THE ROLE OF CAPACITY BUILDING IN COMMUNITY HOME BASED CARE FOR HIV/AIDS PATIENTS: AN EXPLORATORY STUDY OF TASO: SSEETA-NAZIGO COMMUNITY AIDS INITIATIVES PROGRAMME

by

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submitted in part fulfilment of the requirements for the degree of

MASTER OF ARTS

in the subject

DEVELOPMENT ADMINISTRATION

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: MRS. A LIEBENBERG

DECLARATION

Student number 3238-282-0

I declare that "The Role of Capacity Building in Community Home Based Care for AIDS Patients: An Exploratory Study of TASO: Sseeta-Nazigo Community AIDS Initiatives Programme" is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

[Signature]

DATE 23/09/2002

(Mr. Michael Kiwombojo)
ACKNOWLEDGEMENTS

Living with this dissertation for the last two years would not have been possible without the encouragement and support of friends, colleagues, and my family. It has brought new friends and I have been overwhelmed by the generosity with which some people have lent me their time and their skills. Therefore I wish to acknowledge the following people for their guidance and support whilst I was undertaking this study.

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DEDICATION

To my father, Edward Ssekankya, and my Mother, Donanta Nanteza, who enabled me to see this world and to my late Grandmother, Tereza Namitala, for bringing me up as a responsible human being and for making an early contribution to my education. To my wife, Grace, my three sons, Deogracious Bazanye, Dennis-Mitchell Ssekankya and Daniel-Davis Wabbi-Wantate.
EXECUTIVE SUMMARY

The focus of this study is the role of capacity building in Community Home Based Care (CHBC) for HIV/AIDS patients.

The study forms part of my Master’s in Development Administration programme, undertaken through UNISA. The dissertation was accomplished by studying the TASO community initiative in Ssese-Nazigo, Mukono District, Uganda. It explores the concept of capacity building and its applicability to CHBC.

The primary data was gathered by conducting Key Informant Interviews (KII's) and Focus Group Discussions (FGD). The secondary data was gathered by reviewing literature to augment the primary data. In addition, data was gathered through observations within the community.

The findings have identified seven critical components of capacity building: community mobilisation, skills development, Information, Education and Communication (IEC), Voluntary Counselling and Testing (VCT), networking and collaboration, support and supervision, Monitoring and Evaluation (M&E).

The study observed that capacity built in the above areas resulted in three outcomes: skills development, improvement in procedures, and institutional development.

Informed recommendations were subsequently made related to the seven components of capacity building in CHBC.
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<td>AIDS</td>
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<td>ARVD</td>
<td>Anti Retroviral Drugs</td>
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<td>CBO</td>
<td>Community Based Organisations</td>
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<td>CCA</td>
<td>Community Counselling Aides</td>
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<td>CHBC</td>
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<td>CORP</td>
<td>Community Own Resource Persons</td>
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<tr>
<td>DANIDA</td>
<td>Danish International Development Agency</td>
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<td>DHT</td>
<td>District Health Team</td>
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<td>District Medical Officer</td>
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<td>FAO</td>
<td>Food and Agriculture Organisation</td>
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<td>Income Generating Activities</td>
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<td>ISS</td>
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<td>LC</td>
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<td>MASO</td>
<td>Mukono AIDS Support Organisation</td>
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<tr>
<td>M&amp;E</td>
<td>Monitoring and Evaluation</td>
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<tr>
<td>MoH</td>
<td>Ministry of Health</td>
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<td>Multi-Sectoral AIDS Committee</td>
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<td>MTCT</td>
<td>Mother To Child Transmission</td>
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<td>NACP</td>
<td>National AIDS Control Programme</td>
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<td>NGO</td>
<td>Non-Government Organisations</td>
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<td>ODA</td>
<td>Official Development Aid</td>
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<td>PAC</td>
<td>Parish AIDS Committee</td>
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<tr>
<td>Abbreviation</td>
<td>Description</td>
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<td>PE</td>
<td>Peer Educators</td>
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<td>PLWH/A</td>
<td>People Living With HIV/AIDS</td>
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<td>RDC</td>
<td>Resident District Commissioner</td>
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<tr>
<td>SDA</td>
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<td>UNISA</td>
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<tr>
<td>UPE</td>
<td>Universal Primary Education</td>
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<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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The role of Capacity Building in Community Home Based Care for AIDS Patients

Key Concepts:

Building Structures
Capacity Building
Community Home Based Care
Information, Education and Communication
Models in Capacity Building
Networking and Collaboration
Organisation-to-Organisation Mentoring
Skills Development
Support and Supervision
Voluntary Counselling and Testing
OPERATIONAL DEFINITIONS

Clients
This refers to people who benefit from a wide range of services from TASO and Sseeta-Nazigo Community AIDS Initiative Programme.

Programme Implementers
This is collectively used to describe the different service providers in the community such as the PAC and the ACW.

Community structures
These are as local organised community groups at the grassroots.

Community
This refers to a group of individuals organised in a unit and in some instances sharing similar interests. As used in this study it refers to people living in the same village or Local Council (LC).

Development
General improvement in peoples' living conditions.

Local Council
These are government administrative units with Local Councils I (LC I) as the smallest unit at village level.

Mackintosh
This refers to a soft piece of rubber material used mostly with incontinent patients to prevent soiling of their linen.

Training
Refers to a process of transfer of knowledge and skills through practice and instructions by employing different methods of learning.
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CHAPTER ONE

INTRODUCTION AND BACKGROUND

1 Introduction

While worldwide people are grappling with the problem of HIV/AIDS and its devastating consequences, a number of initiatives for prevention, care and support of People Living with HIV/AIDS (PLWH/A) and their families have emerged. These initiatives to deal with the epidemic were established based on various models and approaches including capacity building. It is believed that the success of these responses is one of the reasons why the rate of HIV infection has been reduced in Uganda (Kayita and Kyakulaga 1997: 6, Noredine et al 2001: 4, UNAIDS 1998: 5). However, some of these models and approaches to HIV/AIDS care and support have been successful whilst others have failed due to a number of reasons.

The study, conducted in Uganda, explored the concept of capacity building and its applicability in Community Home Based Care (CHBC). This involved examining the response to the HIV/AIDS epidemic taken by TASO through its capacity building approach in one of its communities, Sseeta-Nazigo. It also entailed analysis of the services offered by TASO centres and how the organisation built the capacity of the Sseeta-Nazigo community to offer these services.

1.1 Background of the Problem

One of the cruellest assaults on human dignity in Uganda in the past two decades has been the emergence of HIV/AIDS. There is increasing evidence that our existence on earth is vigorously and gradually being challenged by HIV/AIDS (Klinck 2001:1), yet our responses to the epidemic in some instances have been less than encouraging, especially at the community level. This low response inevitably impacts negatively on the development of the countries affected.
In December 2000, WHO/UNAIDS (2000:4) projected that the global number of PLWH/A will have grown to 36.1 million by 2000. The report also highlighted that the epidemic had not been overcome and that HIV/AIDS was affecting all countries worldwide, with 95% of infections prevalent in developing countries (WHO/UNAIDS 2000:4). The report further painted a gloomy picture for Africa. The continent was still a home for 70% of the adults and 80% of the children living with HIV/AIDS in the world (UNAIDS/WHO 2000:11). On the other hand, there was evidence that the infection rate had stabilised or declined in some countries such as Uganda and Zambia (WHO/UNAIDS 2000: 4). This could be attributed to many reasons, including capacity building.

The first AIDS case in Uganda was discovered in Rakai District in 1982. Since then, AIDS has become part and parcel of the social, economic and political life of Uganda. The Ministry of Health, Uganda (1999: 1) estimated that the cumulative number of people infected with HIV was 1.9 million, which was approximately 9% of the global total affected by the epidemic. It was further estimated that over 500,000 AIDS related deaths had occurred since the onset of the epidemic and that 1,400,000 (7% of Uganda’s population) are living with AIDS. In 1998, UNAIDS (1998: 23) estimated that approximately 10% of the adult population was HIV infected by the end of the year.

Records from hospitals in Uganda indicate that AIDS related signs and symptoms account for 12% of annual deaths and that AIDS has surpassed malaria and other conditions as the leading cause of death among individuals aged 15-49 (Ministry of Health, 1999:6). However, this is not to say that all is lost because the reported death in a given year may signify infections that occurred a long time ago. Therefore, it does not necessarily imply an increase in infection. Thus, there is a challenge to professionals to devise alternative intervention strategies to protect the 90% of the population which may still be AIDS free.
1.2 Statement of the Problem

Building the capacity of communities is considered a key strategy in the struggle against the HIV/AIDS epidemic. Since 1982 when the problem of HIV/AIDS was acknowledged in Uganda, a number of initiatives have been introduced to help care and support PLWH/A. With the increasing number of HIV/AIDS cases, there has been a corresponding demand for such assistance. The Government of Uganda and UNAIDS therefore has encouraged Non Governmental Organisations (NGOs) and Government departments to build the capacity of communities so that they might share responsibilities in the struggle against HIV/AIDS and promote improvement in the well-being of the communities affected.

While communities responded in a number of ways, including establishment of CHBC programmes, little was known on how to build their capacity to deal with the problem at the grass root level. This puts to question the whole idea of capacity building as a viable strategy in HIV/AIDS and CHBC, and in particular, the care and support of PLWH/A at the community level. Some documentation on the processes of capacity building exists, but unfortunately, it focuses mainly on organisations such as TASO and Chikankata (Van Praag 2001:9, Osborne et al 1997: 139). Little is known on how capacity building in CHBC could be approached at the community level.

Understanding the role of capacity building in CHBC is essential because the epidemic is still spreading. Authorities have pointed out that there might be no cure for HIV/AIDS in the next ten years (UNAIDS 2000: 17). In the absence of a cure for AIDS, more effort is still needed in caring for and supporting PLWH/A and their families. Even if a cure is found, not many Ugandans infected by HIV/AIDS could afford the related costs due to the general poverty level. In Uganda, 54% of the population live below the poverty datum line with an estimated US $ 330 as income per capita (UNDP 2000).

All this explicitly emphasizes the necessity of analysing those responses that have worked in building communities’ capacity to deal with AIDS, so that sustainable approaches for providing care and support for PLWH/A and their families can be
found. Recent sentinel surveillance reports (1997, 1998, 1999) have shown a significant decline in new HIV infections in Uganda, but a lot needs to be done to consolidate this achievement. As Piot\(^1\) (1997) stated, "AIDS is not over," and more interventions are still required to help communities affected by HIV/AIDS to cope with and mitigate the adverse effects of the epidemic.

Further research, documentation and sharing of information is required to determine those best practices which have worked well, such as TASO's experience to prompt learning from each other. In 1999, UNAIDS warned that the negative consequences of AIDS felt today will be present for many years ahead and also philosophically stated that action taken or not taken over the next few years to fight AIDS will have a big impact on the future course of action of the epidemic in Africa (WHO/UNAIDS 1998: 1). This compels us to take collective responsibility to build and strengthen the capacity of communities to deal with the problem of HIV/AIDS on a sustainable basis. Much can be learned from successful responses.

In 1997, Mandela\(^2\) stated that, "although HIV/AIDS has been with us through the 1980s and 90s, it is a problem whose solution continued to elude us". This calls for the need to study responses that have been established like the Sseeta-Nazigo community AIDS initiatives with a view of sharing the lessons learnt and "best practices". Thus capacity building in CHBC has to be analysed and strengthened in order to facilitate prevention, care and support of individuals and the communities affected by HIV infection and disease.

Within this context, capacity building in CHBC should focus on building the structures of community organisations. This includes efforts to find and support local community groups and to go through the process of identifying their problems, planning and delivering an implementation and evaluation of their activities. Another critical issue that needs to be addressed is skills building for community members.

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\(^1\) Peter Piot is the Director General of UNAIDS. He made this statement during a meeting on International Partnership against AIDS in Africa in 1999, in New York.

\(^2\) Nelson Mandela, retired President of South Africa, in 1997, while addressing the World Economic Forum on the theme; AIDS facing the global threat reiterated that consequences of the epidemic would
This is based on the argument that building people means the development of members and leaders who have the skills and experience they need to run their organisations more effectively within local groups (Skinner 1997:18, Smith 1999: personal communication). In addition the skills of the organisation must be analysed to establish the levels of competence required to sustain the organisation in the various tasks necessary for the successful implementation of a CHBC programme.

1.3 Organized Responses to the Epidemic

According to the Uganda AIDS Commission (UAC), (2000: 21), the response to the HIV/AIDS epidemic in Uganda has been championed by Government, Non Government Organisations (NGOs), religious groups, individuals, local and international donors. The details are elucidated below.

1.3.1 Government Response

The Government of Uganda has been credited for taking centre stage and creating an enabling environment conducive for an organised response to the HIV/AIDS epidemic (Kayita and Kyakulaga 1997: 5, UNAIDS 1998: 4, Noredine et al 2001: 6). This has resulted in the reduction in the prevalence rate of HIV from double to single digit figures\(^3\). Below are some of the initiatives that the Government of Uganda has undertaken since 1985 in order to respond to the epidemic. The first response by the Government was the establishment of the National Committee for the Prevention of AIDS (NCPA) in 1985.

This was followed by the formation of the AIDS Control Programme (ACP) in the MoH in 1986. The ACP was charged with the following functions: conducting epidemiological surveillance; ensuring a safe blood supply (for transfusion); providing HIV/AIDS Information, Education and Communication (IEC); provide counselling to patients; preventing and controlling other Sexually Transmitted Infections (STIs). The ACP has made tremendous progress since then. The Government also

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\(^3\) According to the UAC, the HIV infection rate in Uganda has been reduced from 30% in 1992 to 6.2% in 2000.

In 1988, the ACP in the Ministry of Health was reviewed and it was realized that HIV/AIDS activities required involving all sectors, levels of Government and the community at large. This led to the formation of the previously mentioned Uganda AIDS Commission (UAC) in 1992 by Act of Parliament. The UAC was established to address the problem of HIV/AIDS in a broader perspective and was charged with the responsibility of spearheading the Multi-Sectoral AIDS Control Approach (MSACA) which, had been adopted by the Uganda Government in 1990/91.

MSACA advocates for the active involvement in AIDS control activities by all members of society, individually and collectively, with coordination at various administrative and political levels, down to the grassroots level (UAC 1993: 21). Besides AIDS prevention and care, MSACA also coordinates the active response to and management of the consequences of the epidemic. Lastly, the approach emphasises organisational capacity building for sustainable activities among sectors and individual organisations. Unfortunately, it does not articulate how this capacity building could be approached at the community level.

In 1997, the Government of Uganda adopted a policy of providing free Universal Primary Education (UPE). The promotion of the UPE strategy was commended as a good strategy to reduce early school drop out at the primary level especially of the girl child (Kayins and Kyakulaga 1997:9). It is believed that UPE will inevitably contribute to HIV/AIDS prevention and control. The contribution of UPE to HIV/AIDS prevention is yet to be evaluated since it only started in 1996.

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4 This is based on the argument that with UPE, young girls will spend more time at school instead of going into early marriage and postpone their first sexual contact thus decreasing their vulnerability to HIV infection. Besides, in 1997, WHO counselled that the health and education of the girl child is of paramount concern. It also noted girls face continued discrimination, increasing violence and preventable health problems (WHO 1997: 8). Thus the education of girls would not only lead to improved health of women but also enable them to make informed decisions on issues pertaining to HIV/AIDS.
The Role of Capacity Building in CHBC

The Government of Uganda also designed a strategic plan on poverty aimed at increasing savings among poor households. At the moment, the Government is in the process of mobilising the required resources to implement the programme (Kayita and Kyakulaga 1997: 9). It is believed that this will make an immense contribution to HIV/AIDS prevention and control through improved household income. However, its impact will depend on how effectively the programme will reach more people in the rural areas.

1.3.2 Responses by NGOs

NGOs, CBOs and international donors, with the blessing of the Government, have played a critical role in HIV/AIDS prevention and control (Kayita and Kyakulaga 1997: 30) and in this way they have promoted development at different levels. The NGO efforts were mostly directed towards sensitisation in order to create awareness about AIDS, provision of IEC, Voluntary Counselling and Testing (VCT) and care. Some of the organizations include, TASO, Hospice Uganda, Mild-May, AIDS Information Centre (AIC), Nsamba and Rubaga Mobile Care, Uganda Catholic Secretariat, Medical Protestant Bureau, Moslem Initiatives by Imams, to mention but a few. In addition, a number of CBOs are involved in different HIV/AIDS activities. These organisations have made a significant contribution in their respective mandates. However, information is scanty on how they approach capacity building at the community level.

