals, as this was acceptable to all the members.

Five focus group meetings were held with the selected group. The initial meeting being a workshop to orientate the group members to the research process and to provide information on the various needs assessment tools that could be chosen for the study. The issue of HIV/AIDS and the target communities understanding of HIV/AIDS was discussed in the following focus group meeting and further focus group meetings concentrated on discussions relating to the most appropriate method of conducting needs assessment on services needed relating to HIV/AIDS

Although the focus group participants decided upon dates, times and venue of focus group meetings, the attendance at the third and fourth meetings dropped significantly. This can be contributed to the members' involvement in the pilot project as well as a number of other factors.

Furthermore, once participation is secured involvement in the research process is usually neither continuous nor predictable. Commitment and interest waxes and wanes over time. People may enter a participatory research process with preconceived ideas of desirable outcomes, when it is apparent that these are not project priorities their enthusiasm wanes (Cornwall et al 1995:1673).

Participation is time-consuming and often participants are too busy securing the basic necessities of life.

The first focus group meeting was held four weeks after the orientation workshop, this was the date that suited most as many of the members had other commitments to take care of in January. Eight of the ten members attended the meeting.

The purpose was to explore, through dialogue, the participants understanding and perceptions on the issue of HIV/AIDS.

As Van Rooyen (in Gray 1998:42), states: The initial phase should involve the systematic gathering of information by people who are both affected by the problem and want to solve the problem. This is done by gaining familiarity with community issues and perceptions through discussions with the members of the community affected by the problem.

In this focus group meeting the members expressed their feelings and knowledge surrounding the issue of HIV/AIDS. The discussion then moved to their perceptions and ideas of how their community viewed the issue of HIV/AIDS and the reaction to it. The discussion then diverted from the issue at hand to the Child Welfare pilot and its funding as well as to issues of unemployment and poverty.

The decision to use an already existing group as the focus group raised questions of power and control. Baker and Hinton (in Barbour &Kritzinger 1999:79), say each individual, whether researcher or participant, has their own expectations and personal agendas. Existing social relationships will, to some extent, affect the decisions made by interest groups regarding their choice of development activities and how these are to be implemented (Burkey 1998:147).

I agree with the statements of Baker, Hinton and Burkey, in that my existing relationship with the focus group members and their involvement in another project created expectations that the study would benefit the project and thus the individuals involved. This negatively affected the direction of the discussions and the information given.

At this time an interim meeting was held with the focus group members to discuss my pending resignation from the Organization and thus my termination with the pilot project, as well as to ascertain whether the group where still willing to continue to be involved in the study. All members expressed their commitment to the research study.

In order to overcome the limitation and to broaden the group's representativeness, in the second focus group meeting an additional four members (with the consent of the original group), were added.

The inclusion of new members that where not involved with the pilot project added a new dimension to the group discussions, in that the focus on the issue of home-based care (which is the concept of the pilot project) was diverted and the group could focus on the issue of HIV in general.

Maintaining a flexible approach to the sampling frame is desirable (Barbour & Kritzinger 1999:7). Having determined the ideal sample, it is useful to add extra members or groups that can lend greater depth or scope to the study.

I am in agreement with Barbour and Kritzinger that adding members to the original chosen focus group can be beneficial if the circumstances so demand, and can add new direction to the discussions. This provides the researcher with a broader view of the opinions of the community under study.

The second focus group meeting was held according to schedule and ten members attended. The meeting was opened with a review of the role of the focus group and the reasons and purpose of the research study, as well as a review of the issues discussed in the first meeting. My reason for doing this was to ensure that the group was focused on the issue under study and that the new members were informed.

Further discussion revolved around ways of entering the community when conducting a needs assessment, the communities' feelings towards outsiders and the issue of using questionnaires as a method of assessing the need for services related to HIV.

It was decided that the members would hold community meetings regarding ways to conduct a needs assessment and would bring the communities views back to the following focus group meeting in order to plan implementation.

In the third and fourth meetings the aim was for the group to explore the most appropriate method of conducting a needs assessment in accordance with the feedback received from the community meetings. The group meeting is the key event in the participatory approach and in the life of the group (Burkey 1998:144).

Only three members arrived at the third focus group meeting. The failure of members to attend was as a result of them having other commitments relating to their respective political affiliations. The members had also failed to hold the agreed upon community meetings, and thus no feedback was forthcoming. With only three members present no meeting took place and the time and date of a follow up focus group meeting was arranged. The members' present accepted responsibility for

informing the other members. As only one member in the group could be contacted telephonically, this member was chosen by the group as the coordinator and his role was to contact the other members as and when required. Although all members had a list of meeting times and dates, the coordinator was still contacted before each meeting as a reminder.

One member of the focus group arrived for the fourth focus group meeting. As Cornwal &Jewkes(1995:1673) indicate local people may be highly skeptical as to whether it is worth investing their time and energy in the research, particularly if it seems to offer little in terms of direct benefit.

The failure of progress within the focus group process, not only had an impact on the study but also a significant impact on my confidence in the process I had chosen to undertake

Due to the setbacks, I reviewed and re-strategised my approach to the study and after consultation with my research Supervisor, I decided to recruit two additional focus groups of community members, using the same sampling technique.

The additional focus groups were characterized by homogeneity, by this is meant participants who have something in common that allows them to contribute to the study, but have sufficient diversity among the participants to allow for contrasting opinion (Krueger et al 2000:71).

With regard to the two additional focus groups, the members all belonged to the same community/neighbourhood, and also had an existing relationship with the Child & Family Welfare Society. In terms of diversity, the members were varied in age, gender, education and status within their community.

My decision to conduct two additional focus groups, and thus to deviate from the process, was as a result of the lack of participation from the members of the initial focus group and my need to ensure that I met the academic requirements as expected

in the study. By making this decision and thereby changing the process, the process became more structured in a group-work process and less as genuine participatory research.

But, as Petersen, Magwaza and Phillay (1996:72) found in their Participatory Research to Facilitate Psychological Rehabilitation Programmes for Child Survivors of Violence in a South African Community, full participation by participants every aspect of the research and intervention process may not always be feasible, depending on their level of expertise and interest demonstrated.

The decision to deviate from the planned method as stated in the proposal is that the process determined the method of this study. The unplanned termination of the participants and their personal agendas affected the process and changes were made accordingly.

Gibson & Macaulay (in Morse, Swanson & Kuzel 2001: 168), say that people become involved in research for various reasons. There are gatekeepers in communities who act as individuals but claim to represent a particular community. Selected representatives may not be able to speak adequately for the diversity of viewpoints of community members. It is suggested that the broader the base of community consultation the more validity added to the process.

A fifth focus group meeting was conducted with the newly formed focus group, which consisted of seven diverse community members. I presented the group with a brief discussion of the purpose of my study and gave feedback on the discussions held with the previous focus group. Once all members had clarity of the purpose and their role in the process, I then introduced the participatory techniques of timeline, time trend and Venn diagramming to the group in order to facilitate the process of information sharing.

Walker (in Mouton, Muller, Franks & Sono 1998:244) states that in participatory research, data is systematically collected and analyzed, the research design is flexible and may shift in the light of events. Analysis and reflection on data help to shape further action and decisions. It is for these reasons that the participatory techniques were introduced within the newly formed focus group earlier than was planned with the initial focus group.

# 3.4.2 Participatory Techniques:

The timeline, time trend and Venn diagramming techniques were used to facilitate the community members/focus group to produce and analyze their own information according to their own priorities (Cornwall et al 1999:1671).

Chambers (1997:123), refers that questionnaire surveys used to gain insights, especially for project formulation, select and simplify reality and can be misleading and reconfirm the realities of the elitists, missing local complexity and diversity. In contrast PAR methods such as timeline, time trend, Venn diagramming and matrix ranking enable local people to express their knowledge, needs, priorities and preferences.

The techniques chosen were beneficial in that they assisted the group participants to share information, and through visualization the participants were able to contradict, confirm and clarify information that was given. The techniques encouraged participants who felt less skilled to feel free to share their ideas and opinions, the techniques are not intimidating to participants who are less educated.