1.4 The Concept of Community Home Based Care

According to the WHO (1993: 3) a home care programme, through regular visits, offers health care processes in a home environment for those with HIV infection. A number of CHBC models such as the hospital, clinic, NGOs and the theoretical model have been developed to deal with the problem (Shepard et al 1995:10, Osborne et al 1997: 140, Van Praag 2001: 10). The details of each model shall be articulated in Chapter Two.

CHBC has been considered preferable to institutionalised care for a number of reasons. It is thought to be cheaper than institutionalised care and is also preferred by
patients. In some instances hospital care is simply not available at all (WHO 1993: iv). The development of the CHBC programmes and their existence shall be discussed in the next chapter.

1.5 The Concept of Capacity Building

According to Skinner (1997: 1), capacity building is “development work that strengthens the ability of community organisations and groups to build their structures, systems, people and skills so that they are better able to define and achieve their objectives and engage in consultation and planning, manage community projects and take part in community projects in partnership and community enterprise.” Based on the above definition, it is important to recognise that in order for capacity building to achieve its objectives it should include training, organisational and personal development, resource building, organised in a planned and a self-conscious way to embrace the principles of empowerment and equality. This is why it is important to look at capacity building in HIV/AIDS activities as a major development issue at a community level.

Skinner (1997: 2) argues that capacity building is specific and requires the development practitioner to make a detailed analysis of the training needs and the development requirements of the organisation. Capacity building is comprehensive as it assesses the individuals in the organisation, the organisation itself and the environment in which it operates. Capacity building is also forward looking, requiring the practitioner to take account of the existing situation and to assist community groups to plan ahead in terms of determining the skills and the type of organisation they desire (Skinner 1997: 2). Each of these elements will be further articulated in Chapter Two.

1.6 The TASO Community Initiatives Programme

TASO is a national NGO established in 1987 and represents one of the first organised responses to the HIV/AIDS epidemic in Uganda. TASO came into existence in order to address the needs of people affected/infected by HIV through provision of counselling, medical and nursing care and material assistance.
The organisation was founded in order to contribute to a process of restoring hope and to improve the quality of life of people and communities affected by HIV. The TASO movement philosophy is guided by the principle of "positive living" whereby people with HIV/AIDS are supported to live positively (TASO 1995: 1). At present TASO operates eight centres countrywide. The centres offer HIV/AIDS counselling, provide medical care, social support, run day care centres and support community initiatives, as shall be seen in Chapter Three.

The TASO community initiatives programme was conceived in 1990 when TASO realised the need to expand its services to the community. The main aim was to extend TASO related services such as AIDS education, counselling and home care services to the community hence extending services closer to the people and to empowering the community to mitigate the impact of the epidemic. The programme was established with the overall goal to decrease the transmission of HIV infection and improve the quality of care in the selected communities.

The first TASO community initiatives programme was located in Sseeta-Nazigo. This community was selected for intervention because of its proximity to one of the TASO centres, Mulago. In addition, the parish\(^5\) where the programme is situated had a high prevalence of HIV infection. This was based on the fact that by 1991, there were about 100 PLWH/A registered with TASO (Burnnel et al 1991: 10) out of an estimated population of 6,000 people. Based on the above reasons the community in partnership with TASO initiated a CHBC programme. The details shall be discussed in the forthcoming chapters.

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\(^5\) According to the administrative structures in Uganda at the local level, the smallest unit is a village. A number of villages constitute a parish (for example Sseeta-Nazigo parish consists of ten villages) and a number of parishes form a sub-county. Sub-counties are combined to form a county. From the county level, one moves to the district as the next administrative unit.
1.7 Objectives of the study

The primary objective of the study is to establish a relationship between capacity building and CHBC so as to improve practices in CHBC. The secondary objectives are elucidated below:

a) To assess the critical factors that constitute capacity building in CHBC.
b) To explore the concept of capacity building in CHBC.
c) To establish a link between capacity building and CHBC in order to improve practice.
d) To contribute to the level of knowledge in capacity building and CHBC.
e) To provide a background for future researchers interested in capacity building and CHBC initiatives, especially the TASO model.

1.8 Study Hypotheses

This was an exploratory study, which focused more on qualitative data collection methodologies. However, as emphasised by qualitative researchers (Bryman 1988: 65, Ackroyd and Hughes 1992: 28), one of the major advantages of qualitative research is its flexibility and lack of structures that could limit a researcher in a number of ways. Based on this, the researcher opted to use the qualitative approach.

In this case there were no preordained hypotheses because of the nature of the study. This open research strategy enhanced the ability of the researcher to be exposed to entirely unexpected issues that were of interest to the research problem. This is because there is limited literature specifically on the concept of capacity building as it relates to CHBC in Uganda.

1.9 Research Methodology

In the field, data collection was conducted at three areas: TASO Headquarters, Mulago Centre and in the Sseeta-Nazigo community. The data was gathered by conducting four Key Informant interviews (KII), two in the community and two at Mulago
centre. To guide the collection of data, a checklist was prepared to ensure consistency. The checklist (interview schedule) for KII s is attached as appendix I on page 112.

In addition, four Focus Group Discussions (FGD) were held with TASO Mulago counsellors and trainers at Headquarters. The interview guide used is attached as appendix ii on page 115. At the community level FGD were held with representatives of programme implementers (checklist attached as appendix II on page 115). These were the Parish AIDS Committee (PAC) members, AIDS Community Workers (ACW), Community Counselling Aides (CCA) and condom distributors.

Secondary data specific to the study was reviewed from the libraries of Makerere University Centre for Basic Research, University of South Africa (UNISA) and the University of Botswana. The researcher also reviewed reports from TASO and the Sseeta-Nzigo community.

Finally, observations were made in the Sseeta-Nzigo community, in order to augment the information collected through the other methods.

1.10 Analysis of Field Findings

The data generated was analysed in two stages. The first stage involved the analysis of the data realised from the key informants. The second stage entailed a descriptive compilation of information received through FGD to constitute a coherent knowledge base. Given this, the data was analysed based on key issues related to capacity building in Sseeta-Nzigo in the following sequence: mobilisation of the community, skills development, IEC, support and supervision, VCT, networking and collaboration, M&E.

1.11 Limitations of the Study

The study did not intentionally target the beneficiaries of the programme, PLWH/A, orphans and children living in difficult circumstances. This was due to time and financial constraints. Thus the findings only reflect information gathered from
programme implementers and TASO personnel who participated in the FGD and KII.

However, a critical view in the profile of the programme implementers and TASO personnel interviewed revealed that specific issues regarding PLWH/A and orphans were articulated in the FGD. It is also important to acknowledge, that as members of the community, the programme implementers are also as affected by the epidemic as anyone else. To a certain extent their responses provided clear clues on the issues regarding PLWH/A, orphans and children living in difficult circumstances.

The study also focused specifically on one of the TASO supported communities in Sseeta-Nazigo, which is in the rural area attached to Mulago centre. Yet TASO has eight centres established in different parts of the country. While variations in the results could be anticipated, they may not necessarily influence the findings significantly. This is because the TASO guidelines for establishing community initiatives are the same in all centres. In addition, training of staff for implementation and monitoring of the programme at all the centres was conducted by trainers from TASO headquarters for quality assurance and uniformity in service delivery. This gives greater assurance in terms of applicability of the findings in other centres.

The study will add significantly to the body of knowledge on capacity building and CHBC at this critical time when the HIV/AIDS epidemic is ravaging our communities. The study discusses relevant practical issues and the findings should provide a valuable framework that can be adopted by those development practitioners working with the communities who are involved in CHBC. Such a framework could help to mitigate the impact of the HIV/AIDS epidemic at the grass roots level.

1.12 Organisation of the Dissertation

The dissertation is organised into five core chapters. As already noted, Chapter One focused on the introduction, background and statement of the problem. In the same chapter the different responses to the epidemic were reviewed. Chapter Two will articulate the concept of CHBC and capacity building. Chapter Three will present the
TASO services, including CHBC and will also discuss the Sseeta-Nazigo Community AIDS Initiatives Programme. Chapter Four will state the findings of the study, followed by Chapter Five which focuses on the analysis of the findings, recommendations and conclusions.

1.13 Summary

In summary, this chapter focused on the introduction of the study by giving the background and statement of the problem. In addition, the responses to the epidemic by the Government and NGOs were presented. The objectives of the study were stated followed by a discussion on its limitations and finally the organisation of the dissertation was outlined.

In the next chapter, the focus will be on the two key concepts in this study, CHBC and capacity building. The discussion of these two concepts is aimed at providing an insight for the presentation of the findings, analysis, recommendations and conclusions and these are presented in Chapters Four and Five.
CHAPTER TWO

OVERVIEW OF THE CONCEPT OF COMMUNITY HOME BASED CARE (CHBC) AND CAPACITY BUILDING

2 Introduction

This chapter discusses the two critical concepts: CHBC and capacity building in detail. The discussion of CHBC will focus on the definition, rationale and the models of CHBC while the discussion on capacity building will focus on the definition, major elements and models.

2.1 The Concept of CHBC

As highlighted in the previous chapter, in Uganda there are a number of organisations that are involved in the care of PLWH/A, either through institutionalised care or through CHBC. It is argued that CHBC has been a common practice in Africa for generations (Mensah 1994: 59). Communities have a long history of helping one another in times of sorrow. However, with the advent of HIV/AIDS, CHBC has been brought to the limelight because of the magnitude of the epidemic and its adverse social economic effects on families and communities.

2.1.1 Definition of CHBC

Van Praag (2001: 8) described CHBC as “a set of activities responding to medical psychological needs of people infected by HIV/AIDS in their home environment.” McDonnel et al (1994: 430) also attempted to define home care as “simply the day to day care (medical, psychological and material) that a person with AIDS receives in his or her community.” However the above two definitions do not articulate the role of the community in care and support of PLWH/A.

CHBC is defined as the care offered to individuals in their own natural home environment. The care is provided by their families and supported by skilled social welfare officers and the communities, who meet their spiritual, material and psycho-
social needs, with the person being supported playing a crucial role (Ministry of Health 1996: 3). This definition is more comprehensive as it describes the role of the client, the community and the families towards the care of PLWH/A.

From the TASO perspective, one can describe CHBC as care provided to PLWH/A and their families in the community supported by family members and the caring community. The package of CHBC services offered by TASO, includes community and individual counselling, community education, medical and social support and home care/ visits at the grass roots level.

2.1.2 Rationale for CHBC

CHBC is deemed appropriate in Uganda for a number of reasons. The HIV infection rate is still high, estimated in Uganda for example at 7% (WHO/UNAIDS 2000: 15). This means that more people will continue to develop AIDS and therefore their care will be very critical. With the admission rate to hospitals, due to HIV/AIDS estimated between 60-65% (WHO/UNAIDS 1998: 7), CHBC remains one of the most viable intervention strategies to reduce the ever-increasing hospital admissions.

CHBC is also appropriate because of the nature of the disease itself. Some clients discharged from hospitals often require re-admission because of their reduced immunity that can increase their vulnerability to opportunistic infections. With decreased immunity and hospitalisation, the client is continuously exposed to other diseases such as TB, which can aggravate the patient’s condition, causing him/her to waste away faster (Chipandwe 1999: 1). In such a situation it may not be in the interest of the client to be admitted whenever he/she is sick, especially as some of these infections can easily be managed at home.

When patients are cared for at home, they benefit from easy access to both psychological and material support provided by the family, relatives and the community at large who may otherwise be excluded when a patient is hospitalised. 

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6 AIDS patients often require care for prolonged period and by being cared for at home carers may be able to pursue income generating strategies in their home environment which would be difficult if they had to stay with the patient in hospital or continuously visit the patient (Mensah 1994: 58). Besides, there
(Chipandwe 1999: 3). In a home setting patients have a greater freedom of choice, such as being able to choose when and what to eat, compared to a hospital setting where the meal times are dictated.

Caring for patients at home also reduces the costly hospital bills (Chipandwe 1999: 2, Van Praag 2001: 13). The financial burden of the sick person’s family is increased when hospitalised. It is the norm in Ugandan hospitals for the caregiver to assist the patient whilst in hospital. This means that, the costs of maintenance, meals and transport of the caregiver, relatives and friends are threefold. All this can be avoided when a client is cared for at home, hence the need to assess initiatives that have been successful in order to improve practice.

Research carried out in Botswana, Zambia and Zimbabwe revealed that community initiated care is cheaper than institutional/hospital outreach services. Osborne et al (1997:139) citing studies done in Zambia by Misisika, Chela, Sichone and Mwinga, and another study in Zimbabwe by Hansen, Woell and Jackson in Van Praag (2001: 4) revealed that CHBC was cheaper than hospitalisation and outreach care. For example, a hospital outreach in Zambia costs US$14-37, in Zimbabwe it is estimated at US$ 16-42 and in Botswana at US$ 49, while a home based care visit by a community rooted project in the Zambia Copper belt was estimated at US$ 2 (Osborne et al 1997: 139). All this boils down to the necessity to build the capacity of communities to establish initiatives that can deliver CHBC services.

Studies done on the acceptance of CHBC in Botswana (Ministry of Health, 1996: 33), Zambia (Chela, 1991: 16) and anecdotal evidence from a good number of clients cared for by TASO, Kitovu Hospital Mobile AIDS Care in Masaka (Chela 1991: 5) and Nsamba Catholic Hospital (Duggan 1991: 12) in Uganda, have demonstrated that clients prefer to die at home supported by their relatives and dear ones. However, is evidence that the families in Uganda are responsible for much of the nursing care and support of patients in and out of hospital (Kalibala, Kaleeba 1989: 174, Muller and Abbas 1990: 78). This underlines the importance of building the capacity of communities in order to empower families with skills to take care of PLWHA.

7 This view was shared by Havens (1999: 1) when she stated that families and informal network members want to continue taking care of their members who need care. She also further noted that people who require care continue to remain in their own homes and communities.
this alone does not justify CHBC; there could be other reasons related to the financial implications for the caregivers in a hospital. But if PLWH/A choose to die in the hands of their family members, it is imperative that their rights are respected and they are allowed to die with dignity (Ursula 1991: 15). This therefore calls for the need to build the capacity of families and communities to manage the problem at a local level.

CHBC increases the coverage of more people especially in the rural areas. Most rural communities in Uganda are poorly served by health facilities. For example, Sseeta-Nazigo is about 35 km from the main referral hospital and 20 km from the district hospital. Coupled with this distance, the area has poor gravel roads and transport is problematic. There are also no telephone lines. Before 1992, the local clinic was poorly staffed and often lacked essential drugs and there were no outreach programmes from the referral or the district hospitals. As Osborne et al (1997:139) noted, in the absence of CHBC, the inadequacy of outreach services sometimes equates to home neglect amongst poor households. Building a sustainable CHBC programme can bridge this gap.

CHBC answers the question of human resources, which are readily available in the community in the form of volunteers attached to their catchment areas and, this also minimises the transport costs. This is exemplified by a project in Kabalore, Uganda, which reported an increase in coverage from 3%-11% over 2 years by involving community based carers. Another example is the Zambia Copper Belt initiative, which reported coverage of 60% of all people with chronic illnesses in 1996 (Osborne et al 1997: 140).

Finally, a CHBC programme, built on the premise of community involvement, could be a good entry point for facilitating communities to share responsibility in HIV/AIDS prevention, the care of PLWH/A and in supporting them to live positively with the virus\(^8\) (Abel et al 1995: 75). It is argued that this can make a significant impact

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\(^8\) By sensitising the community to understand and take responsibility for caring and protecting their members from getting infected with HIV, CHBC helps to prevent the discrimination against PLWH/A and their families because the whole community becomes part and parcel of the problem solving process (Steging 2000: 5).
on prevention especially if an atmosphere of openness is encouraged (Osborne et al 1997: 140).

All in all, in the absence of a vaccine or a cure for HIV/AIDS, the CHBC intervention strategies are significant in care, education and prevention⁹ (Chela 1991: 16, Ngongco 1999: 20). As families and communities are targeted for sharing the challenge and taking responsibility, CHBC provides the family and communities with the ability to prevent¹⁰ cross infections, develop collective community prevention strategies and provide care for PLWH/A and their families.

2.1.3 Models in CHBC

The Concise Oxford dictionary (1995: 875), describes a model as “a representation...of an existing person or thing or of a proposed structure.” According to Dye (1995: 20) models are simplified representations of some aspects of the real world. Hanekom (1987: 46) describes models as “…simplified representations of the real world that are used to interpret situations and also assist in explaining and predicting the outcome of a specific choice.” Thus models in CHBC can be described as rules, regulations and guidelines adopted in order to guide the implementation, management and evaluation of a given CHBC programme.

Ever since the HIV/AIDS epidemic emerged in the mid 1980s and early 1990s, the health care institutions have realised the problems related in caring for AIDS patients in hospital. This resulted in the establishment of hospital home care services and the development/expansion of NGOs to respond to the wide care needs of PLWH/A and their families. As a consequence, a number of CHBC models have been developed to deal with this problem (Van Praag 2001: 15).

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⁹ This view was also shared by Stefling (2000: 5) where she affirmed that CHBC has a greater potential to unite the aspects of care and prevention. She based her argument on the fact that by including the family and community in the care of AIDS patients it becomes possible to discuss prevention with the community.

¹⁰ For example, in a CHBC programme in Zambia, we are told that during the initial visit, every effort is made by the health staff to educate family members and provide information on issues such as good diet and positive attitudes, including prevention (Mukonka 1991: 19).

2.1.3.1 Clinic Centred Model

Under the clinic centred model, health workers, who are stationed in a given health clinic, conduct home care visits to PLWH/A as part of their expected health care routine responsibilities (Shepard et al 1995: 10). The CHBC services are also integrated in the existing primary health care. An example of this model is the Good Samaritan home care initiative in Mengo Hospital, Uganda.

2.1.3.2 Hospital Model

This model is sometimes referred to as the hospice model. It provides full resources, which are usually available in a hospital, such as 24-hour nursing care, drugs and counselling to PLWH/A and their families, but in the home setting (Shepard et al 1995: 10). Various examples of this model have been documented, such as the Uganda Hospice Association and the Botswana Bamaleti Lutheran Hospice. The advantages of the hospital and clinic centred models include the availability of quality inputs, such as gloves, crutches and mackintoshes, all of which are essential in care. These are easily accessible and supplied by the health care institutions. However, the two models can be expensive and tend to be limited in coverage as already discussed in 2.1.2.

2.1.3.3 NGO Based Model

The NGO based model focuses on the link between the hospital, CBO and support groups in the community. According to Osborne et al (1994: 138) the NGO model often bridges Government and NGO activities. It is argued that the present NGO CHBC centred model depends on community volunteers in the execution of CHBC services (Shepard et al 1995: 10). This reliance on volunteers is a source of strength for the sustainability of the programme. This is the model widely used by organisations involved in CHBC, such as TASO in Uganda, Chikankata and a CHBC initiative by Ndola Catholic Diocese in Zambia and FACT Mutale in Zimbabwe.
2.1.3.4 The Theoretical/Integrated Model

According to Shepard et al (1995: 10) the theoretical model could be conceptualised based on the strengths of the three models discussed above. This is the model, which Van Praag (2001: 7) described as the integrated approach, because it borrows its operational principles from the clinic, hospital and NGO model in order to implement CHBC services. This can be demonstrated by the TASO approach, which combines a number of ideas, such as care of PLWH/A in the home environment and training of volunteers to implement CHBC services at the grass roots level. CHBC bridges the gap between hospitals and clinics at the community level, as shall be discussed later.

There could be other models in CHBC, but experience shows that each model is applicable depending on the environment in a given area. One can combine two models or more, or elements from each model, to design an appropriate one for programme implementation. Thus the TASO CHBC initiative borrows some principles from the clinic, NGO and hospital centred models to care for PLWH/A.

2.2 The Concept of Capacity Building

The term capacity building is not new. For instance it has been used in community development circles (Lisk 1996) and International Aid agencies (Oxfam 1994, Aede 1997). It is also used in public sector management (Grindle and Hildebrand 1995, Corkery 1997, Land 2000) and recently in governance (Cloete 1999, Cox 2001, personal communication) to mention but a few cases. The implication here is that capacity building is a multi-dimensional concept, which goes beyond mere training and education or organisational strengthening. However, there is not much information on capacity building in CHBC and hence the relevancy of this study.

2.2.1 Definition of Capacity Building

According to ADEPT® (1997), capacity refers to the ability of the group to play its role, in partnership or process, towards economic or social regeneration. In the same way capacity can result from the internal features of any of the stakeholders or from
the partnership arrangement. Grindle and Hildebrand (1995: 443) described capacity building as the ability to perform appropriate tasks effectively and in a sustainable manner. Cohen (1995: 409) argued that capacity building is "... improvements in the ability of public sector organisations, either singularly or in cooperation with other organisations, to perform appropriate tasks".

This definition is similar to the one advanced by Mpango in 1995\textsuperscript{12}. In 1995, Mpango referred to capacity building as the investment made with the purpose of enhancing the ability of individuals to achieve their development goals. In this way capacity building entails deliberate policies and actions at the national and sectoral levels to bridge the capability deficits. Capacity is interlinked, as a capacity deficit in one sector can inevitably affect the capacity in another.

Therefore, capacity building in CHBC is the phenomenon referred to by Cloete (1999: 15) meaning availability of and access to concrete or tangible resources (human, financial, material, technological, logistical and many others). Thus in the context of CHBC, capacity building should be part and parcel of both tangible and intangible requirements for leadership, motivation, commitment, willingness, endurance and other essentials for development and sustaining CHBC programmes.

2.2.2 Main Components of Capacity Building

According to Skinner (1997: 3) and ADEPT (1997), there are five main components of capacity the details of which are elaborated below:

2.2.2.1 Management and Leadership

The principle objective of capacity building is to establish, in a network of activities at community level, the levels of competence that will sustain organisations in the various tasks essential to produce the intended outputs. As ADEPT (1997), correctly argued, local community groups should be in position to operate more effectively within the

\textsuperscript{12} ADEPT is a community development and capacity building agency based in Coventry, UK. It offers services to community organisations, statutory and voluntary organisations and it also works with them to strengthen their performance.
partnership structures. Mpango (1995), echoed this view by asserting that capacity building encompasses managerial effectiveness, which inevitably implies good leadership and internal administration.

Capacity building also involves maintenance of harmony and management of technical assistance and other institutional resources as well as external relations in such a manner that the objectives set are achieved with minimum costs. In this case the community must have accessibility to expert/technical and objective advice where necessary. The community should be assisted to identify their core competencies as well as their principle roles. They should also receive assistance with training, mentoring, support, and guidance to enable them to flourish as effective organisations. This shall be expounded further in Chapter Four on how TASO built the capacity of Sseeta-Nazigo community to deliver CHBC services.

2.2.2.2 Building Structures/Institutional Support
According to ADEPT (1995), capacity building is "...development work that strengthens the ability of community organisations to build their structures..." The main purpose here is to give local groups reason and opportunity to involve themselves in the programme. Any local group that takes up this initiative should then be provided support in various ways, such as through training, mentoring and guidance. In this way the organisations, networks and structures for local involvement, grow both in what they are able to achieve and in what they are capable of achieving.

Mpango (1995) argues that capacity building embraces institutional autonomy. This means that the community at the grass roots level is facilitated to carry out their duties unhindered. This shall be further elaborated in Chapter Four when discussing TASO's approach in building the capacity of Sseeta-Nazigo community to deliver CHBC services.

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12 Mpango in 1995, developed a discussion paper for the European Centre for Development Policy Management (ECDPM) for the workshop on development of and training on approaches and methods for national capacity building, Maastricht 26th-29th 1998.
2.2.2.3 Building the Capacity of Partners

The purpose of capacity building is to establish a network of activities at community level and the level of competence that will sustain an organisation through its required tasks whilst meeting its targets (ADEPT, 1997). However, competence at the grass root level requires a level of success and needs the cooperation of other partners, within the community sector groups, on a structured and continuous basis. This can be a reality only if the other partners understand the challenges facing the community groups.

2.2.2.4 Building the Skills of Individuals and the Organisation

Organisations require competent individuals who can effectively participate in their activities. This means developing goal orientated professionalism and standards of behaviour at the work place Mpango (1995). Therefore building people means the development of members and leaders within local groups who have the skills and experience they need to manage the group as an effective agency. As ADEPT (1997) argued, individual organisations need the ability to manage the group as a competent organisation in its own context and also to know how the group should behave in relation to other organisations so as to get the best possible results for their community. The role of skills development in CHBC shall be presented in the findings in Chapter Four.

2.2.2.5 Identifying and Involving the Community

Within the perspective of a community-based programme, capacity building endeavours to support local community groups to enable them to participate in problem identification, assessment of solutions, planning and implementation (ADEPT 1997). As such, all the various stakeholders have to be given a chance to participate in the design of the programme in any way they wish.

For example, this could be in the form of contributions of various resources such as their time, labour, technical support, providing venues for training and many other resources. However, all this depends on how the organisation concerned reaches out to the community groups and makes them understand their roles and responsibilities.
for the task in hand. This could be in the form of community mobilisation, which is further discussed in Chapter Four, related to CHBC.

The five components of capacity building can thus be summarised to include viable institutions and organisations, leadership commitment and vision, effective work practices and standards and financial and material resources, with the freedom to develop and apply them.

2.2.3 Models in Capacity Building

In the discussion on CHBC (2.1.3), ‘a model’ was referred to as a known way of doing things in an orderly and systematic manner. There are a number of models in capacity building. However, for purposes of this study, the discussion shall focus on only five capacity building models as described by Aede (1997: 30) and listed below:

a) The first model entails working through intermediaries. Aede (1997: 30) argues that this can be affected through local NGOs or CBOs. The relationship between the NGO and its counterparts is through grant funding for specified purposes and any other form of support.

b) The second model is generating synergies. This is where an NGO works with a specific combination of counterparts in order to generate changes at several levels (Aede 1997: 38). This is the model employed by Oxfam\(^\text{13}\) to support CBOs in the Philippines on environmental issues.

c) The third model is described as promoting representative organisations. This model promotes the emergence of federated CBOs such as farmers’ unions, trade unions, and NGO alliances (Aede 1997: 40). This is based on the assumption that when the federated CBOs mature they become self-accounting and self-sustaining. A typical example of this is the rural literacy health programme in India cited in Aede (1997: 40). The idea was to encourage slum dwellers to form local associations aimed at improving their

\(^{13}\) Oxfam is an NGO based in UK with field offices in many countries specialising in capacity building of NGOs, development and emergency relief.
housing and educational facilities, raising wages, uplifting the status of women and promoting local participation in local bodies. This model is similar to that utilised by TASO in supporting communities to deal with HIV/AIDS.

d) The fourth model is generating independent organisations. This is where a project at the community level initially funded by an NGO becomes an independent organisation. A good example of this model is the Arid Lands Information Network in Senegal, which started as an Oxford based networking project (Aede 1997: 42), and is presently an independent organisation.

e) The fifth model denotes situations where Government and non-government structures work in parallel. This model describes a setting where an NGO or CBO can work through the state by establishing a relationship with a specific sector (Aede 1997: 43). The institution in question is supported to provide training to individuals, other NGOs, the public and private sector. Oxfam in Nicaragua, for example, used this model in the 1980s to support Government development programmes.

Thus, capacity building models are relevant in guiding practice and also play an important role in streamlining programme implementation.

From the above discussions, it is evident that capacity building is systematic and involves taking a full and detailed look at the training and organisational development needs. Capacity building is also comprehensive as it looks at the needs of individuals in the community organisation, the organisation itself and the environment in which the organisation operates. It is, therefore, forward looking and takes stock of the existing situation.
2.3 Summary

This chapter focused on the concept of CHBC and its rationale in the Ugandan context as an intervention strategy for care and support of PLWH/A. The four CHBC models have been discussed. However, it was emphasised that although each model can operate independently, on the other hand, two or more models can be combined to guide implementation. In addition, the concept of capacity building, its models and its elements have been articulated. It was also recognized that literature on the applicability of capacity building in CHBC is limited. In the next chapter the emphasis shall be centred on TASO services, including its CHBC initiative in Sseeta-Nazigo.
CHAPTER THREE

OVERVIEW OF TASO SERVICES AND THE COMMUNITY HOME BASED CARE INITIATIVES

3 Introduction

This chapter presents an overview of TASO, its objectives and the services offered by the organisation. These include mobilising and supporting community initiatives, VCT, complimentary medical services, psychosocial support, skills development of service providers, networking and collaboration, IEC and M&E. These services have been selected purposely, because the researcher regarded them as the major components in capacity building in CHBC, which is the focus of this study.

3.1 The AIDS Support Organisation (TASO)

As Piot (1997) stated, the AIDS epidemic is spreading in Africa and greater involvement of civil society in responding to the crisis has increasingly becoming critical. He reiterated the same sentiments when he argued that civil societies/NGOs were pivotal in the prevention of AIDS and their extensive participation at every point was significant in rolling back the epidemic (Piot, 2000). Thus, the formation of organisations such as TASO was a positive step in the right direction in the struggle against HIV/AIDS.

3.1.1 Historical background of TASO

TASO is an indigenous NGO in Uganda and represents one of the first organised responses to the HIV/AIDS epidemic. As mentioned earlier in Chapter One, TASO was founded to address the needs of PLWH/A and their families. TASO activities are organised at two levels, at the headquarters in Kampala and at the eight centres. At the

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14 This will involve an in-depth discussion of the Ssenta-Nezigo Community Based AIDS Initiatives Programme. Ssenta-Nezigo was one of the first communities supported to offer TASO like services described above through TASO capacity building approach.
15 Peter Piot, the Executive Director of UNAIDS, echoed this during his presentation in 1999 on the challenges of Norwegian civil societies to take a larger role in African AIDS response.
headquarters, TASO is managed by a board of trustees and an executive director who is responsible for overseeing the activities of the organisation.

At the centres, an executive committee manages TASO\(^{16}\). The involvement of these committees in the management of centres was also an aspect of capacity building to create local structures to ensure sustainability of the programme. Each centre is managed by a manager who coordinates the day-to-day implementation of TASO activities, including mobilising and building the capacity of communities to respond to the epidemic.

The TASO philosophy is guided by the principle of positive living\(^{17}\). Positive living calls upon individuals, families and communities to uphold the rights and responsibilities of people affected and infected by HIV/AIDS and their communities (TASO 1994: 2, Kaleeba 2001: 6). The philosophy advocates for provision of medical, emotional and social support services to people infected and affected by HIV/AIDS. The philosophy also seeks to enable people affected and infected by HIV/AIDS to cultivate self-esteem, hope, respect for life, respect for their community, care for self and support for dependents (Noredine et al 2001: 7). It also agitates for the rights of the community to protect itself and stresses the community’s responsibility to prevent the further spread of HIV/AIDS (TASO 1995: 3). The positive living approach emphasises the necessity to build the capacity of the communities to take a lead, through CHBC, in the care and support of PLWH/A and their families.

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\(^{16}\) TASO has so far established eight centres in districts such as Mulago, Masaka, Mbarara, Tororo, Jinja, Mbale, Entebbe and Arua. Executive committees are made up of community volunteers who assist to monitor, plan, control the budget and raise funds for the centre.

\(^{17}\) The MoH counsellor training manual describes positive living as a concept that promotes and involves developing coping strategies to live a healthy, normal and productive life with HIV infection (Ministry of Health 1999: 28). In a nutshell, the strength of positive living is based on the central premise that individuals, families and the community helpers, institutions and the nation demonstrate understanding of the needs of the people infected and affected by HIV/AIDS.
3.1.2 TASO Objectives

TASO objectives are as follows:

a) To offer counselling services to people with HIV/AIDS and their families.

b) To train counsellors for TASO and other organisations and to ensure effective provision of counselling services.

c) To complement available medical services.

d) To sensitise the public and to promote a positive attitude towards people with HIV/AIDS and their families.

e) To minimize the social ills caused by HIV/AIDS through material support to clients and their families.

f) To build and support community based efforts initiated to respond to the AIDS epidemic.

3.2 Services offered by TASO

TASO offers a wide range of activities, however, this study will be confined to the seven areas listed in the introduction of this chapter as they not only constitute capacity building but are also linked to the elements discussed in Chapter Two.

3.2.1 Mobilising and Supporting Community Initiatives

TASO mobilised the community to participate in the care and support of PLWH/A through seminars and workshops. Abeyakoon (1999: 3) defined community mobilisation as “a process in which people work together to overcome problems and gain more control over their lives”. According to the WHO and UNAIDS (2000: 26), the participation of communities affected by HIV/AIDS is critical for a responsive campaign. This is because the more the users participate, the more the services become responsive to the expectations of the people. This signifies the importance of community mobilisation in CHBC.

Broader participation also ensures that there is a multiplicity of efforts and skills essential for the scale and complexity of the epidemic (WHO/UNAIDS 2000: 26). Participation calls for recognizing, strengthening and supporting through partnerships
designed to develop the capacity of the community members to identify, protect and care for those affected and infected by HIV/AIDS. Capacity building in CHBC should be analysed in view of the strategies for mobilising the community to be involved in problem identification, designing, implementation, monitoring and evaluation of care and support strategies. After realising that many clients who received support at the centres had little community support, in 1990 TASO started the community initiatives programme. At the same time, community groups and CBOs had approached TASO offices requesting support on how to respond to the epidemic.