### 3.4.2.1 Time line / trend

As described by (Chambers 1997:118), this technique allows local people to list major local events, and people's accounts of how customs, practices and general community

life was and in what way it has changed and the impact this might have on the present functioning of the community.

## 3.4.2.2 Venn diagramming

Through Venn diagramming, local people identify individuals and institutions important in and for a community or group and their relationships (Chambers 1997:118).

# 3.4.2.3 Matrix scoring / ranking

The local people list criteria that have been identified and then rank or score each item from least important to most important (Chambers 1997:119). This technique is useful in gaining information on the community's expressed preferences and priorities.

I chose to implement the above-mentioned techniques as described by Chambers, as they are tools that encourage the focus group members to participate by enabling them to provide their own information in their own way. Information that only they have access to and cannot be provided by an outsider. This has an empowering effect on the members.

Furthermore the description of the history of the community as presented through the use of time line and trend as well as the Venn diagramming provides the researcher with a profile of the community as expressed by the community members. The community profile is an important aspect for a researcher when planning to conduct a needs assessment (Lombard 1991:251-252).

The situation analysis or community profile can be taken as an assessment of the situation within a community, by gathering information of the account of or existence

of needs and problems, and a reflection of the resources and potential of the community. This profile provides a complete picture of who and what the community consists of and should thus supply a point of departure for further planning, entering into the community and implementation of the plan (Lombard 1991: 245, 251). Lombard continues to say that the question of community needs can only be broached if the community as a whole identifies itself with the profile and that if they themselves have not identified the needs and problems, then there is little cause for community motivation or participation in the implementation of services or projects.

Therefore the choice to use the participatory techniques of timeline, time trend, Venn diagramming and matrix scoring is to ensure that the above steps of community development are correctly followed.

The technique of matrix scoring or ranking is used to express preferences and to prioritize needs. All three techniques encourage and demand participation from the community members. This is thus in-line with the phases necessary in order to conduct a viable needs assessment.

The timeline and time trend techniques were implemented to allow the group to reflect on and discuss the history of their community by looking at the population, structure, education facilities, health and welfare aspects in their community 15 years ago, and then to review the development that had taken place and the present structure and aspects of the community.

The feedback was written on a chart, for the group to view. Each piece of information placed on the chart was discussed in order to gain clarity. Displaying the data ensures that all members of the focus group are aware of the full range of information shared and can debate, contradict or agree with the information.

Visual representation is an analytic act that reveals issues and connections and encourages sharing of ideas (Cornwall et al 1999:1671). Visualization enhances the

focus group discussions. Through this process the group identify changes and development, either positive or negative.

Once the group was satisfied that all the information that they felt to be important was represented on the chart they proceeded, through the use of the Venn diagramming technique, to identify community needs, community structures, leaders and service organizations and held a lively discussion on their relationship with the community, the roles that they fulfill and the needs that should be given attention.

In the sixth and final focus group meeting; there were sixteen members made up of community members from the initial focus group, community leaders from street committees (SANCO), members from the ANC women's league, members from community based volunteer project, people living with AIDS, members of a church group, child care workers from a street children's haven, a student social worker and other interested community members.

The data collected through the participatory techniques of timeline, time trend and Venn diagramming were visually reproduced with the all 16 members. The group had the opportunity to discuss, contradict, confirm and add to or change the data viewed.

The group was encouraged to share information, either verbally or written. The information was then placed on a chart for the entire group to view.

The displayed information was then discussed. I observed that the members of the original focus group appeared to dominate the discussion and appeared to influence the importance that was placed on certain of the identified needs.

In an effort to overcome this, I encouraged the large group to form mixed subgroups. The purpose of each subgroup was to implement the technique of matrix ranking. The members of the subgroups were to discuss and list the issues or items from the most important or most preferred to the least important. In the subgroups, the less dominant members were more able to share ideas, thoughts and opinions.

Feedback from the subgroups was represented on the chart for the entire group to view and through discussion the needs assessment was conducted.

The data was recorded by note taking during and after each group meeting and by collecting the data on the visual chart. Barbour et al(1999:15), discuss that the most basic level of recording focus group discussions depends mainly on note taking and the use of a flip chart to construct, with the group participants, a summary of the meeting. Barber suggests that tape recording provides a far richer research access to the discussion. It can be noted as a possible limitation to the research that I was not able to tape record the group meetings due to the members' reluctance towards this method of recording.

In order to minimize the effect of this limitation great care was taken to check through visual feedback all information gathered. The data gathered in previous meetings was produced at the beginning of each new meeting for verification and data gathered in the present meeting was checked for verification at the end of the meeting.

## 3.5 DATA ANALYSIS

Analysis involves drawing together and comparing discussion of similar themes and examining how these relate to the variation between individuals and between groups (Barbour et al 1999:16).

The most basic method of analysis in focus groups is to identify themes, similarities and variations or differences, this is carried out by the participants themselves through the use of matrix ranking.

Analyzing focus group data involves analyzing the groups rather than the individual's perception and striking a balance between looking at the picture provided by the

group as a whole and identifying the individuals viewpoint within the group setting. One should try to distinguish between opinions expressed in spite of, or in opposition to the group and the consensus expressed or constructed by the group (Barbour et al 1999:16).

The PAR methods have been classified as visualized analysis (Chambers 1997:116), a method of reproducing data that can be shared and viewed by the participants for scrutiny. The data collected in this study was visually displayed in the focus group meetings to enable the members/participants to discuss and analyze their data. The information is visible, semi-permanent and transparent to the group and can be checked, verified, amended, added to and owned by the participants (Chambers 1997:135).

### 3.6 ETHICAL CONSIDERATIONS:

Ethical issues are relevant to all stages of focus group research design, from implementation to presentation.

The first issue is that of informed consent, the community members who participated in the focus group discussions were provided with an explanation of the reasons and process of the research study. I took careful consideration to make it clear to the participants that their involvement was voluntary, and that participation was at their own discretion. The initial focus group selected consisted of members who were an already existing group with whom I was involved, this could have had the effect of encouraging the group to agree to participate as they possibly viewed the study as an extension of the project with which we were already involved. To overcome this possible ethical dilemma, I continuously, throughout the entire process, explained the separate purposes of the focus group research and the Child & Family Welfare Society's project.

The group's permission was requested to audiotape the discussions, the groups felt uncomfortable and anxious with this, their feelings were respected and the discussions were not audiotaped. Instead, the content of discussions was recorded by means of note taking.

Although the decision not to audiotape the discussions has implications and thus limitations on the reliability of data collection and analysis, I made the decision with the view that the priority lay first with the respect for and consideration of the community members with which I was to be involved.

The second ethical issue that arose was dealing with group dynamics and power imbalances within the group. The more dominant or higher political / community role that certain members hold within their community had an effect on the issues raised and the importance or priorities placed on certain issues. The less dominant members were not confident enough to voice their opinions. Similarly, my presence, that of a known social worker of the area and of a different race group to the participants, may have had an impact on the group dynamics.

I attempted to encourage participation from all members by asking individuals for their contributions and opinions directly and by dividing the group into smaller subgroups for discussion. In these sub-groups the less dominant felt more confident to partake in discussions. I, as the researcher, distanced myself from direct involvement within the sub-groups by transferring the note-taking responsibility to one member in each group.

Baker and Hinton (in Barbour et al 1999: 95), have written that the research partnership continues after the required data has been collected. The group discussions and interactions led to expectations and plans for action. Involving community members in participatory research study highlights the researcher's

responsibility not only to the participants of the focus groups, but to other members of their community and those that work on their behalf.

In the past, the teaching of most developmental professionals has been top-down. Students are taught about people not as being infinitely diverse, but as universally standard. They become entities to be counted, or objects to be dissected, be it through census, completed questionnaire surveys or laboratory studies (Chambers 1997:60-61). Professional methods have been to extract, process and analyze data and then use it to decide what to do to, or for, the people and communities. The processing and analysis of data are private activities under the control of professionals and the plan is retained in their hands and expressed prescriptively for others (Chambers 1997:54).