In some communities, the local people had responded to the problem by initiating counselling, care and education activities. However, the major setback in their response was lack of skills and confidence to manage the initiatives effectively. Therefore, TASO recognized the need to empower and build the capacity of the people at the local level to tackle the problem of HIV/AIDS. At the same time, clinics at the TASO centre had been stretched thin. The demand for services increased greatly when TASO started sensitising communities on how they could respond to the epidemic and the services the organisation offered. Thus more people flocked to TASO centres seeking counselling and medical services.

TASO held discussions with selected communities (including Sseeta-Nazigo community), which expressed commitment and interest. It was agreed that community members should be empowered with skills in home care, counselling and AIDS education in order to respond to the AIDS epidemic and thus extend TASO services to more people in the community. As a result, TASO Mulago centre and Sseeta-Nazigo community initiated a pilot project. With the lessons learnt from Sseeta-Nazigo, TASO scaled up the community programme to all the centres through mobilisation of civic leaders, community groups and other structures to participate in HIV/AIDS activities. By the end of 2000, twenty-eight communities had been mobilised and trained by TASO\(^{18}\) including the Sseeta-Nazigo Community AIDS Initiatives Programme.

\(^{18}\) The number of communities trained was secured through personal communications to the researcher by the staff at the centres and headquarters.
3.2.1.1 Sseeta-Nazigo Community Based AIDS Initiatives Programme

Sseeta-Nazigo community initiatives programme was the first TASO supported community response. The community is located in Mukono district, 25 kilometres from the capital city Kampala, in Sseeta-Nazigo parish. In 1991 when TASO decided to extend its services to the community, a criterion\(^9\) was set to guide the selection of the community in which the project could be piloted (TASO 1995: 15-16). Sseeta-Nazigo community met the required criteria. With a population estimated at 6,000, the community had been hit hard by AIDS and a number of clients from the community were already registered with TASO.

The community was also accessible in terms of transport and was near to TASO Mulago centre. The community was also well mobilised with a number of self-help projects such as drama groups for the youth, religious organizations such as the Roman Catholic, Protestant and Seventh Day Adventist (SDA) churches. Entry into the community was made easier through these structures. On their own initiative, a group of community members formed a drama group that performed plays giving AIDS education (Burnnel et al 1991: 10). Community members then requested TASO to provide training in AIDS education that could help them to improve their plays. They also asked for information on home care, since many families were caring for AIDS patients. TASO conducted a site investigation to ascertain the level of commitment and interest in the programme at the grass roots level.

Site investigation involved TASO trainers visiting the site and holding informal discussions with community leaders. These were aimed at assessing the ability of the community to support a community based AIDS programme. This was followed by a mobilisation workshop with community leaders. This marked the beginning of the role of TASO in building the capacity of Sseeta-Nazigo Community AIDS Initiatives

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\(^9\) At the beginning of the community programme, TASO established a criterion (guidelines) for considering communities requesting to be supported in HIV/AIDS activities. These include; community initiative illustrated by existence of other community initiated projects, programme or structures, community proven ability to support own programme, demonstrated interest to do something about HIV/AIDS on their own and the prevailing community attitude towards PLWH/A (TASO 1995: 15-16). The trainers used these guidelines to assess potential communities for support before selecting one for intervention.
Programme to offer TASO like services. The activities of the programme in Sseetanazigo community initiative included: training of programme implementers, community mobilisation, AIDS education and sensitisation, condom distribution, referral, home visits and home care, and distribution of material support to clients and their families. These activities are discussed later.

3.2.1.2 Objectives of the TASO Community Initiatives Programme

The goal of the TASO community initiatives programme was derived from the overall TASO objectives stated in 3.1.2, section iv. In 1990, at its inception, the following were stated as the specific objectives of the programme.

a) To provide AIDS education and accurate information on HIV/AIDS prevention and care at the grass roots level.
b) To promote positive attitudes and build community capacity to manage and care for those infected and affected by HIV/AIDS.
c) To stimulate community sensitivity and promote positive behaviour change geared towards curbing the further spread of HIV.
d) To stimulate and support collective community responses to the socio-economic consequences of the AIDS epidemic.
e) To set up a referral system for TASO and other service organisations.
f) To provide technical support to Government departments and NGOs which may wish to integrate AIDS in their programme.

However, at the community level, the supported initiatives were encouraged to formulate their own objectives to suit the needs and priorities of the respective community. In view of the above objectives, a number of activities, as listed earlier, were accomplished.

3.2.1.3 Basic Principles of the TASO Community Initiatives Programme

TASO's model of working with communities is based on four principles: community ownership of the programme, referral system, collaboration with other bodies and long-term support.
3.2.1.3.1 Community Ownership

Ownership means that people's values are responsible for and will be accountable for their state of affairs (Abel et al 1995: 75). TASO believes that an outside organisation cannot force behaviour change on the community (TASO 1995: 9). This implies that, for changes in people's behaviour and attitude to be sustainable, it must come from the community. In this respect the facilitators from outside play the role of catalyst to facilitate the community to set its own objectives and plan and, to manage and own the programme. Therefore, the role of the trainer is to support the community to deliver CHBC but not to make it dependent.

3.2.1.3.2 Referral System

TASO emphasises development of a referral system in CHBC as a strategy for linking the programme to resources outside the community. TASO built the capacity of communities by enabling the community to understand the importance of different organisations in CHBC. This was based on the premise that for a community to respond effectively to AIDS care and prevention, there is need for an effective referral system (TASO 1995: 10). Therefore, TASO together with the PAC members and the AIDS Community Workers (ACW), identified and negotiated the nearest accessible facilities for HIV testing, professional counselling, medical care and support organisations for PLWH/A.

3.2.1.3.3 Networking and Collaboration with Other Bodies

TASO networks with a number of organisations for different purposes. For example, there is collaboration between TASO and the Uganda AIDS Commission for policy formulation, the AIDS Control Programme and other AIDS support organisations. This was aimed at improving service delivery based on the principle that the AIDS epidemic is multifaceted (UNAIDS 2001: 4). The epidemic presents a number of problems related to different sectors, such as health, development and the general well being of the population.

The International HIV/AIDS Alliance (2000: 8) recommended that collaboration through networking and partnership would be critical for NGOs since it increases their impact. Therefore, capacity building in networking and collaboration should
emphasise enabling a CBO or an NGO to forge effective links with other organisations and sectors in order to build partnerships. TASO felt that communities should be supported and encouraged to seek out other Government and NGO bodies that can support them to cope with the social economic consequences of AIDS. This would be one of the areas of discussion when presenting the findings on how TASO built the capacity of Sseeta-Nazigo community.

3.2.1.3.4 Long-Term Support

The community trainers should maintain ongoing support for the community in terms of training, home visits and technical support (TASO 1995: 11). This is based on the understanding that the epidemic is dynamic, therefore the community has to be kept appraised with up-to-date information. In addition, it has been proven that HIV/AIDS work can be stressful (UNAIDS 2000: 5), therefore the community has to be supported in order to cope with the challenges of care and support on a long-term basis.

3.2.2 Voluntary Counselling and Testing (VCT)

TASO built the capacity of its centres to offer VCT services. Counselling is one of TASO's activities. There is evidence that the quality of counselling is significant in attracting people to VCT (Alwano 2000: 65, Campbell et al 1997: 92). According to Jonga (2000: 18), "counselling is a dialogue that involves interpersonal relationship between a person or group of people seeking help on a problem(s) and someone willing to listen and assist in solving the problem." TASO (1996: 20) defines counselling as a helping relationship to assist clients to help themselves in coping with HIV/AIDS. From the above discussion, capacity building in VCT should be examined under skills development and improvement procedures.

TASO counselling services are provided at the centres, in hospitals and at homes of registered clients by trained counsellors. The TASO training curriculum is revised on a regular basis to keep pace with the dynamics of the epidemic. TASO counsellors have been trained to offer counselling services to all people irrespective of the client's condition. However, after counselling, clients interested in testing were referred to
testing centres, such as AIC and Mulago hospital for patients in need of both treatment and testing.

It should also be emphasised that counselling is voluntary, and there should be access to testing facilities, thus the term voluntary counselling and testing. HIV/AIDS counselling aims at providing accurate information, reducing stigma and assessing risk reduction, which can lead to change in behaviour. It also aims at helping the affected/infected cope with HIV/AIDS. Osei-Hwedie (1994: 42) argued that understanding and dealing with the psychological reactions and processes that an infected individual goes through is the most fundamental requirement for effective care.

In this case counselling should also aim at enabling the caregivers, including the counsellors, to cope with the task of caring for PLWH/A and their families and hence, the need for care for carers. In this respect, capacity building in counselling should involve developing appropriate curricula, identification of programme implementers with the right attitude, skills building and strategies for supporting and supervising their work in order to ensure the quality of the service.

Besides HIV/AIDS, the counselling package also focuses on STIs and places emphasis on prevention and seeking early treatment. It also includes provision of family planning services aimed at preventing mother to child transmission (MTCT) and assisting women who have limited control over the use of the male condom to have alternative birth control measures. As already noted, counselling was offered at TASO centres by trained counsellors and little is known on how it was approached at the community level. Thus part of the significance of this study is to assess the role of VCT in CHBC by analysing how TASO built the capacity of the Sseeta-Nazigo community to offer VCT services at the community level.

3.2.3 Complimentary Medical Services

TASO provides palliative medical care to its clients for treatment of opportunistic infections. Due to resource constraints, only outpatient services are offered. TASO built the capacity of its centres in medical services by establishing them within the
Government district hospitals. This was because the Government hospitals already had the capacity in terms of infrastructure and skilled personnel. The strategy promotes sharing of available treatment as well as personnel and equipment, such as laboratories and x-ray facilities, in order to maximize utilization of available resources.

Medical services involved diagnosis, treatment of opportunistic infections and sexually transmitted diseases using standard essential drugs, which were provided free. All registered TASO clients received this service at the clinics in a way that complimented the available medical services in Government hospitals. Clients unable to attend the clinic are seen at home by the home care team. Complicated cases are referred to specialised clinics or hospital with which TASO has established a working relationship and if the need arises, the patient may be admitted.

According to Family Health International (2000: 5), “People living with HIV/AIDS need medical services that will reduce morbidity and mortality and optimise their quality of life”. Van Praag (2001: 7) summarized these services as appropriate diagnosis, treatment and prevention of tuberculosis and management of HIV related illnesses (opportunistic infections) and palliation. Therefore, capacity building in CHBC should focus on how the above key medical issues can be addressed at the community level.

3.2.4 Psychosocial Support

There is overwhelming evidence that individuals who are diagnosed with HIV face great challenges in adapting to the reality of a disease that currently has no cure and for which there is limited access to treatment (Raneri et al 2000: 149, Khan and Stegling 2000: 4), especially in developing countries. As Osie-Hwedie (1994: 39), rightly argued, the social nature of humans underlies the critical importance of social support in facilitating adjustment to stressful situations such as HIV/AIDS and in decreasing vulnerability to stress related disorders.

TASO operates HIV/AIDS clinics twice a week for its registered clients at the centres. During clinic days, counselling and medical services are provided to clients.
Green (1994: 59) described social support as relating to different aspects of social relationship, such as, the existence of quantity and type of interpersonal relationships and the functional context of these relationships (emotional, psychological, tangible or informational support). HIV/AIDS is often associated with profound psychological distress (Osie-Hwedie 1994: 33-34). It also affects livelihoods of PLWH/A, through the course of the disease in a number of ways, such as loss of income, isolation and unmet needs of children. These should be addressed at all stages of HIV infection (Van Praag 2001: 12).

It is, therefore, important to build the capacity of individuals, of PLWH/A, of family members and the community so that psychosocial support can be provided. Capacity building should aim at empowering the client, families and the community to mitigate the negative consequences and to support the creation of community safety nets, which families could rely on. In view of the above, TASO established social support services for PLWH/A and this is covered in the discussion that follows.

3.2.4.1 Day Care Centres
TASO established day care centres in order to facilitate mutual training, sharing of information, experiences, discussion and encouragement among clients and hence support fellowship and mutual support. In the day care centres, clients are taught skills, for instance, handcrafts, knitting, weaving, embroidery and other income generating activities (IGA). The IGA are justifiable because as McGrath et al (1994: 123) asserted, the HIV/AIDS epidemic has increased social responses that could disrupt normal family and group functions, such as economic activities. Skills development aims at building the capacity of the clients, especially those who are unemployed, to carry out self help projects in order to improve their personal income.

In the day centre clients also participate in music, dance and drama to raise awareness on HIV/AIDS. The drama groups are a strong asset in creating awareness in TASO supported communities and outreaches. According to the 1998 annual report, 20,976 people were sensitised in 188 performances (TASO 1998: 3).
3.2.4.2 Material Assistance

TASO provides material assistance to its registered clients to aid their nutritional status. FAO (2000) argued that peoples’ nutritional status is determined by various factors such as household food security, health and care, which is affected by HIV/AIDS. Research on this subject (Page and Davies 1999: 82, Food and Nutritional Technology Assistance Project [FANTA[2000]]) suggests that HIV/AIDS aggravates the problem of food insecurity amongst households. This is attributed to the fact that morbidity and mortality due to HIV/AIDS reduces the time and human capital available to households (Ainsworth 1993: 3). This underlines the need for provision of food assistance as a mechanism to enhance care for PLWH/A and their families. Capacity building in this context, therefore, should encompass access to food by needy families on CHBC as a residual measure, strategies that address increased availability of food and enabling the families to be self reliant in food production.

In order to alleviate the problem of food shortage amongst clients, TASO provides food commodities to needy clients. This is provided through the “it works project” which involves distribution of food commodities such as: sugar, rice, powdered milk, beans and cooking oil to clients through organised community groups. The food items were donated by local and international organisations to provide nutritional supplements for assessed needy clients. By the end of 1998, more than 50,000 clients benefited from this arrangement (TASO 1998: 8).

3.2.4.3 Child Support Scheme

It has been proven that PLWH/A and their families, including children, are confronted with severe threats to their livelihoods throughout the course of the disease (Noreidine et al 2001: 6, Akinade 2001: 6). A study by FAO (2001) revealed appalling situations where children were forced to discontinue school as the families needed help and could not meet school expenses due to HIV/AIDS. Another revelation of the study was that time dedicated for childcare was sacrificed (FAO,

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21 According to TASO, “It works” is a term used to describe taking services to where the people live in the community in order to de-stigmatise HIV/AIDS and its associated services. It works is derived from the notion that, empowering communities to actively participate in the care of PLWH/A and their families works. This shall be further elaborated in Chapter Four.
This calls for support, through capacity building, for children to enable them to cope with the challenges of the epidemic.

Child support in TASO involved provision of educational support to children of clients in the form of school fees and scholastic materials. In 1998, TASO supported 165 needy children affected by HIV/AIDS in various institutions. The major contributors to the scheme were funders from abroad and other well-wishers. However, experts stress that donor support can produce long-lasting results when it is undertaken with an emphasis on supporting the natural networks of immediate and extended families (Family Health International 2000: 6).

In the next chapter the focus will be on how this service was replicated in Sseetanazigo community by TASO through its capacity building approach to support orphans and children living in difficult circumstances.

### 3.2.4.4 Skills Development of Service Providers

Green et al (1980: 98) defined skills development as a performance oriented educational method, which stresses the development of specific personal competencies. WHO and UNAIDS (2001: 22) stresses that the response to HIV/AIDS requires additional skills and approaches that may not have been characteristic and common to the different service providers at all levels of the continuum of care. This calls for building and developing the skills of service providers\(^\text{22}\) in counselling, home nursing and home care, infection control, effective clinical management of PLWH/A, and ethical and legal issues. It also requires mobilising families and communities to respond to the epidemic and building the management and leadership skills of those enrolled in CHBC programmes.

Skills development should also include in-service training on new interventions such as counselling and any other new emerging issues. In other words, capacity building in this context should be analysed to see how best an organisation can design strategies.

\(^{22}\) This was further acknowledged by UNAIDS (2000: 8) when they stated that the acceleration of national and community level efforts to expand the responses to the HIV/AIDS epidemic has substantially increased the demand for technical resources, both for information and technical advice.
and train communities in specific skills to deliver and improve CHBC services. Capacity building should also endeavour to examine the training strategies used as for example, organisation to organisation mentoring, applying the concept of Schools Without Walls (SWW), involving participants in learning by seeing and doing in a real setting through structured visits, organisational mentoring, organising individual apprenticeships and specialised skills clinics (Beatson 2001: 5).