The major difference between the more extractive data gathering of traditional research and participatory research is evident in roles, behaviour and attitude. In participatory research we allow the people/research participants to take the lead to determine much of the agenda, to gather, express and analyze information and to plan (Chambers 1997:131).

The role of the researcher is that of facilitator, learner and consultant. Outsiders do not impose their reality, but encourage and enable local people to express their own (Chambers 1997:131, 103).

In considering the ethical issue that research should not only be for the benefit of the researcher, but that it should be used to enhance or plan services that will benefit the people involved in the research and the broader community under study. I have informed and consulted with the Child & Family Welfare Society rendering services in the community and have provided feedback to the society on the progress of the research.

It is for the above reasons that the information gathered in this research study will be provided to the Uitenhage Child & Family Welfare Society, to enable the service provider to continue with the process that was begun with this study.

Furthermore I have held discussions with the organization, regarding their commitment to use the results of the needs assessment to plan and initiate projects or services, in consultation with the members of the focus groups.

### 3.7 STRENGTHS AND WEAKNESSES OF FOCUS GROUPS:

## 3.7.1 Strengths

The use of the focus group method is highly efficient in that the sample size can be kept fairly small and can be increased as the need arises, and the time taken to gather information is reduced in comparison to questionnaires or individual interviewing.

Focus groups have the ability to produce concentrated amounts of data on precisely the topic of interest and give access to a wide range of topics that may not be observable (Morgan 1997: 14).

Consensus and diversity in the focus group discussion can provide direct data on issues. Quality controls are placed on the data collection in that participants check, confirm or dispute each other's views (Morgan 1997:15).

Through focus group discussions community members are encouraged to become involved in identifying their needs and providing ideas and thoughts on solutions to these needs.

The techniques of timeline, time trend, Venn diagramming and matrix ranking enables all members of the community, no matter how unskilled, to contribute By sharing ideas and expressing preferences, all community members are able to participate, not only an elite few (Morgan & Krueger 1997:17).

#### 3.7.2 Weaknesses

There are practical or logistical problems for focus group members, especially members of disadvantaged communities, with regard to travel or transport to and from the venues of focus group meetings.

The researcher is driven by his/her interest and research aims and must at times direct and maintain group focus on the research issue. Maintaining group focus could influence the group interaction (Morgan 199714). Although there is no hard evidence that the focus group facilitator's impact on data is any greater than that of the researcher's impact in participant observation or individual interviewing.

Researcher/facilitator influence on data is an issue in almost all qualitative research.

The group members may influence the nature of the data it produces, by their level of involvement with the topic of study, too low involvement would mean scattered information is collected and too high involvement, with participants having their own agendas, forces the facilitator to work hard to control the discussion (Morgan1997: 15).

Focus groups offer a compromise between the strengths of participant observation and individual interviewing. As a compromise between the strengths and weaknesses of these other two qualitative methods, focus groups are not as strong as either of them in their specialized domain. The respective weaknesses of participant observations and individual interviewing however, allow focus groups to operate across traditional boundaries. This flexibility may be the greatest strength of focus groups (Morgan 1997:16).

#### 3.8 LIMITATIONS OF THE STUDY:

The lack of attendance and the premature termination of certain members from the focus group can be contributed to the reality that members are more concerned with securing the basic necessities of life, Cornwall (1995:1673), especially when considering that the target community has a high unemployment rate and poverty is rife. The methodology chosen allows for the participation or involvement of members to be unpredictable causing various fluctuations as interest wanes.

The deliberate choice of the committee members as the initial focus group, had unforeseen consequences, in that the information could be manipulated to suit personal agendas. The inclusion of two additional focus groups of community members was a deliberate attempt to address this.

The non-probability sampling method used is limited in terms of representativeness (Marlow 1998:136), and the outcome of the data collection can then not be expected to be generalized.

A further limitation is that of the linguistic differences between the members of the focus group and myself. Chiu and Knight (in Barbour et al 1999:102), note that for qualitative researchers, linguistic and cultural skills are crucial in the access to and accurate interpretation of experiences of group members. Although the group discussions where conducted in English and members were able to communicate and understand, from time to time side conversations would take place between members in their home language, Xhosa.

HIV as an issue in the target community appears to be seen as a low priority in comparison to the more pressing material needs, due to the economically deprived situation of the community.

An examination of the limitations of this study would not be complete without discussing my own weaknesses and precincts within the research process.

Firstly, my lack of knowledge and experience with the application of participatory techniques and processes, resulted in the process being rather unstructured in the beginning and had I possibly, introduced the PRA techniques earlier, the unplanned termination of members may have been prevented.

My anxiety to obtain results could be seen as a limitation in hurrying the process, instead of allowing the process to proceed more slowly, which would have been more empowering to the community members.

As a result of the above-mentioned limitations or weaknesses that arose in the process, the group interaction took on a more structured form, that of group work process and less in the line of true participatory process. The research study was successful in that community members of the target community participated from the implementation of the method of data collection through to data analysis. The use of participatory processes to facilitate empowerment in the target group and community is limited.

My argument for stating the above is that the participants were not involved at every level of planning, execution, decision making and reporting, as I, as researcher, made decisions that affected the process by introducing extra focus groups and implementing the techniques.

The members did not themselves, after the process, initiate any action from the data gathered, but instead expressed the need for the information to be provided to a service provider to initiate action in consultation with the community .The process was started, data gathered, but action still needs to take place.

The participatory methods used in this study, were useful tools to enable the community participants to express their view and feelings and to establish needs that the community consider priorities. These contrasted with what service providers

consider priorities; this process was a learning experience for the researcher as well as for service providers in the particular community. The information gained is a useful tool to assist in ongoing planning and service provision for the community.

## 3.9 CONCLUSION:

Participants should ideally be involved at every level of planning, execution, reporting and action or implementation. This ideal is not always possible, particularly when participatory research is conducted on issues that are generally given low priority by deprived communities due to pressing material need (Petersen, Magwaza & Pillay1996:72).

In this chapter I have tried to describe the methods used, from recruitment and selection of members, through to the data collection process and analysis, taking into account the ethical aspects and the strengths and limitations of the research process undertaken.

# 4. CHAPTER 4: DATA ANALYSIS AND FINDINGS

# 4.1 INTRODUCTION:

My aim in collection and analysis, is firstly, to gather information on the research goals:

- ➤ the most appropriate way of conducting a needs assessment relating to HIV/AIDS services in a particular community;
- to design a needs assessment tool, which could be implemented in the community;
- > to use the analyzed data to describe a process of implementing a sustainable service.

Secondly, the answers to these questions will hopefully assist the Uitenhage Child & Family Welfare Organization to understand the dynamics and needs of the particular community in order to plan programmes and services accordingly.

According to Huberman & Miles(in De Vos 1998:340), the three sub processes of data analysis occur before, during and after data collection.

The data, in this study, was analyzed by drawing on Huberman and Miles' three sub processes; data reduction; data display and data verification.

Huberman and Miles's three sub processes are relevant to this study in that they facilitate the analysis of data and correspond with the application of the participatory techniques used within the focus group discussions.

Participatory action research methods usually engage the analysis of local people, enable the expression and sharing of their diverse and complex realities, give insight into their values, needs and priorities and can also lead to action.

For this reason, this study was conducted using participatory action research approaches. This approach was carried out by implementing the PAR techniques of timeline, time trend, Venn diagramming and matrix scoring/ranking through the use of focus group interviews of selected members of the target community.

Methods such as timeline/ trend, Venn diagramming and matrix scoring amongst others have enabled local people to express their knowledge, priorities and preferences. Local analysts are often committed to ensuring information is complete and accurate. As no methods are foolproof, room is made for triangulation and cross-checking (Burkey 1993: 123).

My analysis was conducted using the above-mentioned methods, and will be discussed further in the chapter. Burkey (1993:64); participatory action research is essentially an on-going process of analysis - action - reflection, as follows;

#### FIGURE I. PARTICIPATORY ACTION RESEARCH:

# ANALYSIS ---- ACTION ---- REFLECTION REFLECTION ---- ACTION ---- ANALYSIS

As Comstock and Fox (in Burkey 1993:63-64) point out, the validity of the results of participatory research can be gauged first, by the extent to which the new knowledge can be used to inform collective action and second, by the degree to which a community moves towards the practice of self-sustaining process of democratic learning and liberating action.

A true development process is based on a continuous series of analysis - action - reflection - action. Beginning with awareness and analysis, local people must mobilize their own resources and link into sources of external credit and technical assistance in order to initiate action. When the action has been taken, the results are

reflected upon, these reflections lead to a new analysis and to new action, and the development process hopefully continues (Comstock et al in Burkey 1993:64).

Participatory action research takes place in time as part of the analysis-action-reflection process, with the clearly defined purpose of creating knowledge to be shared by both the people and the researcher; knowledge that leads to action and through reflection to new knowledge and new action.

This study created knowledge that was reflected upon and reassessed. Knowledge was thus generated, which will lead to action in the future.

#### 4.2 PROCESS OF ANALYSIS:

In Chambers(1997:158), the process of analysis is diagrammatically described as follows:

## FIGURE II. GROUP VISUAL SYNERGY:

(facilitator- initiates - observes - assess)

(group - cumulative process - visual - cross checking/triangulation - group)

A group visual synergy often develops with cumulative group enthusiasm, adding and amending detail in order to create a complete and accurate picture. Outsiders initiate, facilitate and then critically observe the process of analysis, especially visual analysis by groups. In contrast with most questionnaire surveys, this group visual analysis gives the observer time and freedom to watch interactions, to see how much cross-checking and correction take place, to assess commitment to presenting complete and accurate information and to judge whether information is being distorted or withheld (Chambers 1997: 159).

Through discussion the focus group members determined the topics. They gathered, expressed, prioritized and analyzed information. The three dimensions described are relevant to the study as they are compatible with the data analysis process conducted in participatory research. The data was analyzed by using the following three dimensions, as referred to by Marlow (1988):

- > descriptive accounts
- > constructing categories
- > validation

## 4.2.1 Descriptive Accounts:

The basis of qualitative analysis often consists of description, this includes observations, interviews, case records or impressions of others. These accounts are referred to as case studies. Case studies can take the form of practice evaluation or in reference to this research study, a description relating to a needs assessment for services (Marlow 1988:209).

## 4.2.2 Constructing Categories:

Patterns, themes and categories emerge from the data rather than being developed prior to collection. There are two main strategies for identifying categories once the data has been collected: indigenous and researcher- constructed categories (Marlow 1988:211).

Marlow refers; indigenous categories are constructed from data using the elicitation technique of frame elicitation. This approach works well for needs assessments when gathering data on services needed. By using indigenous categories one can be assured that the information gathered is from the client's perspective. Indigenous categories are recurring patterns or themes in the data, these are identified through the process of visualization - analysis- reflection (as illustrated in figure I) within and by the participants of the focus groups.

#### 4.2.3 Validation:

The process for validation of qualitative data include consideration of rival or alternative hypotheses, consideration of negative cases, the process of triangulation and preservation of the context of the data. With respect to the study undertaken, I made use of triangulation. Triangulation involves different research approaches to the same research question. Using triangulation may result in what appears to be conflicting data, this does not automatically invalidate the data, but adds another dimension to our understanding of the topic under study. In my study this is evident in that using different focus groups elicited contradicting information. The choice of the PAR method also caused the process of data collection and analysis to be rather unpredictable (Marlow 1988:219).

In this study I made use of two approaches; visualization and different sources.

Through the use of visualization, the data received could be cross-checked by the participants, argued against or agreed to. Triangulation by different sources was achieved in this study in that I introduced two extra focus groups to the process and all information obtained in each session was replicated in the following group sessions for reflection and verification. Furthermore, three participants were taken from the focus groups and individual interviews were held.

Themes/categories and perceived needs which had been expressed in the focus group meetings were put to the individual participants for comment, as well as my own questions relating to certain aspects of the process.

The information of the three individual interviews was compared to the data expressed in the focus groups for verification and clarity.

#### 4.3 DATA DISPLAY:

Five focus group meetings were held with the initial sample chosen. The first meeting held was to workshop needs assessment tools and methods and thereafter further group discussions were held.

The participants that made up this group were an already established committee who were involved with the Welfare organization in a pilot project related to HIV/AIDS. The group was made up of ten participants. The committee members had been involved with the Organizations pilot project for approximately 12 months. This first focus group meeting was held 4 weeks after the initial workshop on participatory methods.

# 4.3.1 Focus Group 1

I will provide a descriptive account of this first focus group meeting. The purpose of this discussion was to create a baseline for the group and myself to first develop awareness and understanding of each member's perceptions on the issue of HIV/AIDS, before proceeding to explore how their community perceives the issue. This was done by facilitating open communication and the participants directed the flow of discussion.

Eight out of the 10 members participated in the first focus group meeting, and the discussion revolved around the participants' feelings, concerns and understanding of the issue of HIV/AIDS. During the discussion the participants at different times veered off the topic of HIV and introduced the issues of poverty and unemployment.

In discussing the issues of poverty the participants expressed strongly that job creation and income-generating activities were seen as part of the issue surrounding any programme or project relating to HIV. As the group participants came from the community that is disadvantaged and only three of the eight participants had stable

employment, it became evident that any service aimed at prevention or caring, was not only viewed from a health and social perspective but was viewed firstly from an economic perspective.

This relates to Maslow's (in Biesheuvel 1997:304), theory on hierarchy of needs, in that without jobs, basic needs may not be satisfied and higher needs may not emerge. Therefore, the issue of HIV/AIDS is not given the same priority, as that of finding food and shelter.

Furthermore the issue of secrecy was raised. People in the community were afraid to be exposed and hesitant to talk about the issue of HIV, instead the true illness of a family member would be hidden and the family would tell other community people that the member was suffering or had died from TB or cancer.

In this respect the focus group participants differed in their opinions. Five participants said that people in the community were afraid to talk about HIV, whereas three said that the people do talk about HIV. With the concept of home-based care, the issue of people being visited in their homes by caregivers came up.

These visits would expose the family to the community and neighbours who would then know that they were affected by HIV. The five participants then contradicted themselves by saying that the people would accept being visited in their homes and would want these visits. It is thus clear that the participants interest in the homebased care project and the anticipated financial benefit from this had influenced the information given.

On reflection, the information gained from the eight participants is open to distortion due to the group's existing involvement with the Child Welfare Organization's

home-based care project, and this information will need to be cross checked, by using triangulation and by consulting different sources, such as including additional participants in the focus group.

Through the use of the indigenous categories approach, the following categories were identified for further reflection, discussion and analysis:

- > poverty
- > unemployment
- > financial assistance
- > home-based care project

The problem of HIV/AIDS and its impact on the community appears to be seen only as a priority issue in relation to the above categories.

# 4.3.2 Focus Group 2

Six members of the first focus group attended and four additional participants were included. An interval of two weeks existed between the first focus group meeting and this one.

The information shared in the first meeting was reflected upon, discussed and further reflected upon. Action occurred in the form of planning. Through this method the group concluded that a questionnaire survey or large community meeting was not the most appropriate tool to use to do a needs assessment in their community.

The participants proposed that, the involvement of small groups of key people be elicited who would then facilitate the process within the broader community. The key people would take the information to the broader community and would gain feedback for the focus group meetings discussion, reflection and planning.

The purpose of the information sharing in focus group interviews one and two was to find answers to the first two critical questions of this study. The data gathered did answer critical question one and partially answered critical question two, in that consultation with the community was planned as were further focus group meetings. This was then the action agreed upon after reflection and analysis took place.