To this end, TASO through its training section has trained HIV/AIDS counsellors in Uganda across the continuum of care. At the community level, training was conducted for the Community Own Resource Persons (CORPs). Training of Trainers (ToT) courses were also conducted for community based trainers. TASO also developed different curricula for different stakeholders. The curricula for training counsellors, counselling coordinators, ToT and community volunteers were developed (TASO 1999: 2) in order to develop the skills of different programme implementers. TASO also trained counsellors for other organisations within and outside Uganda and is a member of the Regional AIDS Training Network (RATN) for East, Central and Southern Africa.

In 1998 alone, two hundred HIV/AIDS counsellors from within and outside Uganda were trained by TASO’s training department (TASO 1998: 13). It is important to establish how this activity was approached and its impact at the community level. This study will assess the role of specific skills development in CHBC by analysing how TASO built the capacity of the community to conduct training and also how it built the capacity of others to deliver CHBC services, and the impact of this approach.

3.2.5 Networking and Collaboration with Districts and NGOs/CBOs
Maguire (1984: 198), defined networking as “the process of developing multiple interconnections and chain reactions among support groups.” Schenck and Louw (1995: 89) described networking as a process of communication that spreads across

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23 TASO has a national training centre based in Kampala, which is responsible for curriculum development and training of a wide range of care givers for its centres and other organisations.
24 The CORPS, this is a term used to describe the different service providers trained by TASO at the community level such as the PE, ACW, the PAC, condom distributors and CCA. These are engaged in
interests, problems and solutions to offer support in the execution of tasks. Networking can be done in many ways, (Maguire 1984: 84), for instance: personal networking, networking for mutual and self help, human services networking, networking with professionals and organisations, and networking within communities for community empowerment.

There is also evidence that programmes having the ability to develop partnership with other service providers and care agencies have the capacity to succeed (Russell and Schneider, 2000). Capacity building in networking in CHBC is essential in developing skills and providing quality care services, emotional support guidance and financial assistance.

Germain (1986: 619) defined collaboration as a “cooperative process of exchange involving communication, planning and action on the part of two or more disciplines.” CHBC networking and collaboration has to be assessed on how a given organisation developed, planned, conferred and consulted with other organisations to improve service delivery at all levels, to ensure continuum of care. It may also entail analysing the existence of an enabling system\(^{25}\) and its importance to the organisation.

TASO collaborates with a number of organisations for different reasons. At the centre level, TASO collaborates with districts and CBOs/NGOs to enable them to integrate HIV/AIDS activities in their programmes. The districts identify NGOs, CBOs and initiatives that could benefit from this project. Then TASO conducts training in prevention and care for staff and volunteers of identified CBOs and NGOs. The leaders of the organisations are given additional training in financial and project management. By 1998, seven districts had benefited through this arrangement. This resulted in the training of fifty-eight HIV/AIDS counsellors, sensitisation of ninety-three community leaders and training of thirty-one CBOs staff leaders (TASO 1998: 10).

\(^{25}\) According to Chavis et al (1983: 48) an enabling system refers to a coordinated network of organisations, which nurture the development and maintenance of a grass roots community.
The above experience was exemplary at the TASO centres. However, information on how this concept could be applied at the community level is very scanty and therefore, this study seeks to establish the role of networking and collaboration in CHBC at the grass roots.

3.2.6 Information, Education and Communication (IEC)

According to Gaborone (2000: 2), IEC refers to targeted specific packages of printed and electronic materials designed to inform, educate and communicate relevant information. IEC is aimed at increasing the level of awareness, consciousness, concern and responsibilities of individuals and groups. IEC enables the target groups to develop positive attitudes and behaviours towards the prevention of HIV/AIDS. Hawaz (1998: 2), described IEC as the “application of a variety of methods that result in the education and mobilisation of community members in action for resolving health issues and problems that affect the community”. In CHBC, capacity building related to IEC has to be analysed according to the different channels and strategies used in order to promote best practice.

There are a number of methods through which IEC can be implemented. These include: the mass media, community organisation, strategic planning, skills training, legislation, policy-making, advocacy and many others. TASO used a number of strategies to disseminate information by utilising the radio, pamphlets, brochures, posters, quarterly newsletters, regular press releases and booklets. In addition, drama groups, consisting of PLWH/A, were used for sensitisation.

TASO initiated a number of radio programmes that were broadcast in the local languages, which helped to increase AIDS awareness, especially in the rural areas. Other initiatives included the organisation of the World AIDS Day activities, candle light memorials and making a quilt in remembrance of the TASO clients who died of development process through the provision of resources, incentives and education. This could be appropriate for lobbying for support of organisations involved in care and support.

26 Health in this context is described using the WHO criteria which stresses a state of complete physical, mental, and social well-being not merely the absence of disease and infirmity.
HIV/AIDS. TASO also operates a reference library at headquarters where a collection of reading materials and videotapes of international and national responses to the HIV/AIDS epidemic are kept. The library has become a major resource and reference centre for researchers and higher institutions of learning.

All the above strategies of IEC were conducted at TASO centres and headquarters and therefore they have to be analysed with respect to their applicability at the community level. This study will further attempt to establish how TASO built the capacity of the Sseeta-Nazigo community to develop and implement its IEC strategy.

3.2.7 Monitoring and Evaluation (M&E)

Monitoring and evaluation is one of the key activities of TASO. Some authors have rightly attempted to link M&E with action research (Udoh 1998: 3). Cunningham (1993: 4) described action research as a spectrum of activities that focuses on research, planning, theorizing, learning and developing. He also stated that it is a continuous long-term process and includes experimenting and implementing. As Udoh (1998: 3) emphasized, capacities in all the other factors require regular and periodic renewal through research and innovation. Research is seen as a critical issue not only in M&E for capacity building but also in other areas. This could be one way of improving the quality of care in CHBC.

UNDP (1997: 9) refers to monitoring as an ongoing process, which aims at providing management and main stakeholders of an ongoing programme with an early indication of the progress or lack of progress/complete lack of achievement of the programme objectives. Evaluation is a time bound activity that attempts to assess in a systematic and objective manner the relevance and performance of a given ongoing programme (UNDP 1997: 10).

WHO and UNAIDS (2000: 27) advised that programmes offering comprehensive HIV/AIDS care should include a monitoring and evaluation component to refine, adapt and strengthen existing and new services. This was based on the argument that programmes could be effective if they were evaluated to measure their effectiveness, efficiency, quality, and usage in the community.
Thus, capacity building in M&E, in this study, should focus on how TASO empowered the Sseeta-Nazigo community with knowledge and skills in information collection, actual care delivery and outcomes of their activities. It should also consider the action research that aimed at improving service delivery.

In order to streamline M&E activities, TASO established a monitoring and evaluation unit at the headquarters where a number of M&E activities have been conducted. For example, monitoring tools had been developed, monitoring was integrated in the project design and counsellors are required to compile monthly reports. Since, the approaches mentioned above were at the centres and headquarters the study will look at the applicability of M&E in the community.

3.3 Summary

Chapter Three presented an overview of the background of TASO. It also articulated the services offered by the organisation that focused on capacity building in CHBC. These included supporting community initiatives, including the Sseeta-Nazigo community AIDS Initiatives Programme, IEC, VCT, medical services, social support, training, institution capacity building, networking and collaboration, and monitoring and evaluation. In the next chapter, the findings on how TASO built the capacity of Sseeta-Nazigo community to deliver CHBC services at the grass roots shall be presented.
CHAPTER FOUR
FINDINGS OF THE STUDY

4 Introduction

The primary objective of this study is to establish a link between capacity building and CHBC in order to improve practices within CHBC. Consistent with this, the findings are presented in seven sections as follows: community mobilisation, skills development of programme implementers, IEC, support and supervision, VCT, networking and collaboration, and M&E.

The study concentrated on these seven areas, because as mentioned in Chapter Three, they constitute capacity building in CHBC and also enhance community development at the grass roots level. The findings are, thus, related to the Sseeta-Nazigo community AIDS initiative.

4.1 Community Mobilisation

The findings on community mobilisation are presented in the following order: site investigation, baseline survey, community sensitisation workshops and initiation workshop.

4.1.1 Site Investigation

Site investigation was the first activity to be carried out by TASO in the Sseeta-Nazigo community. TASO made a number of visits to the various stakeholders in Sseeta-Nazigo to establish the viability of the community for the HIV/AIDS programme. This involved discussions with KIIIs such as the Local Council27 (LC) I, II and III, opinion leaders, religious leaders, clients from the area, the District Health Team (DHT), Department of Community Development and the Resident District Commissioner’s (RDC) Office.

27 Local Councils in the Ugandan context represent the administrative structures responsible for implementation of development programmes at the local level.
The site investigation established relevant information on the infrastructure, leadership and resources existing in the community that could be mobilised in implementing the CHBC programme. The information generated during site investigation contributed to the approach used in building the capacity of the community to implement the CHBC programme. TASO used the information to evaluate the ability of the community to support the programme.

4.1.2 Baseline Survey

TASO built the capacity of the community through a baseline survey. Information on this subject was secured through two FGD with TASO trainers and programme implementers and KIIIs. As earlier mentioned, in 1991 TASO conducted a baseline study in ten villages which constitute the Sseeta-Nazigo community\footnote{The villages that constitute Sseeta-Nazigo community where the baseline study and eventually the implementation of the programme took place include: Busimbe, Butooke, Kavule, Kirija, Kirondo, Kirwanyi, Kitebi, Kiteza, Kyamakata and Sseeta-Nazigo.}. A sample of two hundred and fifty residents out of an estimated population of six thousand participated in a study on HIV/AIDS Knowledge, Attitudes, Behaviour/Practices (KAB/P).

FGD and KII were conducted to collect qualitative data especially on people's opinion and beliefs about HIV/AIDS. The study also aimed at establishing existing community initiatives involved in HIV/AIDS care and support and mitigation of the impact of the epidemic. FGD were held with church leaders for example, the Roman Catholic, Protestant and SDA Churches. The discussions centred on getting their opinion about the problem of HIV/AIDS and what the community (including the church) could do in a collective manner.

During the baseline study, the LC officials participated in a number of ways. They identified and informed the households about the data collection exercise and guided the interviewers to locate the respondents. They also participated in the random sampling of households that were included in the study. All this built their capacity in participation and understanding the programme. During this exercise, the names of households from each village were written on slips of paper and folded. Through this
exercise the community leaders randomly selected the respondents who participated in the study.

The capacity built through participation of the local council in this exercise enabled the community to understand their importance in the programme. In addition, the random selection of respondents by the community members built their capacity to understand and dispelled their suspicion that TASO only deals with people infected with HIV since many families were involved. This assisted in destigmatising the programme at an early stage. Besides, the residents of Sseeta-Nazigo served as guides for TASO interviewers and facilitated the process of introducing them to the selected respondents’ homes. The residents introduced the TASO team before proceeding with the interviews.

Participating in the baseline survey built the capacity of the community in understanding how TASO works and the future relationship of the community to the organisation. At the same time TASO built the capacity of the community to mobilise itself through the PAC. After selection and training, the PAC members mobilised the community through the local councils. As earlier noted, the LC were sensitised through participation in the baseline study. In the subsequent community activities, the PAC liaised with the local council’s officials and information was disseminated in all the villages.

4.1.3 Community Sensitisation Workshops

TASO built the capacity of the community by holding sensitisation workshops in all of the ten villages. Data on community sensitisation was collected through FGD with programme implementers and TASO trainers. Through the sensitisation seminars the local people were mobilised to take part in the programme and the seminar resulted in the selection of volunteers from each village as their representatives in the programme. TASO trainers also mobilised other community structures, for example the churches and drama groups such as Segibwa Sounders.

The sensitisation workshops built the capacity of the community to select participants to represent them in the programme. They also selected the date and venue where
the first community meeting was held. The selection of participants from different structures built the capacity of the community in understanding the impact of the epidemic and taking collective responsibility to deal with the problem as a team. This enhanced the capacity of the community to implement the CHBC programme throughout the villages. It also built the capacity of the community to understand their roles and to be involved in the programme activities as shall be seen later.

The dissemination of the baseline findings by TASO trainers through seminars also built the capacity of the community. LC took the lead and mobilised residents in each council while the TASO trainers shared information and disseminated key findings from the baseline. The same venue was used to share with the rest of the community members a broader picture on HIV/AIDS using the statistics from the Ministry of Health and their respective DHT. This exercise built the capacity of the community members to question the magnitude of AIDS in their locality and the country at large, which increased their thirst for more information. Thus the dissemination of the KAP study findings was a mobiliser by itself.

Observations from reports showed that ten sensitisation/dissemination workshops were conducted in the ten villages. Reports also revealed that more than 1000 of an estimated population of 4000 in Sseeta-Nazigo attended the various information dissemination sessions on the outcomes of the study. The sessions were significant in TASO's bid to build the capacity of the community to implement CHBC activities. They promoted understanding of the programme and clarified what was expected of the local people. As a result, the community pledged and committed additional support to the programme.

4.1.4 Community Initiation Workshop
TASO built the capacity of the community through the initiation workshop. This was a one-day mobilisation workshop organised specifically for community and opinion leaders and representatives from the community structures. The workshop took place after mobilisation and selection of representatives for the programme from all the structures. During the workshop, participants were sensitised on the prevalence of HIV/AIDS, its effects on the community and possible responses and they were
encouraged to play an active role. Furthermore, they were introduced to the steps\textsuperscript{29} in establishing a community based HIV/AIDS prevention and care programme. The roles and responsibilities of the community and programme implementers in general and possible community action were discussed.

The initiation workshop built the capacity of the participants to examine the effects of HIV/AIDS as well as to explore ways of tackling the problem. It further enabled them to identify and own the strategies the community later adopted in addressing the problems caused by the epidemic. Participants were also sensitised on the importance of establishing their own community based programme with a coordinating structure. This culminated in the selection of eleven PAC members. Each village (local council) was represented on the PAC by one member. TASO advised\textsuperscript{30} the community to co-opt an additional member on their committee. In the subsequent workshop the capacity of the PAC members was further strengthened. This was through training on their roles and responsibilities in the programme, which included identification and selection of AIDS Community Workers (ACW).

In summary, building capacity in community mobilisation promoted the programme within the community. It has been established that the community participated in the baseline survey, sensitisation seminars and the initiation workshop at the inception of the programme. In this case capacity building meant the community working under the supervision of TASO. The capacity built by working with TASO enabled the programme implementers to mobilise the community and the neighbourhood to respond to the epidemic as shall be discussed later.

\textsuperscript{29} According to TASO, the steps in building and supporting a community based AIDS programme are divided into broad areas (TASO 1995: 12), each with a number of activities. The steps include formation (site identification, investigation and selection), baseline evaluation (data collection, analysis and dissemination of findings), start up (mobilisation seminars, community initiation, selection and training of programme implementers), take off (ongoing trainings, community education events, ongoing support and supervision and specialised training), development (IGA management and outreach trainings) and checkpoint phase (evaluation, re-planning and phasing out). These were discussed with the community to enable them to understand the task ahead of them.

\textsuperscript{30} The additional person was recommended by TASO to ensure representation of one of the structures that had been left out of the selection.
4.2 Skills Development of Programme Implementers

Skills development was identified as a factor in capacity building. The findings in this section are presented in the following sequence: management and leadership, facilitation, counselling skills, home nursing/care and infection control.

4.2.1 Management and Leadership

TASO built the capacity of the community in management and leadership through training and mentoring of the PAC members. The findings revealed that during the baseline survey, TASO identified the gaps in knowledge, skills and attitudes of the community. In the subsequent initiation workshop, TASO assisted the local groups to identify their core competencies as well as their partnership roles. This enabled TASO to design a training, support and guidance programme which enabled the initiative to grow as an effective organisation. The capacity of the PAC members was built through training in leadership and management skills, which enhanced their competence to coordinate the programme.

The PAC training was organised in two phases. The first phase, initial training, was aimed at enabling the PAC to understand basic facts on HIV/AIDS, review their roles and responsibilities such as, mobilising and organising the community for educational events and supporting ACW. The course also involved setting programme objectives and planning for selection of programme implementers. This process built the capacity of the PAC members to understand their responsibilities in the programme from the onset.

The capacity of the PAC members was further developed through ongoing trainings. Ten training sessions were conducted to build the capacity of the community to perform specific tasks related to the programme. They were trained in leadership and management, mobilising the community, record keeping and reporting, support and supervision of the community AIDS programme activities, and problem solving techniques. Other areas of emphasis included networking and collaborating with other organisations, identification and management of IGAs and writing project proposals.
They were also introduced to the concepts of conducting outreaches, monitoring and evaluation.

All in all, building the capacity of the PAC members through training in specific skills has enabled them to coordinate the programme at the grass roots level for the last ten years. It has also assisted in the identification and selection of twenty-five ACW from the ten villages of Sseeta-Nazigo and other community structures. During the training, the PAC set a criteria for the selection of the ACW. They further organised for the training of the ACW by setting the dates and identified the venue in the community. They also mobilised food locally for the workshops while TASO provided facilitators, stationery and funds for the training.