# 4.3.3 Focus Group 3

The third focus group meeting was held after a three week interval. The purpose of this meeting was to gain feedback from the key members on the communities' opinions relating to the conducting of a needs assessment relating to HIV/ AIDS services. Only three participants arrived for the meeting. The failure in attendance can be attributed to key participants having community/political commitments to attend to, as well as lack of motivation, and failure to see direct benefit for themselves in following the process.

The lack of attendance highlights the difference in priorities between community members/research participants and the preconceived priorities that Service organizations and social workers have when engaging with a community. The differences in priorities relate to the problems experienced by the Thandanani Association based in Pietermaritzburg, namely logistical problems such as lack of transport resulting in participants having to walk long distances making attendance at meetings difficult; community leaders having other priorities such as local elections; the communities lack of trust in the ability of the NGO to deliver and the need for the project to establish itself as credible.

# 4.3.4 Focus Group 4

The purpose of this meeting was to redefine the data collection method through the implementation of the participatory techniques of timeline, trend and Venn diagramming. Only one participant arrived for the meeting. It was quite apparent that the participants did not view the research process and their involvement in it as beneficial. Participatory literature confirms that to local people, especially those in disadvantaged communities, want and need is often not what they are thought to be by professionals in Service Organizations (Chambers 1997:179).

# 4.3.5 Focus Group 5

In order to overcome the difficulties and gain further data, a meeting was held with a newly selected focus group. I facilitated the gathering of data by implementing the participatory techniques of time line, time trend and Venn diagramming. The data was displayed and analyzed through the use of indigenous categories, thereafter data verification was carried out through the process of validation, using triangulation.

Data gathered in the previous focus group meetings was visually displayed to allow the group, to comment, disagree, change, add to or confirm the information represented. This relates to the analysis diagram (Figure III) of group- process of providing data - visualization- cross-checking/reflection - back to group for verification.

The data gathered confirmed and contradicted the data gathered in the previous focus group meetings. The participants confirmed that economic issues were a priority in their community. The participants were also in agreement that a questionnaire survey is not an appropriate method of conducting a needs assessment in their community, but proposed the targeting of community groups of key people.

The participants did not however place home-based care as a priority, in that they argued that visits targeting homes of HIV affected people would expose the people. This also confirms the issue of secrecy discussed in the previous focus group meetings. There also appeared to be disagreement surrounding the identification of key persons or community leaders, between this group and the previous focus group.

# 4.3.6 Focus Group 6

A sixth focus group meeting was held where all the data gathered in the previous five meetings would be analyzed and reflected upon and verification would be sought. This meeting consisted of 16 participants, comprising of six participants from the initial focus group, five members from the second focus group formed and five additional community members there were selected to participate in the process to add further depth and variation to the analysis. One of the reasons for forming this combination focus group is the fact that data from the focus group participants reflected that the most appropriate method of conducting the needs assessment, is by approaching groups of specific community members.

Through the reproduction of the participatory techniques of timeline, trend and Venn diagramming, the processes of data reduction, data display and data verification were carried out. The data was reduced by method of constructing categories that were visually displayed and analyzed, by the participants, through discussion, reflection and further analysis.

The following themes or categories were constructed;

- > poverty
- > unemployment
- > education
- awareness
- > home-based care

- > health services
- > housing/sanitation
- > welfare services
- > community involvement

Through my observation of the group process it became evident that the members of the initial focus group (the Child Welfare pilot project committee members), were dominating and influencing the group to place emphasis on the home-based care concept. In an effort to limit this control the group was divided into three subgroups. Through the participatory technique of matrix scoring/ranking the participants in the subgroups expressed their preferences regarding services by prioritizing the identified themes. The themes were ranked: most important, important and least important. The data was displayed visually to elicit discussion and verification.

The most noteworthy finding was that the subgroup that did not have a participant from the initial focus group, did not make mention of home-based care in their ranking.

FIGURE III: THE MATRIX RANKING

	Most important	Important	Less important
Home-based Care	* *	*	
Education/Awareness	*	* *	
Increased Health Services		*	* *
Improved Housing and Sanitation	* *	*	
Unemployment	* * *		
Poverty/Neglect	* * *		
Welfare Services		* *	*
Community Involvement		* *	*

In determining the perceived needs of the community with regard to services relating to HIV/AIDS, the issues of poverty and unemployment were ranked highest, with improved housing, sanitation and home-based care a close second.

Following on this came the issue of education and awareness especially within the schools and with the youth; more involvement and visibility of welfare organizations within the community; as well as the importance of motivating the community themselves to become more involved in income-generating projects. Improved health services were rated of lesser importance.

#### 4.4 INDIVIDUAL INTERVIEWS:

To ensure validation, I implemented the triangulation approach of different sources by carrying out individual interviews with three of the focus group participants (Marlow 1988:216). The data analyzed, through the method of matrix ranking/scoring, was presented to the individual participants for reflection, analysis and verification (Chambers 1997:134-135). The matrix diagram as depicted above was presented to each individual for comment and explanation..

## 4.4.1 Home-Based Care:

Home-based care was only expressed as a top priority by Mr. K. It is interesting to note that Mr. K. is a committee member of the Child Welfare pilot project. The other two participants interviewed, mentioned that home-based care should be given consideration and may become important in the future, but they placed no immediate emphasis on it as regards a service or project that they feel is presently needed by the community.

#### 4.4.2 Education/Awareness:

All three participants responded that education within the schools and especially with the youth is of extreme importance and that programmes in schools in their community is limited.

## 4.4.3 Improved Health Services:

Mr. K. commented that a clinic is needed in the community so that ill people do not have to walk far to neighbouring areas to obtain care. Mrs. S. commented that she would like an increase in the mobile clinics visiting the area. Mr. M. felt that the health services in existence are sufficient.

## 4.4.4 Improved Housing and Sanitation

All three participants responded that housing and especially improved sanitation was a priority in the community, in that poor housing and sanitation leads to people falling ill with TB and other illnesses. Mr. K made mention of the housing development project that is being planned for the community and the impact that this is having on the community and community leaders, in that each individual is struggling to secure his/her plot.

# 4.4.5 Unemployment:

Once again all three participants expressed the problem of high unemployment in their community and lack of work opportunities. Mr. K. and Mr. M. remarked on the unwillingness or inability of community members to offer their services voluntary to programmes or projects as people want payment in order to put food on the table. They both used the example of food gardens where only a few community members

are willing to work as benefits are not gained immediately and most people need instant remuneration.

# 4.4.6 Poverty:

Poverty, as with unemployment, was seen by all three as the greatest problem in their community and the priority need finding ways to combat this.

Mr. K. and Mrs. S. both referred to the high incidents of neglect in their community, especially that of neglected children, as a result of poverty.

#### 4.4.7 Welfare Services:

Mr. K. stated clearly that he viewed the Welfare's role, with reference to Uitenhage Child & Family Welfare Society, as being to assist with the construction of or obtaining of donations/sponsorship for the construction of an office in the community where the "group" (group being the project committee) can operate from to provide services to HIV affected people. Furthermore, that the Society continues working with the "group" to further the HIV home-based care project.

Mr. M responded that if the Welfare wished to initiate programmes or projects in the community, they should approach the community through community groups and establish relationships with these groups to firstly determine community needs. Such groups being Women's groups or church groups.

Ms S felt that the Welfare needed to be involved in the schools presenting school programmes as she felt that this is lacking in their community.

All three individual participants stated that homes for orphan babies were to them not a priority as they could not identify orphans in their community. They did say that, there is a need to care for the high number of neglected children. They could identify numerous families who were struggling to care for their children due to lack of income

Two participants mentioned the increase in alcohol abuse and the impact that they perceived this to have on the HIV epidemic. Mr. K stated that alcohol abuse leads to sexual promiscuity in young people as well as rape, which impacts the spread of HIV.

Mr. M commented that people abuse alcohol when they find out that they are HIV positive as they are afraid, this in turn affects their state of health even more.

Both Mr. K and Mrs. S said that people in the community talk about TB, but not about HIV/AIDS.