4.2.2 Facilitation Skills
TASO built the capacity of the programme implementers to facilitate community trainings by equipping them with facilitation skills. Information generated through two FGD and KIIIs concurred that, after the initial training of the PAC members and ACW implementation of the programme activities started. Results from the field confirmed that initially the programme implementers concentrated on activities such as home visits, HIV/AIDS education and condom distribution in the ten villages of Sseeta-Nazigo Parish. However, the community started receiving invitations from neighbouring communities to assist in establishing TASO-like services. Therefore, the community requested for assistance from TASO on how best they could help the neighbouring communities to respond to the epidemic.

A meeting was held between TASO, the PAC and ACW on this subject and it was agreed that TASO would train two qualified ACW as Trainer of Trainers (ToT) in order to enhance their facilitation skills to enable them to conduct AIDS mobilisation, education and outreach activities in the neighbouring communities. Information on the ground suggested that this strategy of building the capacity of the community paid off. The ToT have mobilised and trained community workers in four other communities outside Sseeta-Nazigo.
4.2.3 Counselling Skills

TASO built the capacity of the community to offer counselling services by integrating counselling into the curriculum of the ACW. The findings of the study indicated that the ACW were equipped with basic counselling skills. This built their capacity to provide community based counselling to PLWH/A and their families at the community level. The ACW revealed that at the inception of the programme, they offered basic counselling at the family level and made referrals for further counselling and support to the fulltime counsellors at TASO Mulago. However, during the review of the programme in 1995, it was realised that there was need for counselling at the community clinic especially when patients reported for treatment.

As a result of the above efforts, TASO and the community organised an intensive HIV/AIDS training course in counselling for six Community Counselling Aides (CCA). The training enabled CCA\textsuperscript{31} to acquire more knowledge and skills to offer counselling services at the community clinic on a rotational basis. As a result, between 100-150 clients from Sseeta-Nazigo community received counselling from the ACW and CCA on a monthly basis. It was also stated that the provision of counselling services led to a reduction in the referrals made to TASO for psychosocial support.

4.2.4 Home Nursing and Care

FGD interviews revealed that TASO personnel built the capacity of the 25 ACW in home nursing and care through training. The emphasis was on how to nurse a patient at home while involving the family and other community members in the care of the patient. They were also taught how to handle common infections, first aid, nutrition, self-care and, general principles on hygiene and cleanliness in a home setting. The ACW were further trained in management of common symptoms for diseases such as fever, pain and night sweats and how to advise patients on these respective conditions. Other areas of emphasis included how the programme implementers could deal with patients suffering from mouth sores, diarrhoea, vomiting, skin diseases and tuberculosis (TB).

\textsuperscript{31} The CCA were selected from qualified trained ACW who were ready to volunteer to undergo intensive training in order to offer counselling services at the community clinic.
Capacity built in this respect enabled them to train clients and their families. This was followed by emphasis on the importance of positive living with HIV/AIDS. On further enquiry on the management of complicated cases, KIIIs stated that these were referred to other institutions for specialised management. Two FGD where this issue was raised, concurred that programme implementers were introduced to a number of referral organisations such as the community clinic, TASO centre and Mulago Hospital. In most situations, the programme implementers’ intervention on referral was based on assessment done on patients during their home visits. Capacity built in this respect led to improvement in procedures of care and support.

4.2.5 Infection Control
TASO built the capacity of the community to prevent the further spread of HIV/AIDS and its related diseases by training the programme implementers in infection control measures. FGD with programme implementers on home care and home nursing concurred that the training strongly emphasised prevention of cross infections from the patient to the caregivers and the family. It was revealed that besides HIV/AIDS, a number of common infections such as diarrhoea, skin rash, pains, malaria, vomiting and oral thrush were discussed in the training, along side their causes and how they could be prevented in a home setting (as stated in 4.2.4).

In addition, the training emphasised social marketing of condoms, which included, condom use, storage and disposal, to prevent sexual transmission of HIV. Participants were also introduced to the concept of safer sex. The training assisted in dispelling myths that the participants held on condoms in general.

In order to strengthen the community ability to promote condom use, TASO conducted an appraisal on the subject. Based on the findings, TASO further built the capacity of the community by training more condom distributors selected by the community. After the training, TASO supplied the community with free condoms and later introduced another brand for sale. As a control measure the PAC chairman acted as the focal person for condoms in the community. He received and distributed the condoms to the other members. This improved the delivery of service as witnessed
in the improvement in access and availability of condoms in the community as a result of the training of more distributors.

In summary, building capacity through skills development of programme implementers strengthened the ability of the community to improve the procedures and delivery of CHBC services. However, the skills development concentrated more on the medical and psychosocial issues. On the other hand, little emphasis was put on legal, ethical, economic and children's issues. This might be due to the programme design at that time, where priority was on prevention, counselling and care.

4.3 Information Education and Communication (IEC)

IEC was identified as a key factor in capacity building and the findings are elucidated below.

4.3.1 AIDS Awareness Materials

Production of locally produced HIV/AIDS awareness materials was regarded as one of the key components of capacity building in this study. In 1991, when TASO established the community AIDS programme, local IEC materials were produced in the form of pamphlets to sensitise the community. These were aimed at increasing awareness on HIV/AIDS. FGD with TASO trainers and programme implementers revealed that TASO empowered the community to use music, dance and drama to educate and disseminate information on HIV/AIDS. As earlier discussed, at the inception of the community programme at Sseeta-Nazigo HIV/AIDS activities attracted tremendous support from a local drama group, Segibwa Sounders, which comprised mostly of youths.

The programme built on the experiences of this group and music, dance and drama became one of the strongest avenues for IEC as HIV/AIDS messages were integrated in drama. The group was encouraged to incorporate HIV/AIDS messages in songs, poems and plays. TASO trainers offered technical support in editing the manuscripts especially with regard to accuracy of the information on HIV/AIDS. The capacity built in this area enabled the programme implementers to conduct more than 200
sensitisation seminars using drama. It was also reported that more than 1000 people attended the shows not only as an entertainment but also as a source of information and education. Some of the participants who attended the shows made follow-ups on issues such as testing, living positively and condom use with the ACW.

4.3.2 Production of Training Manuals and Curricula

This was another area of capacity building established during the FGD with TASO and the community trainers. It was observations that in 1991, TASO developed a Community Initiatives Trainers’ Manual. This was used in building the capacity of the programme implementers to deliver CHBC services. The manual was used by TASO trainers as a guide in mobilising the community and during the training of the PAC, ACW, ToT and CCA.

The ToT also received orientation on how to use the manual. As already discussed in skills development under facilitation skills (4.2.2) the trainers used the manual to conduct AIDS education and sensitisation seminars and as a guide to support neighbouring outreach communities. Building the capacity of the ToT in applying the manual enabled them to expand the coverage of the programme by training more programme implementers.

4.3.3 Community Education on HIV/AIDS

Community education was considered a factor in capacity building in CHBC under IEC. The capacity of the community was built through the training of PAC and ACW in AIDS education. Information on this subject was generated through FGD with TASO trainers, ACW and PAC members. It was established that community education was offered in the form of AIDS education, group discussions on HIV/AIDS, AIDS sensitisation and through the outreach programme. Programme implementers conducted house-to-house sensitisation sessions on HIV/AIDS. They also held AIDS awareness seminars for community members.

Community education was also offered during organised community trainings such as political education, popularly known as ‘chakamchakwa’. During such seminars, the ToT were invited to make presentations on HIV/AIDS and the community programme.
Capacity building for the programme implementers enabled them to initiate AIDS education activities in the community such as the AIDS week. This assisted in raising awareness on HIV/AIDS at the community level, as stated by one of the community workers below.

"During the AIDS week, we reminded our people of the number of cases diagnosed with HIV/AIDS in our community, those who have passed away and the number of orphans they have left behind, in order for them to appreciate that HIV/AIDS is a reality and lives with us. In the end participants asked questions on prevention, others requested for individual counselling afterwards".

(Stated by a community worker from Kirijja.)

The programme implementers initiated a number of activities during the AIDS week such as traditional chess, netball, house-to-house mobilisation and poems in schools. The AIDS week was used for AIDS awareness. Interviews further revealed that the CCA offered health talks to attendees at the community clinic on clinic days. During health talks, the CCA discussed topics such as MTCT, the importance of self-care, positive living, counselling and infection control at the household level. According to reports, this created a big impact at the clinic with an average attendance of 100-150 patients per month.

All in all, capacity built in community education enabled the programme implementers to disseminate information on HIV/AIDS in the community. It further enabled the community to identify risk behaviours, which predispose the residents to HIV infection and to consider collective intervention strategies to prevent the further spread of the epidemic. It also facilitated the community to consolidate their support to the programme since it served their needs.

In summary, building the capacity of Sseeta-Nagigo programme in IEC enabled the community to raise awareness on HIV/AIDS. Strategies such as production of HIV/AIDS awareness materials and production of training manuals and curricula paid dividends. Building the capacity of the community in music dance and drama enabled them to reach more people through AIDS awareness seminars and performances. Building the capacity of the ToT on how to use the manual assisted them to apply it
during training ACW in the outreach communities. However, at the time of this research there were few locally developed IEC materials documented. Also, information on experiences of the Sseeta-Nzigo community was not available in written form. This could have been due to lack of appropriate skills or because of other competing needs. Therefore, documentation of these practices was not given the recognition it deserved.

4.4 Support and Supervision

Support and supervision was another area identified for capacity building in CHBC. The findings are presented in the following order: technical support for community meetings, supervised home visits, ongoing/supportive training, orientation of medical personnel and support during outreach activities; material aid with food supplements for clients, support to orphans and children living in difficult circumstances, IGA for volunteers, transport for programme implementers, medical support and provision of materials for prevention of cross infections.

4.4.1 Technical Support

As already indicated in community mobilisation (4.1.2), TASO conducted a baseline study, which established the level of knowledge, attitudes and practices in the community. This enabled TASO to identify the gaps and therefore determine the technical support required to assist the community to implement CHBC services. FGD with TASO counsellors at Mulago and trainers established that at the inception of the programme, two trainers were deployed to work with the community to establish the programme. As already discussed, the trainers led by the community leaders conducted a baseline study and were also responsible for its mobilisation.

The trainers built the capacity of the programme implementers in training in various skills such as community mobilisation, facilitation skills, home care and home visits, counselling, management of IGA, sex and sexuality, problem solving and record keeping. These skills have enabled the programme implementers to continue with the programme since 1995. Volunteers have been able to conduct AIDS awareness seminars through music, dance and drama. In addition they have mobilised nearby
communities to establish outreach activities. The following presents the specific approaches adopted in technical support.

4.4.1.1 Community Meetings
TASO built the capacity of Sseeta-Nazigo community through meetings at the grass roots level. FGD with programme implementers revealed that at the inception of the programme they held consultative regular meetings with TASO for planning purposes. The meetings were conducted in the community with TASO trainers and programme implementers before embarking on any programme activity that affected the community. For example, community meetings were held before mobilisation, training of volunteers, sensitisation and education events. Such meetings were significant for capacity building in updating and defining roles of each part in the planned activity.

Such meetings also assisted in building a sense of cooperation amongst programme implementers, which resulted in the sharing of responsibilities amongst stakeholders. For example, the PAC was responsible for mobilisation of the community for training and AIDS education and meals, while TASO provided the trainers and logistical materials for the seminars. It also led to definition of roles and subsequently avoided conflicts. Capacity built in this respect enabled the PAC members to continue with planning meetings and to inform one another of any new developments in the programme when the need arose. This has contributed to the community remaining as a team.

4.4.1.2 Supervised Home Visits
FGD and KIIIs revealed that TASO built the capacity of the community through organised supervisory visits for the ACW at the community level. As a follow up to the training, the trainers conducted home visits together with the ACW trainees. This provided an opportunity for the ACW to gain first hand experience in home visiting and home care. In practice, during their home visits, the ACW were accompanied by an experienced TASO trainer to assess the quality of service offered and for subsequent support.
The trainers compiled notes on the way the ACW handled the sessions on home visits and supported them in areas that required improvement. Building the capacity of the ACW through supervised home visits enabled them to gain experience and build their confidence in handling clients. This could be one of the reasons for the continued acceptability of the programme implementers by the clients for counselling and home visits.

4.4.1.3 Ongoing/Supportive Training

Ongoing supportive training was another area of capacity building in technical support. It involved specialised training for the programme implementers. Discussions with TASO trainers revealed that the training of the programme implementers was divided into different modules. As earlier discussed, the PAC training in Sseeta-Nazigo received the initial training. This was followed by ten other subsequent sessions on topics such as community mobilisation, record keeping and reporting, support and supervision, problem solving techniques, organising community education, networking, project proposal writing and management of IGA.

The PAC were also trained in monitoring and evaluation and outreach services to other communities. Similarly, the initial training of ACW was held for five days. It covered topics such as introduction to TASO and the community programme, facts on HIV/AIDS, community education, introduction to HIV testing and stages of HIV infection and disease, MTCT, prevention and positive living. It also included training in STDs, behaviour change, and counselling. These additional skills enhanced the capacity of the programme implementers to deliver CHBC services. However, when the issue was further probed in FGD, it was asserted that ongoing trainings were still essential especially since the epidemic was still spreading.

4.4.1.4 Orientation of Medical Personnel

Capacity building in CHBC was also examined from the medical point of view. As already articulated in the previous discussions, TASO worked in collaboration with the local clinic in Sseeta-Nazigo to offer treatment to clients in the community. Results from the KIIIs with the TASO medical coordinator indicated that TASO built the capacity of the communities through workshops organised for medical assistants.
working in its supported communities, including Sseeta-Nazigo. The Medical Assistant\textsuperscript{32} received orientation in diagnosis, management and treatment of opportunistic infections and sexually transmitted diseases (STDs). The capacity of the Medical Assistant from Sseeta-Nazigo was built through on-the-job orientation\textsuperscript{33} and interaction with health workers at TASO Mulago. This enabled the officer to acquire more knowledge and appreciate TASO’s strategy of working with communities to support clients and their families. After the training, TASO continued working with the Medical Assistant through the outreach programme in Sseeta-Nazigo once a month.

During the outreach activities, TASO medical personnel worked closely with the community clinic personnel in treating clients with opportunistic infections and management of STDs. This built the capacity of the latter in handling patients with HIV/AIDS at the local clinic. Even when the trained medical personnel were transferred to other clinics, TASO continued orienting the new officers in order to ensure delivery of quality services at the clinic. Following results from KIIIs with the medical assistant, TASO medical staff and a FGD programme implementers were in agreement that the provision of improved quality medical and counselling services led to increased utilisation of the health facility. Information from the field revealed that because of the improved support system the DMO use the clinic for practical apprenticeship of Medical Assistant Trainees.

\subsection{4.4.1.5 Support During Outreach Activities}

Supporting the community during outreach activities was another area identified for capacity building in CHBC. FGD with TASO trainers and programme implementers revealed that the outreaches were established to empower communities which were being supported by TASO to mobilise and train nearby communities to deliver CHBC services. As already discussed under skills development in 4.2.2, the programme implementers mobilised and supported outreach activities in the areas of Ngogwe,

\textsuperscript{32} It should be noted that in Uganda medical assistants are highly qualified professionals next to doctors; however as part of TASO policy, all its employees including medical personnel go through an orientation on their respective jobs, to enable them to develop a positive attitude towards PLWH/A.
Busabaga, Namuyenje and Kiyola. TASO further built the capacity of the community by supporting the ToT when mobilising communities for implementation of CHBC services in the outreach areas.

Further capacity building on this subject was mentioned during the initial three mobilisation seminars and training of twelve ACW in the first outreach community. The TASO trainers supported the ToT during these activities in the outreach community. This built the confidence of the community trainers in facilitating community training and they were able to conduct the subsequent sessions without TASO’s support. While the activity is commendable, according to observations made, there were no clear guidelines on the number of outreach communities, which should be established by the programme implementers.

4.4.2 Material Support
Material assistance was also examined as a critical factor of capacity building in CHBC. Information on this issue was generated through FGD with TASO trainers at the headquarters and with counsellors. It was revealed that at the inception of the programme, TASO approached charitable organisations such as the Red Cross, European Union through Inter Aid and UNAIDS to consider providing material assistance to needy patients supported by TASO. The findings are presented in the following order: food supplement for needy clients, school fees for needy orphans and children living in difficult circumstances, drugs and motivational materials for programme implementers.

4.4.2.1 Food Supplements for Needy Clients
According to the findings, food supplements became a necessity because bedridden patients referred to TASO were unable to work and fend for themselves. It was also necessary because relatives spent more time caring for the patient instead of farming. FGD with TASO trainers and counsellors concurred that since 1987 food supplement has been part of TASO’s care package for clients. This aid was intended for clients

33 This practically entailed the medical assistant attending TASO clinics, working with a team of experienced doctors, nurse and counsellors in the treatment and management of opportunistic infections and being introduced to basic principles in accountability and stocktaking related to drugs.
who experienced food shortages as a result of sickness. FGD and KII were in agreement that the majority of TASO clients suffered from nutritional deficiencies. It was emphasised that material assistance supplies in the form of powdered milk, rice, cooking oil and beans to needy clients was part of the organisation strategy in promoting positive living. TASO built the capacity of the community in the management of the food supplements which led to the introduction of the “it works” project. This resulted in a decentralisation of the distribution process of food supplies to the community. In FGD it was stated that before the programme was introduced to the community, consultative meetings were held with the community members on how they felt about taking over this new challenge.

FGD with programme implementers revealed that the PAC was responsible for the delivery of materials from the TASO centre. They distributed the food commodities to the clients, charging a reasonable fee to recover the money spent on transport. The programme enabled the community to raise some funds through a nominal fee charged as cost sharing for transportation of the material assistance. After deducting the transport charges, the balance was retained in the bank account of the programme, which is managed by the PAC. FGD with the PAC established that the approach of taking material assistance from TASO centre to the community was appreciated by both the patients and the programme implementers. Capacity built in the PAC to handle food distribution saved patients the cost of transport and time incurred when they picked up the materials from the TASO centre themselves.

The distribution of food supplies in the community was planned and coincided with the community clinic day. This greatly enabled the programme implementers to keep in touch with their clients and therefore update their records on a regular basis. On the other hand, information availed to the researcher showed that the provision of food supplies was done on a continuous basis. This brought into question the concept of food provision in the form of handouts in an agriculturally rich area. Despite further probing on the issue, the study never found concrete strategies of increasing availability of food locally on a long-term sustainable basis. This could be attributed to lack of capacity within TASO to deal with the problem. However, the inclusion of food supply and building the capacity of the community to manage food distribution
in what started as a health related programme showed the commitment of TASO to improve the delivery of services. The capacity built in the PAC members enabled them to coordinate the programme.

4.4.2.2 Support for Needy Orphans and Children Living in Difficult Circumstances

As a result of the death of clients in the community, there were a number of orphans left behind. In 1993 TASO realised the need to support children of needy clients to enable them to attend school. According to observations and reports by the counsellors, the majority of patients were poor. Therefore, TASO mobilised funds from the external donor community for school fees and scholastic materials for needy children identified by TASO counsellors and 200 children were supported. However, by 1994, the number of orphans and children living in difficult circumstances had increased and TASO was unable to pay school fees for all the children.

According to FGD, TASO held consultative discussions with the community members on the best way of tackling the problem. Based on the discussions held, in 1997 there was a shift in strategy to include more beneficiaries and support them on a sustainable basis. TASO mobilised funds through UNAIDS and supported the community to improve a school, which the community members had embarked on, that still had poor structures. With the funds secured from UNAIDS, TASO built the capacity of the community in 1998 by facilitating the expansion of a community school.

The money was used to buy materials such as cement, iron sheets, gravel and sand; the community contributed labour and supervision of the project. As a result, three new classrooms were built. On the other hand, there were varied comments on support to children. FGD with TASO trainers and KII hinted that more support was required in addressing psychosocial and emotional problems experienced by orphans and children living in difficult circumstances. The lack of the aforementioned services for orphans might have been due to the fact that there were many patients in the community who

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34 This was based on an assessment done by a counsellor when a patient visited TASO for the first time for registration at the centre. The counsellors had to establish the social economic background of the client in order to help the patient cope with the problem.
needed care and support. Therefore, the programme implementers might have concentrated on care of PLWH/A. It could also be interpreted that there was lack of understanding, planning or capacity in the community to tackle the problem. Maybe the extent of the problem was negligible at that time.

4.4.2.3 Income Generating Activities (IGA) for Volunteers

TASO assisted the community to start IGA. According to the baseline findings, it was revealed that besides the problem of HIV/AIDS there was widespread poverty amongst households. Data availed to the researcher through FGD revealed that IGA in Sseeta-Nazigo were started on the premise of building the capacity of the community to mitigate the impact of the epidemic. They also aimed at making the programmes self-financing and self-sustaining when TASO withdrew35. TASO built the capacity of the programme implementers through training in knowledge and skills in identification and management of IGA. The findings established that the first IGA for the volunteers in Sseeta-Nazigo was a butchery, but it did not give the community the projected dividends due to lack of proper management of the project.

Later on, the community revisited the idea and started making school uniform for children attending the community school. TASO assisted the community by providing the initial funding. By the time of the research, the IGA on school uniforms managed by the community had just started. FGD with the PAC and ACW were in agreement that the project benefited the community as uniforms became cheaper and more affordable compared to open market prices. They were also confident that the project would capture the market in the future. The community contributed their labour and time, and it is hoped that the IGA will enable the programme implementers to raise funds in order to support needy orphans and patients, so that they might gain skills and improve personal levels of income. However, at the time of this research the IGA strategy had only benefited programme implementers and had not yet covered clients and their families. On further enquiry it was noticeable that TASO policy on IGA supported community or group IGA as opposed to individual initiative.

35 Under the community initiatives strategy, TASO was supposed to build the capacity of the community to deliver CHBC services for a period of two years and then withdraw and embark on another community elsewhere.
4.4.2.4 Transport for the Programme Implementers

TASO provided bicycles to the programme implementers as a means of transport in the community. Twenty bicycles were donated to the community and allocated to the 35 programme implementers (the PAC and ACW). During FGD, it was established that the bicycles further facilitated the movement of the ACW and PAC in the community from 5km (an average distance that can be covered on foot) to 25 km while executing programme activities and transporting needy patients to the community clinic and for personal use.

Information availed through observations and FGD showed that bicycles acted also as an incentive for the programme implementers and were easy to maintain. However, the use of bicycles as a mode of transport may need to be revisited. Observations and field findings concluded that the programme had increased its coverage by five more outreach communities since 1996. The new outreach activities extend as far away as thirty kilometres from the community. With the new initiatives TASO and the community may need to reconsider the transport problem.

4.4.2.5 Medical Support

Information on medical support was generated through KII with TASO medical personnel and FGD with the PAC. TASO built the capacity of the community through the provision of drugs. It was established that in 1996 TASO conducted an assessment of the medical requirements of the community clinic in Ssseta-Nazigo. The Medical Coordinator of TASO compiled a report in order to guide intervention on medical issues in the community programme. It outlined the essential drugs for the treatment of opportunistic infections of PLWH/Λ, which were not available in the clinic.66

The report also focused on how the community would sustain the supply of the drugs when the consignment supplied by TASO was exhausted. Based on the findings of

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66 The Uganda Government is responsible for supplying health institutions with the necessary drugs. However, on some occasions the drugs, especially antibiotics, are in short supply or not available at all. This is when organisations like TASO are involved to bridge the gap.
this report, TASO built the capacity of the community to improve delivery of care. TASO fundraised through Australian Aid Agency\textsuperscript{37} (USAID). When funds were secured, a consignment of drugs was bought and donated to the clinic in order to strengthen the care of PLWH/A in the community. The clinic management committee and the programme implementers agreed to charge a cost sharing fee to PLWH/A who could afford to pay for their treatment\textsuperscript{38} and since it is a community clinic, everybody paid. However, the PAC exempted needy PLWH/A on assessment. As part of the motivation for programme implementers, all the volunteers in the programme and their families received free medical treatment in TASO supported clinics at the community level and were also exempted from paying cost sharing\textsuperscript{39}.

Through the funds raised from cost sharing, the community was able to restock the clinic with scarce drugs and remain self-sustaining. When the first consignment of essential drugs donated by TASO was finished, the community contributed to the purchase of drugs through funds saved by cost sharing. The availability of drugs at the local clinic has enabled the community to continue offering medical services even after TASO's withdrawal. However, the recent abolition of cost sharing in Government supported health institutions might affect the ability of the community to continue with this component of the programme. On the other hand, it could result in more Government support, and the funds could be used for other programme activities.

4.4.2.6 Provision of Materials for Prevention of Cross Infections
As already articulated under skills development in section 4.2.5, TASO built the capacity of the community through skills development in preventing infections in a home setting. The training emphasised taking universal precautions, such as wearing gloves and covering wounds when handling patient's body fluids and soiled linen as a mechanism of preventing cross infections. The training also focused on the

\textsuperscript{37} USAID is a development agency through which the Government of Australia channelled funds to support TASO activities.

\textsuperscript{38} Before the introduction of the cost sharing scheme at the community clinic for TASO drugs, the community trainers and the programme implementers held consultative meetings with the beneficiaries and agreed on a fee for cost sharing. They also consulted the community on the fee and the guidelines for assessing the ability to pay and when the patient should be exempted from paying the cost sharing. This enabled the client to have access to treatment at the clinic and also pay for the services.

\textsuperscript{39} The programme implementers also receive free medical treatment in TASO clinics at the centre as an incentive.
importance of consistent use of condoms to prevent the transmission of STDs, HIV/AIDS and MTCT. This enabled the programme implementers to empower clients and their families with knowledge and skills on prevention of cross infections in the family. Also capacity in infection control was built through training of participants in condom use, disposal, storage and social marketing. Capacity was further built by TASO securing gloves and condoms, which were distributed to the programme implementers. After the training, programme implementers were able to educate clients and families on the use and disposal of protective materials to prevent cross infections.

Before this intervention, clients secured supplies of gloves and condoms from the TASO centre. However, with the advent of the programme and the training, TASO supplied the required materials for infection control to the programme implementers. Capacity built in this area led to an increase in the accessibility of the protective materials in the community. There was also capacity building in infection control through provision of patient care kits. During FGD it was mentioned that TASO introduced a patient care kit as a measure to prevent further infections in households.

The patient care kit comprised of a pair of bed sheets, mackintosh and soap. Traditionally, TASO counsellors did assessments to determine eligibility for such assistance. With the establishment of the community programme, this responsibility was handed over to the CCA. The CCA carried out the assessment and made requests from the TASO centres and the kits were delivered to the community. While the community was empowered with assessment skills, it was still dependent on TASO for the patient care kits. To summarise, capacity building in support and supervision has played a critical role in sustaining the programme. However, further input might be required in the presence of increased new infections and hence more people admitted in the programme.

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49 The programme on social marketing of condoms was further extended to shop keepers, youths and other members selected by the community interested in marketing condoms. After the training, the trainees were supplied with condoms and this has greatly increased the availability of condoms in the community to a cross section of people.
4.5 Voluntary Counselling and Testing (VCT)

VCT was another area considered in this study. The study revealed that counselling at the community level was offered by trained ACW and CCA. The ACW assessed patients in need of counselling during home visits while individuals in the community at times contacted them. The ACW offered counselling in people’s homes and referred some to the CCA at the community clinic when the need arose.

The findings indicated that counselling enabled the clients to assess their risks and consider testing for HIV. The CCA and ACW received different cases interested in testing for various reasons such as marriage, having babies and those worried about having been exposed to HIV. Capacity built through VCT enabled the CCA to provide pre-test counselling to clients and to refer them to testing centres after supporting them to make an informed decision to take the test.

Capacity built in VCT enabled some clients who were asymptomatic but HIV positive to undergo further medical investigations to establish whether they were suffering from other infections. This was easier because when patients tested HIV positive, especially when they registered and attended TASO clinics, they were encouraged to participate and benefit from TASO medical services such as early diagnosis of tuberculosis and treatment of other STDs. In addition, when patients joined TASO, they received professional counselling which enabled them to live positively. After receiving their initial counselling, patients from Sseeta-Nazigo community were referred to the CCA in the community for further support. The CCA made follow-ups to support clients and their families to live positively and cope with the infection. In-depth discussions with trainers further revealed that VCT services at the community level enabled the “worried well” and those who were not infected to assess their personal risks in order to adopt and sustain risk reduction behaviours such as sticking to one partner, condom use and testing before marriage.

The “worried well” is a terminology used to refer to people who do not know their sero status but for one reason or another think that they might be at risk of contracting HIV and therefore are interested in knowing more about HIV/AIDS.
At the community level, voluntary counselling was offered to people interested in knowing their HIV sero status, to those intending to get married and to others who were interested in knowing more about HIV/AIDS in order to change their behaviour. All in all, TASO built the capacity of the community to offer VCT services through training of ACW and CCA. The capacity built in ACW and the CCA for VCT enabled them to provide counselling services at the community level which used to be given only at the TASO centre. The study also established that the programme implementers supported the PLWH/A to live positively by adopting safer practices. As a result of capacity building, more people received voluntary counselling while some were referred to the HIV testing centre at AIC, formerly at Bauman House (now AIC at Kisenyi) and Mukono AIDS Support Organisation (MASO).

4.6 Networking and Collaboration

Networking and collaboration were identified and examined as critical factors in capacity building in CHBC. The following section presents the findings on how TASO built the capacity of the community to network and collaborate with other organisations to deliver CHBC services at the community level.

4.6.1 Skills Development in Networking and Collaboration

TASO assisted the community with training in networking and collaboration. FGD with TASO trainers and programme implementers at the community level revealed that networking and collaboration were introduced at the inception of the programme. Trainers reported that during the initial trainings, programme implementers drew mobility and resource maps of the community to establish locally available resources and movement of the people, the places they visited and reasons why they did so. This enabled the local people to establish and compile an inventory of resources available in the community and those that could be accessed from outside the community to support the programme.

The study further noted that, from the inception of the programme, trainers discussed with the community the resources that TASO could contribute to the programme. These included training, counselling, medical services and ongoing support.
Discussions were also held at the community level on the need for additional resources. This was mainly for resources that were not available at TASO yet were essential in the implementation of the programme. Through discussions, the community appreciated and understood the importance of working with other bodies such as Government departments and other AIDS service organisations in order to access their resources. As a result the community realized the importance of keeping accurate programme records as a viable strategy for working with other bodies.

The findings showed that networking and collaboration focused more on matters of health and psychosocial care than on ethical, legal and economic issues, which were not well attended to. Perhaps the reason for this could be that even TASO dealt more with issues of care and support of PLWH/A.

4.6.2 Exchange Visits Amongst Programme Implementers

Exchange visits involved organised visits by community workers of Sseeta-Nazigo community to another TASO supported community in Kaberebere in Mbarara. TASO provided transport and pocket money for the volunteers while the hosting community accommodated their guests. These exchange visits enabled community workers to interact and share experiences with their counterparts in Kaberebere. However, this activity was only done once and moreover the only visit was to a CBO, which was also involved in HIV/AIDS related activities like Sseeta-Nazigo. There was no attempt made to visit any other CBO not supported by TASO or whose area of intent was outside HIV/AIDS.

4.6.3 Development of a Referral System at the Community Level

Development of a referral system was also identified as an issue for capacity building in CHBC. Information generated through FGD revealed existence of a referral mechanism at the community level for cases, which could not be locally handled. At the inception of the programme TASO provided intensive training for the programme implementers on the importance of referral. This resulted in the generation of an inventory of organisations in and outside the community that were instrumental in HIV/AIDS care and the services they offered. In order to strengthen the referral system, a referral tool was developed by the programme implementers together with
TASO. The tool was used to refer clients to the identified organisations for further assistance.

One of the outcomes of capacity building in the community was the development of an inventory of organisations working in the HIV/AIDS field where the programme implementers referred clients. The inventory included organisations such as: the testing centres at AIC Kampala and MASO, the ISS clinic for patients in need of testing and treatment of opportunistic infections in Mulago hospital and Mukono DMOs office depending on individual cases assessed. Much as one would prefer less referrals from the community as an indicator for capacity built, however when the programme implementers came across complicated cases that could not be handled locally, referrals were inevitable. Capacity built in this case assisted the programme implementers to identify organisations that were important in the care and support of PLWH/A. Also the cases referred were those that could not be handled locally due to lack of expertise in testing or medical treatment. Therefore, referring such cases was the best alternative.

4.6.4 Participation of Programme Implementers in TASO Events

Capacity was also built in the community through the participation of community workers in TASO organised seasonal activities such as the TASO Annual General Meetings (AGM), Christmas and TASO Birthday parties, World AIDS day and candlelight memorials. These events brought together people from TASO centres, staff, PLWH/A, executive committees, board members, donors, representatives of Government departments, international agencies, AIDS activists, support organisations and different stakeholders.