Mr. K continued to advocate for home-based care as a priority, this can be seen in light of the fact that he is a member of the committee involved in the Child Welfare project and wishes to promote this for the benefit of the committee or group, as he continually, throughout the interview referred to "our group". In contrast Mr. M mentioned that home-based care would be a benefit only once the community had become more knowledgeable and the stigma of HIV had decreased amongst people Ms S made no comment on the issue of home based care.

## 4.5 DISCUSSION OF FINDINGS:

As the community is a semi-formal settlement inhabited by people migrating through necessity and is expanding and changing constantly, it cannot be described as homogeneous. The preferences expressed must be considered with this in mind as well as the socio-economic factors and participants' personal agenda's.

The data reflects that the community, in analyzing their needs with regard to services needed relating to HIV/AIDS, has prioritized poverty, housing, sanitation and unemployment. HIV to this community is seen as a health problem that is aggravated by poor socio-economic aspects. I am acquainted with the community under study

through my work at Uitenhage Child & Family Welfare Society. The community is characterized by high unemployment, alcohol abuse, child neglect, material need, stress experienced from cuts in maintenance and disability grants, poor infrastructure, increase in population and teenage pregnancies. It is therefore understandable to me that the community has prioritized as above.

Russel and Schneider (2000), found in their study that the containment of HIV and the health of HIV/AIDS affected persons are influenced by poverty and other socio-economic factors. Further literature (Desmond et al 2000:5-6; HEARD 2000:11-13), confirm that HIV/AIDS affected households and communities suffer economic consequences. As breadwinners within the households fall ill or die there is a reduction in income and thus in food security and a danger of malnutrition and sickness occurring. Children who have lost a parent or parents through AIDS related deaths are the most vulnerable.

From discussions with the Service Organization in the particular community, it is apparent that they feel that while they do have a role to play with regard to services relating to HIV/AIDS, they are not sure as to what or how they plan to fulfill this role. The service organization has had a tremendous turnover of staff since March 2001 and the target community's social worker was one of the staff members who left the organization. The rendering of programmes in the particular community has been put on hold.

The Organization stated that the results from this study would be a useful tool for them to plan services in the New Year in consultation with the community members. As a number of the social workers are new and inexperienced, training in participatory methods and techniques would be necessary in order to plan and initiate a project in the community. The Organization is presently involved in the training of community groups in HIV/AIDS counseling and care. This is being facilitated by their consultant from the National Council for Child Welfare.

As I was conducting a needs assessment, the participatory method of focus group discussions and the techniques implemented I believe were an appropriate choice for this study. As described by (Morgan et al 1997:15), focus group discussions provide concentrated data on the topic of interest and give access to the inclusion of other topics that may not be observable. Information gathered can be disputed or verified by the participants and enhances participation. The community is large, with high illiteracy rates and therefore a questionnaire survey would not have been plausible.

Furthermore the PAR techniques used encouraged participation and verification from the community and this ensures that the needs expressed are those of the people and not of the service organization or researcher (Chambers 1997:134).

Given the time constraints the method used was time saving in comparison to lengthy interviews or large surveys

#### 4.6 FINDINGS:

# 4.6.1 Participation and Community Development:

Lombard (1991:108) writes that for many first world countries the concept of development means technological progress and economic growth. This concept resulted in supplying the so-called backward communities with financial and technological means to improve their living conditions.

However, it was soon realized that resources and technology, which are available to a large extent may well be necessary for development, but are inadequate as means to an end. It is essential that people are motivated to apply resources in a rational way and that it is of utmost importance to bear in mind that development is for the people who are in need of it and that those people are experts in the art of survival. Their expertise should be utilized. Thus people skills and participation are of the utmost importance in the development process. People are both the target and the instrument of development. Many failures of developments in the past can be attributed to the

fact that the needs and expertise of those at whom the development was directed had not been adequately taken into consideration (Lombard 1991:108-109).

In the past, development in South Africa (prior to 1994), especially in the non-white communities, was implemented by experts deciding beforehand what would be best for the communities and then attempt to combine the programme decided upon with the needs and decisions of the community (Lombard 1991:114).

According to Masqashalala (in Lombard 1991:114), this is an important aspect when defining community development amongst the black people in South Africa, because the needs of the community are often not taken into consideration. The 'experts' act as if they know what is to the good of the community, they design programmes for them according to their own point of view and then submit these plans to the community for their approval. This causes people to be manipulated or forced to take action. When planning and implementing community programmes, the community should first be granted the opportunity to realize the needs and problems regarding the programme on their own, before it can be expected of them to give their support.

Morse, Swanson & Kuzel (2001), support Lombard in saying that the exclusion of the community from the research process results in inappropriate interpretations of data/needs and results in lack of actual benefit to the community. Thus the objective of participatory research is to create knowledge that is both relevant to the community needs and reflects the interests of the community.

The study undertaken can be said to have achieved this, in that, through the focus group discussions the community members participated in sharing the knowledge of their community and identifying needs and priorities. The information gained through the community members' participation will be used to plan services as they have prioritized. By first gaining information from the target community on their needs, it brought to light the disparity between the needs that the service providers perceived as

necessary and the actual needs felt by the community members. For example, homebased care was taken as the project to be initiated in the community.

Although home-based care was highlighted as a possible future need, the community identified other needs that were of greater urgency to them; namely, the need for job creation, material assistance, increased welfare services to assist with the high incidence of child neglect and family breakdown through alcohol abuse and increased knowledge of HIV/AIDS especially with the young people, as well as improved housing, sanitation and increased health care services within the community.

In a society where the HIV infection prevalence rates exceed 20% in several parts of the country, many children are made vulnerable because of the stress on services caused by the epidemic, the loss of skilled individuals from civic structures and the distress of a nation both confused and grieved by widespread illness and death (Richter 2001:30).

It is true that on the extreme end of the continuum are children affected by HIV/AIDS in particular identifiable ways. This extreme end includes, children either HIV positive, sick, dying or who have a parent who is sick or who has died. HIV/AIDS has an enormous impact on affected households, worst hit are communities who are already weak, with no savings, inadequate infrastructure and limited access to basic services. Further impact of the epidemic is on the socio-economic conditions, it is estimated that 61% of children in South Africa live in poverty. This situation is exacerbated by the distress and need associated with the HIV/AIDS epidemic (Richter 2001:32).

Social workers dealing with the problems surrounding HIV/AIDS in South Africa are called upon to deal with a unique mix of people and cultures in the context of unique time and place in history. Interventions and programmes devised elsewhere cannot simply be transferred and implemented in this country without careful consideration of their suitability to this particular practice context (Woods in Gray 1998:194).

HIV/ AIDS forces people in all communities to confront seriously issues relating to sexuality, which under normal circumstances are often left unaddressed. It also forces individuals and communities to confront human mortality.

The reaction by society to people with HIV/ AIDS provides a further issue that of stigmatizing and prejudice.

Social workers, operating in the wider human sphere, from interpersonal level through to the level of policymaking, cannot ignore challenges such as described above. It is evident that for social worker to deal with the impact of HIV/AIDS, different strategies need to be adopted and initiated. Literature accessed in this study has indicated the relevance of community -based initiates in coping with the epidemic, together with community participation, mobilization and empowerment of communities.

What can be deduced from the above is that when planning services relating to HIV/AIDS no one project will sufficiently meet the communities' needs. Services should be of a holistic nature and the importance of Welfare organizations to network with other services providers to render this service must not be overlooked. It is obvious from the above that a Welfare organization working in isolation will not be able to render an effective service that will enhance the quality of life for the community affected by HIV/AIDS.

A further finding was the misconception that communities are homogeneous entities with strong cohesiveness, values, sentiments and ideologies, when in reality the community is made up of a heterogeneous group of people, with multiple interrelated axes of differences, including wealth, gender, age, religion, ethnicity, power, status, interests and value. This was made clear by the inclusion of two newly formed focus groups to the process. Members from the different focus groups had firstly, varying motivations for participating in the process, different loyalties and status within the community and this in turn affected the weight attached to certain needs, when prioritizing. Although the differences are highlighted, it is important for service

providers to take these into consideration. Once the differences are acknowledged, it is then possible to identify commonalties in interests and needs.

One way to prevent one interest group from dominating the process of identifying needs, is by the inclusion of a wide variety of community participants that is practically and ethically possible in order that ideas, information and needs can be checked and verified by the community members themselves in order to achieve consensus.

In South Africa the success or failure of community and social action, should be seen against the background of another influencing factor, namely the pluralistic society. The Third and First World components which comprises the South African society, has resulted in divergent degrees of disparity in the various population groups (Lombard 1991:100).

Seen against the possibility that community action in South Africa may be the result of social, economic or political considerations, this means that not all forms of community action will necessarily improve the interests of each person or group or even community. The demand is on social workers to bring about reform by means of methods which are ethically acceptable, rather than on the basis of an overriding political principle (Lombard 1991:100).

Taking this into consideration, implementing participatory approaches to achieve community action can be viewed as an ethically acceptable method and was found to be so in the study undertaken and in the literature reviewed.

## 4.7 PARTICIPATORY APPROACHES:

I believe the study showed that the use of the participatory methods and techniques to facilitate the needs assessment process was the most appropriate method of achieving the goals of the study.

The participatory techniques complement the process as described in community development (Lombard 1991:252-253). The techniques of timeline and time trend, were used to gather information about the community and form a community profile, which is the first phase of community development. This being the situation analysis or community profile. Venn diagramming was implemented to identify needs, problems and resources, which is the second phase of community development. Finally, the prioritizing of needs and problems was fulfilled through the implementation of matrix ranking.

Community development is a process that is followed by most social workers and Welfare organizations and it is then important that this study illustrates the connectivity between participatory methods and techniques and the phases of community development. From my experience within the welfare field, most social workers are knowledgeable on the process of community development, but have limited knowledge of the participatory techniques. I believe that this study showed the usefulness of implementing these techniques in encouraging community members to feel secure to share information, ideas and to identify their own needs. This in turn enhances the relationship between the community members and the facilitator or service provider as the members feel that they have been acknowledged and that their views are important. Furthermore, it helps to ensure that the project or programme is what the community need and thereby improves legitimacy of the project or programme within the community and support thereof (Lombard 1991:114).

The use of participatory techniques is an appropriate method of conducting a needs assessment in the target community as the techniques encourage participation,

dialogue and sharing in a manner, which is acceptable to all community members, no matter if, they are skilled, unskilled, literate or illiterate (Chambers 1997:161). The techniques then ensure that people are not excluded because they are lacking in some manner. A questionnaire is an example of a method that would exclude a number of people who are illiterate and inhibits people's freedom to share alternate views and opinions.

The extent of the usefulness of participatory approaches depends on the knowledge and skill of the facilitator and the time available to the person in order to conduct the process. A facilitator must have acquired a sound knowledge of the techniques and methods of implementation before embarking on engaging community members in the process. If the facilitator is insecure regarding the techniques and methods this will impact on the process by affecting smooth progress, community members motivation and the level of empowerment that is achieved. This study showed clearly how the process was affected by the researcher/facilitator's limited experience with the implementation of the participatory techniques.

It must be noted however, that the facilitator's limitations are not the only factors that affect the community members' motivation and participation within the process. As discussed in prior chapters, motivation and participation of community members are affected by a number of aspects, such as inability to see direct benefit for themselves, practical issues such as transportation, commitment to securing basic needs, local and political priorities, lack of interest and personal agenda's not being met (Cornwall et al 1995:1672).

## 4.8 HIV/AIDS AS AN ISSUE:

The study found that the target community's understanding of HIV/AIDS and its impact is rather limited to that of a health issue. Services needed in relation to HIV/AIDS relate to caring for the sick in the form of food, blankets, medicine and other services, which focus on improving the conditions of the sick in order for them to be able to fight the illness. Focus on prevention through behaviour modification of those not yet infected was limited to the youth and school-going children. The participants did not identify AIDS orphans and they were thus not able to visualize the long-term impact that would result in AIDS orphans. This is due to the fact that the target community's energies are directed to issues of poverty and reducing their poverty situation. The AIDS orphans issue is not an immediate need and therefore the priority, as described by Maslow in his theory on the hierarchy of needs, is to satisfy the lower basic needs before priority can be given to other needs (Maslow in Schultz 1990:318).

A holistic approach is needed in service rendering by addressing not only the HIV/AIDS infection, but poverty, concentrating on income-generating projects, improving accessibility to obtaining family support grants and employment opportunities, as well as educating communities in order to break the myths and stigmatization attached to the issue of HIV/AIDS.

Another important factor is networking and genuine partnership between government, NGO's, health services, CBO'S and communities.

Thus when planning services relating to issue of HIV/AIDS, service providers need to develop an integrated approach to service rendering.

# 5. CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

#### **5.1 INTRODUCTION:**

This study had set out to find the most appropriate way to conduct a needs assessment relating to HIV/AIDS in the target community and to design and implement a needs assessment tool. The ultimate achievement is to describe a process of implementing a sustainable service through the analysis of the data collected and the use of the assessment tool.

The assessment process was conducted through the use of participatory methods and techniques. The strengths and limitations in using the participatory approaches within this study will be discussed in this chapter.

#### 5.2 CONCLUSION:

In assessing the process followed and the data generated, I feel that it was an appropriate method to enable the community to express their needs and to ensure that the data analyzed was true to the participants.

I believe that if Organizations wish to conduct research using PAR approaches, then training in the methods is necessary as well as sufficient time to conduct the process thereby enhancing the empowerment potential.

I believe that the findings of my research, although not universal, could be replicated by the Child & Family Welfare Organization for a needs assessment programme. Alternatively, they could form the basis in the planning of programmes or services with respect to the community under study. I am unable to answer whether the findings can be used to implement a sustainable project or service. I feel that the findings are too limited to assess the level of sustainability.

A limitation of the study undertaken, is that the process cannot claim to have achieved true empowerment and community mobilization, as it was conducted in a more structured group work method due to limitations with regard to the application of participatory methods and techniques. The study is limited to data gathering, data analysis and verification of data, actual action must still take place.

A lesson that I gained was that communities are not homogeneous especially disadvantaged communities and individuals often act in their own interests rather than for the common good.

Although the PAR process did not facilitate immediate action with regard to services in the community, the information gathered, lessons learnt and limitations experienced, are in my opinion valuable to the Welfare Organization's plans to initiate programmes in the particular community.

Participatory approaches hold considerable promise for sustainable projects and programmes, but these in turn will require new forms of planning and evaluation. Participatory processes involve intensive time, training and manpower, this will place pressure on organizations to redefine their structures and their mindsets.

When approaching the issue of HIV/AIDS, education within the community, with adults as well as the youth and children, is a first step to developing better understanding on the issue and its impact.

Another important factor is for service providers to develop credibility and visibility within the community, in order to facilitate the entry process and to ensure greater community participation and eventual sustainability of projects and programmes.

South African social workers have not undertaken empirical assessments and

South African social workers have not undertaken empirical assessments and evaluations of their interventions and use these as basis for further planning. Social workers seem satisfied to move from one activity, programme or project to the next.

This is a dis-service to recipients of services and to the social work occupation as a whole (Woods in Gray 1998:197).

The social workers role must thus become that of communication facilitator, relationship mediator, fighter for human rights and participant in policy-making. In a community or neighbourhood setting where not policy but informal patterns determine relations among people strategies of community education, social action and project management would be required to influence transactional dynamics involving HIV affected people (Woods in Gray 1998:199).

Where the need appears to be the need for children abandoned as a result of HIV/AIDS to be placed in caring homes, this would require social workers to be prepared to invest themselves in ongoing work to promote social justice-based transactions between these children and their caregivers and other members of not always sympathetic communities (Woods in Gray 1998:199).

Much transactional change work will need to occur at the interpersonal or intrafamilial level, where the pain of rejection and prejudice is deeper and more damaging than any community or institutional response could be.

Poverty and the associated high levels of violence, crime and uncertainty in South Africa also work against successful AIDS prevention by promoting fatalism and despondency, expecting an individual to take initiatives to prevent an infection today which is silent today and may only cause illness in years to come may be too much to ask from disempowered communities (Woods in Gray 1998:200).

This does not mean that social workers and development workers must give up on prevention and education strategies, but suggests that social workers must become more attuned to the way in which target populations themselves construct reality and to what their major concerns and fears are, as opposed to relying too much on educational packages and methods developed in other countries and for other times (Woods in Gray 1998:200).

Furthermore, every organization's projects, programmes and service interventions should be evaluated to enable social workers to keep abreast of progress and to share with and learn from others.

If social workers work together and focus on networking, then social work as a profession can make a worthwhile contribution to the war against HIV/AIDS.

Responding to the impact of HIV/AIDS requires a long-term commitment and involvement on the part of the organization (NGO). In all HIV/AIDS related interventions, an honest assessment of means, skills, needs and impact will have to be made. Community mobilization and involvement are essential for development and this can be achieved by using participatory methods. The actual involvement of the target community or group should enhance sustainability of a project or programme.

An important factor is that the response to the HIV/AIDS epidemic within communities cannot be carried out by separate sections within the service delivery field. Networking will become essential in order to render a holistic, integrated service that will have an impact on and a benefit to the community.

A key issue in establishing community programmes is in depth assessment and evaluation. The evaluation should be built into the programme. A hastily put together assessment will only yield data that is shaky in terms of validity, but will also miss out on analyzing the processes inherent in any programme.

Community -based research often involves multiparty teams with diverse backgrounds and educational experience that represent different and potentially conflicting groups with disparate organizational mandates. Often community participants are self-selected, representing a narrow band of the community. Efforts to be as inclusive as possible are strengthened by making agendas explicit.

Participants develop agendas of their own. Therefore one should identify all appropriate partners at the outset, in consultation with the various stakeholders (Morse, Swanson & Kuzel 2001:166).

Overlooking a source of relevant expertise can jeopardize the project. Furthermore each time a new person joins the group, there can be a ripple effect with time lost as everyone adjusts to the new relationship.

Most research projects begin with an issue, question or set of related questions intended to collect information and or to solve a problem. A research team is assembled with representation from all stakeholders and it is assumed that all partners on the team are committed to the original issue. However effective research with sustainable results will include a process of negotiation and continual evaluation that acknowledges as many agendas as possible and weaves them into a research design that is acceptable to all (Morse et al 2001:171).

The process involves identification of agendas, negotiation of the shared goals and an element of compromise. Community-based research must meet the research needs of the community, but it should strive to achieve the goals of the partners as well. According to Morse et al (2001: 171), research that is not balanced in its design might be influenced negatively by interpartner tension and invisible agendas. This can affect the outcome and the sustainability of the project, limiting the commitment and willingness of the partners to the project.

The primary purpose for conducting community-based research is often to meet the community's needs in an empowering and equitable fashion. The process must be perceived by all partners to add value through collective decision-making throughout the research process.

PAR approaches hold considerable promise for sustainable research projects, which will in turn require new forms of planning and evaluation.

The role and function of the social worker in PAR can be seen as an obstacle to the use of PAR by service providers. The marginal status of social workers as researchers results in social workers feeling insecure to give up their limited status of scientific investigator to pursue a rigorous path of PAR research. If social workers can look beyond this the approach can be a valuable tool for community-based programmes.

HIV/AIDS programmes cannot be implemented in isolation of their context. One needs to examine the broader environments within which people live, which determine the root causes of the success or failure of any response. Among others these include the levels of poverty, the cultural norms and practices, racism, marginalisation and the extent to which fundamental basic human rights are protected and enforced. This broader environment is strongly influenced by political commitment, action, allocation of resources and the level of participation by civil society (Mukasa Monico 2000:37).

The study suggests that integrating community care and support strategies, as well as prevention and education can have a positive impact on mitigating and decreasing the spread of HIV/AIDS. Community -based services are more accessible to individuals and families and decrease isolation and provide needed interventions, which can contribute to the quality of life for PLWHA. Patients may live longer, experience a better quality of life and improved health status. The burden on both clinics ad hospitals may be reduced as people learn to cope with minor symptoms, addressing them before they progress to more complex diseases (Russel et al 2000:13).

Education and awareness emphasizing care and support for PLWHA also results in greater community acceptance and normalizing of the disease enabling people to talk openly.

It was found through the literature study and from information gathered in the focus group interviews, that any community -based programme requires the investment of resources, these may be financial, manpower or medical services. Russel et al (2000:12), found in their study that by raising awareness of available services and

motivating clients to access services resulted in certain areas and increase in the demand for services. This will in turn place greater demands on the service providers to develop and establish projects and programmes.

## 5.3 RECOMMENDATIONS

The following are recommendations arising out of the study;

- 1) Specific training needs
- 2) Co-ordination and networking
- 3) Development of appropriate programmes
- 4) Paradigm shift

# 5.3.1 Specific training needs

This study highlighted the need for social workers or developmental workers working for NGO's or NPO's to receive training as facilitator within the PAR approaches and techniques. In order for service providers to meet the increasing demand to implement programmes that are community -based the knowledge on the PAR approaches are important to gain the confidence and trust of communities and to ensure that programmes that are developed are for the benefit of the communities and will be utilized by the people in need and will be sustainable.

Further training needs is a refresher course for social workers who have been in service for many years. The course shown incorporate the phases in community development that emphasis community members as partners in developing programmes and services and not only as clients.

# 5.3.2 Co-ordination and networking

Service providers need to come together to plan and conduct impact assessments. The HIV/AIDS epidemic will deplete resources and exhaust manpower and the only method of combating this is for all service providers to co-ordinate services and to assist and support each other in establishing and maintaining projects and programmes. Further benefit networking is to ensure that programmes planned are not being duplicated and thus waste both time and money. This will also ensure that communities that are in need of resources will receive them and those areas that are already receiving services will not be saturated.

# 5.3.3 Development of appropriate programmes

In order to develop programmes that are appropriate, and in this I mean programmes that the community have identified as a need and priority, service providers need to conduct reliable needs assessments before planning any programmes. The programmes must be developed in such a way that there is community participation form planning through to implementation, in order for the programme to receive support from the community for which it is meant.

The study undertaken indicated that the target community had a need for the following programmes;

income-generating projects
preventative programmers within the schools
awareness programmers within the community
home-based care project

# 5.3.4 Paradigm shift

Service providers need to make a mind set change with regard to their dealing with disadvantaged communities and in their manner of service delivery. The shift must be from being the expert who has the knowledge and makes the decisions in the best interests of those less fortunate, to be willing to listen and learn from others and to acknowledge that the disadvantaged do have knowledge on their life situations and are able to decide on what they consider to be in their best interests.

The approach of service providers must then shift from a top down approach to a bottom up approach. Social workers are used to making decisions and finding solutions for client's problems in the name of helper. Social workers need to change their thought process, to allow clients/ communities to find answers to their own problems and develop methods of solving these themselves. Social worker's must move away from the helper role and take on the role of facilitator, in order to break the cycle of dependency. As the impact of the HIV/AIDS epidemic will force social workers to empower communities as service providers will not be able to cope with need to care for those affected by HIV/AIDS and communities will become partners in the fight cope with the impact.

In summary service organizations will need to mobilize communities to identify and address problems facing them. They will need to identify and address core service needs through community mobilization rather than top-down service delivery. Explore how the HIV/AIDS related needs can be integrated into wider programmers and addressing other developmental issues, such as poverty and abuse( AIDS Brief 2001:4).

Finally, service providers will need to build institutional capacity and support staff development, strengthen relationships within communities and support organizations. They will have to move beyond traditional networks and explore new strategic partnerships between NGO's, CBO's, government and PLWA.

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