Above mentioned forums provided an opportunity to programme implementers to interact, motivate and generate solidarity with other people confronting the same problem of HIV/AIDS. Also by recognising their efforts at such a forum, the community workers felt motivated, and this built their confidence and morale. The capacity built in this respect enabled the community to start commemorating World AIDS day at the local level, which they combine with a candlelight memorial to remember clients who died of HIV/AIDS.
4.6.5 Mobilising Support and Connecting the Community to Potential Donors

Information availed to the researcher through KII and FGD established that TASO assisted in mobilising funds and material assistance for the programme implementers and clients through networking and collaboration. It was noted that the funds that were used for the training of programme implementers were solicited by TASO from organisations such as Action AID, USAID, ODA and AUSAID, while material assistance was secured from various sources such as the Danish Government through DANIDA, CAFODE, SIDA, Misserio, and the European Union.

In addition, there were also individual funders for school fees. Through networking with UNAIDS, TASO managed to secure funds for the community. The money was used for expansion of a community school where most of the orphans and children living in difficult circumstances attended school without paying fees. As already discussed, funds were also solicited for purchase of motivational materials such as T-shirts and certification ceremonies of programme implementers. These have motivated and enabled the volunteers to continue with the programme.

However, besides the IGAs mentioned in 4.4.2.3, information availed to the researcher did not indicate clear motivational strategies in the community for the programme implementers. This could be due to lack of capacity within TASO itself or lack of a superior structure in the community to deal with such motivation. In summary, capacity was built in Sseeta-Nazigo in networking and collaboration in areas of medical and psychosocial issues, but the strategy left out key tenets in economic, legal and ethical issues, which form an integral part of comprehensive care and support. The reasons for this could be due to the particular background of TASO as it has had a long history of offering medical and psychosocial services.

4.7 Monitoring and Evaluation (M&E)

Monitoring and evaluation were identified as key precepts in capacity building in Sseeta-Nazigo. According to FGD with TASO trainers and counsellors at Mulago centre, it was revealed that TASO built the capacity of programme implementers in
training. As earlier noted under skills development (4.1), programme implementers were introduced to the concept of planning, monitoring and evaluation during their initial training. The findings on M&E are presented below.

4.7.1 Reporting and Record Keeping

According to observations and reports from the community trainers, it was found that TASO built the capacity of the community through the development of tools for reporting and record keeping. Trainers from all the TASO centres participated in the development of the monthly reporting tool and a reporting format on community activities. These tools have been revised several times to update them and incorporate new ideas. After development of tools at a central level, the trainers assisted the community in developing more tools that were used for reporting. As earlier mentioned, during their training, programme implementers were introduced to the tools in order to understand their relevancy so that they would use them effectively during the implementation of CHBC activities.

Through observation of community reports and discussions with programme implementers, capacity built in record keeping enabled the community workers to compile and submit monthly reports to TASO on programme activities. It was further established that since 1995 the programme implementers have continued with the practice of reporting to the DHT with copies to the LC III Chairperson in Nakisunga, LC II in Sseeta-Nazigo and the Manager TASO Mulago. Through the reports, the programme implementers are able to solicit for support and inform the relevant authorities of the achievements and the challenges of the programme. Keeping records also have enabled them to keep track of their activities.

However, when this issue was further probed, the PAC members revealed some of the issues outlined and assistance requested in the reports had not been attended to. For example since 1997, they had advocated for inclusion in the district budget plans and support visits by the SDMO's office. These have not yet been accomplished. This could be due to the fact that it is not easy to raise Government budget at anytime due to budgetary ceilings. Lack of support visits may be explained by understanding that the SDMO's office is understaffed. Nevertheless, these were positive ideas that could
be explored. The SDMO's office regularly sent Medical Assistant Officer trainees to Sseeta-Nazigo for their practical training.

Also a critical observation of the techniques used in data collection in the community revealed that they were biased towards individuals who could read and write. Besides, there were no assessment tools on home visits and home care documented to guide programme implementers. These matters could be looked at with a possibility for improvement.

4.7.2 Joint Programme Review Meetings
TASO built the capacity of the community through joint programme review meetings. These involved representatives of programme implementers from the supported communities of Sseeta-Nazigo, Bbira, Kyanja and Muswangali42 of TASO Mulago centre. Reports indicated that these meetings provided a forum for capacity building through programme implementers sharing experiences and learning from one another. Each community was represented by three participants from the PAC and ACW, and each made a presentation on what programme activities they had accomplished, problems encountered, solutions and future plans.

TASO facilitated the meetings at its centre (being a central place) and catered for the meals and transport costs for the participants. The capacity of the programme implementers was built through chairing and taking minutes during the meetings on a rotational basis. The minutes from the meetings were shared with other programme implementers. The joint programme review meetings enabled them to revise their programme according to the lessons learnt from their interaction with other communities. It also built their confidence and provided experience in chairing meetings, which they used in their communities, and also promoted sharing of information, challenges and best practices.

42 The initiatives in Bbira, Muswangali, Sseeta-Nazigo and Kyanja, were among the first communities mobilised and supported by TASO Mulago. By 1993 they were offering TASO like services such as community education and sensitisation on HIV/AIDS, condom distribution and basic counselling. The joint programme review meetings brought together programme implementers from these communities.
4.7.3 Community Programme Review Meetings

Field findings revealed that the PAC on monthly basis held internal review meetings with other programme implementers. These always followed after major events, such as community mobilisation, training of ACW and HIV/AIDS education events. Such meetings were important for monitoring, planning and problem solving at the community level. In some instances, the PAC invited TASO trainers or an experienced counsellor to support on technical issues.

During the meetings the programme implementers discussed difficult cases and ways of supporting each other. According to the findings, such meetings were common when preparing for training of community workers for outreaches, AIDS activities (for example the AIDS week) and when discussing community reports before sharing them with stakeholders. Further discussions revealed that community meetings acted as a forum for problem solving amongst programme implementers and for discussion of technical issues related to the programme.

All in all, reporting and record keeping, joint community review and community meetings formed an integral part of capacity building of M&E. According to the findings, M&E strategies used were exclusive, as opposed to a participatory approach involving the community, which would be preferred because of the nature of the programme. This could be attributed to the criteria used in the selection of programme implementers that emphasised ability to read and write as a prerequisite. Similarly, issues pertaining to action research in order to improve practice were not pursued. This could be due to the emergency nature of the problem and probably due to lack of skills and resources to conduct action research.
4.8 Summary

This chapter has presented the findings on how TASO built the capacity of Sseeta-Nazigo community in different areas to deliver CHBC services. The findings were presented in the areas of community mobilisation, skills development, IEC, support and supervision, community counselling, VCT, networking and collaboration and monitoring and evaluation. In a nutshell, this chapter has demonstrated how TASO, using its capacity building approach, managed to galvanise a community-led response to the HIV/AIDS epidemic. In the next chapter, the findings are further discussed followed by the recommendations and the conclusions of the study.
CHAPTER FIVE

ANALYSIS OF THE FINDINGS, RECOMMENDATIONS AND CONCLUSIONS

5 Introduction

This chapter is divided into three parts. Part one focuses on the analysis of the findings. It takes into consideration how the findings were arrived at. In the analysis, issues related to the components of capacity building and CHBC formed the basis of the discussions together with situations elsewhere. The analysis also made comparisons of the issues presented in the theoretical framework. The second part presents the recommendations with the conclusions presented as the third and final part of the study.

5.1 Analysis of the Findings

The analysis is divided into nine subsections reflecting: community mobilisation, skills development, IEC, support and supervision, VCT, networking and collaboration, M&E, relationship between capacity building, CHBC and development, and a general discussion and observations in that sequence.

5.1.1 Community Mobilisation

As defined earlier in Chapter Three, community mobilisation was found to be a key tenet in capacity building. In Chapter Two, capacity building was linked to formation of structures at the grass roots level (2.2.2.2) and it identified the involvement of community as playing a major role. Based on this background, community mobilisation was identified and discussed in Chapter Three (3.2.1). The case study demonstrated that community mobilisation was effectively carried out and it enabled the stakeholders to participate in identifying, designing, implementing, monitoring and evaluating the programme.
The Role of Capacity Building in CHBC

The findings of the study revealed that TASO built the capacity of the community to mobilise other structures through site investigation, baseline surveys, community sensitisation and initiation workshops. These were instrumental in mobilising the community to have an early understanding of the programme and to participate in the planning and implementation. Hence, the community owned the programme. It also proved that the formation of the PAC, as a coordinating structure of the programme, was a positive outcome of capacity building, and thus provided TASO and DHT with an independent framework for implementation of CHBC activities in the district. The findings are similar to the study by SNV\textsuperscript{42} in Kweneng district, Botswana, where the project successfully mobilised the community and solicited their support (Khan and Stegling 2000: 26).

Based on the above, it can be deduced that the theory and the findings on the importance of community mobilisation in CHBC were complimentary. The findings also suggest that a link exists between mobilisation of the community and capacity building. Study findings have proven that where mobilisation seminars and workshops were conducted, the community participated in the programme. This is a characteristic of capacity building in mobilisation, where people work together to improve their conditions. The definition of community mobilisation in Chapter Three alluded to the collective nature of the exercise to involve significant stakeholders. However, FGD pointed out that some stakeholders, especially teachers, were not mobilised and therefore were not actively involved in the programme. Yet these are major stakeholders in support of school children. This could be an area for consideration for capacity development.

In summary, the capacity built in community mobilisation yielded tangible results. The skills developed by the programme implementers were significant when mobilising their own people and the surrounding areas. Given the prevailing circumstances, it could be considered that capacity building was achieved because of the good work of the TASO community initiative in Sseeta-Nazigo. But, on the other hand, capacity

\textsuperscript{42} SNV is a development-oriented organisation based in the Netherlands involved in funding developmental activities in developing countries. By 1999, they had funded two community home based care initiatives in Botswana in the districts of Bobirwa and Kweneng.
building could have become successful due to the LC structures based on the Local Government political institutions. As Government had already set the pace for community mobilisation, TASO’s task was made easier. Another reason for success may be due to the influence on this community by another development orientated NGO, which gave TASO a breaking ground for quick response to community development.

Based on the results, it can be presumed that TASO’s effort in building the capacity of the Sseeta-Nazigo community enabled them to respond in the way they did. The achievement suggests that when communities are mobilised the results are usually positive, but when not mobilised, the results may vary. This was demonstrated by the Sseeta-Nazigo community initiative, which mobilised the un-mobilised, pooled resources to strengthen their activities and in the end owned the programme. The findings concur with a study by Ngcongco (1999: 20) when she found the same scenario in the evaluation of a CHBC project in Bobirwa sub-district in Botswana.

5.1.2 Skills Development of Programme Implementers

Skills development was another issue of discussion in this dissertation. Developing the skills of individuals and the organisation was highlighted as a strong element in capacity building in Chapter Two (2.2.2.4). Emphasis was put on training, mentoring and guiding the local groups to build their capacity to perform specific activities. Chapter three emphasised the importance of training service providers in various skills to enable them to care and support PLWH/A and their families. It called for the use of different strategies in developing the skills of service providers, such as organisation-to-organisation mentoring and SWW and underscored the importance of developing a multiplicity of skills in these providers.

Taking it from the case study, the findings in Chapter Four identified that development of specific skills in management, leadership, facilitation, counselling, home nursing, home care and infection control, were all critical in building and sustaining the CHBC programme. Building the capacity of the Sseeta-Nazigo community assisted the programme implementers to offer CHBC services. This showed consistency between theory and practice. However, inconsistencies between theory and practice on the
same issue exist. While the theory in Chapter Three emphasised the need for multiple skills in care and support, the findings showed that only medical and psychosocial care was provided. This does not agree with the skills advocated for in the theory which include dealing with economic, legal, ethical issues and supporting children. Observation of the training manuals confirmed this omission. Yet these areas are also considered as cornerstones in the care and support of PLWH/A and their families. This could form a platform for action, as also recommended by the service providers.

According to the findings, skills' building was done by TASO. Earlier, Chapter Three pointed out the importance of organisation-to-organisation mentoring and SWW as viable strategies in building the skills of the community. In the case study, it was clear that organisation-to-organisation mentoring for skills clinics and apprenticeship for training were not explored sufficiently by TASO. Probably when TASO started, there were no other mentoring organisations, but it took on that role and helped the community to build their capacity to implement CHBC activities. This could be a further area for capacity building within the Sseeta-Nazigo community.

5.1.3 Information, Education and Communication (IEC)

As defined in Chapter Three, IEC is another factor related to capacity building in CHBC. The main areas included are: the establishment of resource centres, involvement of the media, production of specific materials on HIV/AIDS for sensitisation, awareness, prevention, care and support. The findings in Chapter Four established that TASO built the capacity of the community in IEC, through production of AIDS awareness material, training manuals and appropriate curricula for the sensitisation, mobilisation and support of outreach activities. In this way there was consistency between theory and practice on IEC.

The IEC materials produced were used by TASO and the community trainers to train the programme implements and for supporting the outreach programmes in the neighbouring areas. This was a good indicator of capacity building by TASO. However, there were also inconsistencies on this issue. While in Chapter Three resource centres were mentioned as significant in CHBC, the study found that these were non-existent at the community level. There was no place reserved for
community members to access IEC materials on HIV/AIDS or documents on other organisations involved in CHBC. There is a possibility that at that time TASO did not have the capacity to support the community, or the community did not have the facilities to start the resource centre.

The findings also revealed the need for capacity for programme implementers to enable the community to document its own experiences, as currently this information is only available in the form of monthly and annual reports. Lack of documented information highlighted the need to strengthen the IEC component of the programme. But the capacity built in community education allowed the programme implementers to accomplish a number of activities in the community. According to the findings, the community education events, especially the AIDS Week, mobilised the local people to fight against HIV/AIDS. This could be considered to be one of the best practices in capacity building in IEC because the initiative was taken by the community themselves.

The training of 25 ACW and ToT also enabled the community to provide training and education in four other outreach areas. These findings were similar to a study by Ngcongco (1999: 5) in Bobirwa, Botswana, where the assistance given by the SNV Project Manager helped the caregivers to develop appropriate hands-on skills for working with PLWH/A (Ngcongco: 1999: 5).

The findings showed that it was not clear as to how many outreach communities Sseeta-Nazigo programme would support. This consideration must be taken as the programme is expanding to the neighbouring areas and the programme implementers may need guidance on how best to help others within their limited capacity as volunteers, as they have their own responsibilities besides programme activities. All in all, the study found that building capacity in IEC not only involves the production of materials but also providing training in the different strategies.

5.1.4 Support and Supervision

In the findings, support and supervision made tangible achievements in building the capacity of the community to deliver CHBC services. Chapter Two brought into the
limelight the importance of building structures and institutional support, as an element of capacity building, (2.2.2.2) to enable community groups to improve their standard of living. Support for this was required in a number of ways, for example, in training, mentoring, guidance and providing material assistance. It was against this background that support and supervision activities, such as technical support, material assistance and child support, were examined and found to constitute capacity building in CHBC.

As alluded to above, the study findings pointed out critical areas in capacity building for support and supervision in CHBC. Capacity building through various support and supervision strategies enabled the community to sustain the programme. It also led to the enhancement of the programme implementers’ skills in: mobilisation, counselling, home visits and care, training, AIDS education and management of opportunistic infections.

Building the capacity of the community in the provision of material support, especially food, was significant in its own way and all three FGD highlighted the importance of food provision to needy patients as it supplemented their diet. As already established, TASO empowered the community to manage the “it works” programme. The funds raised from this programme enabled the PAC to open a bank account to manage their activities.

A critical view of the food provision strategy indicated that there were no concerted efforts to assist the clients and their families to address the problem on a sustainable basis because the project also depended on donors. Yet an assessment of Mukono district and Ssceeta-Nazigo indicates that the area is suitable for agriculture which could sustain families in food supply. Possibly the approach adopted by TASO at the inception of the programme was dictated by the beneficiaries’ circumstances, where the terminally ill were unable to work or fend for themselves and so needed emergency food supplies. However, since the project has been in existence for several years, it could be redesigned to focus on supporting families in a more sustainable manner.

The other accomplishment achieved through capacity building was to resolve the problems of school fees for orphans and children living in difficult circumstances.
This was resolved by the community constructing their own school, thus waiving the school fees for the children. It can be concluded that the school will remain useful to the community as long as qualified teachers are available and willing to stay in a rural area.

Information on psychosocial support to children living in difficult circumstances and orphans was not very clear. The programme implementers mentioned that they do not have the skills to support children. Observations made in the curriculum confirmed that this was not catered for. This needs to be addressed to meet the needs of the children.

The capacity of the community to improve their economic status was supposedly built from the funds provided by TASO to start an IGA for making school uniforms. There is evidence that this project has not improved their economic status considerably. It still has a long way to go in terms of addressing the problem of poverty among the programme implementers and the clients. This implies that more support is required to continue building the capacity of this initiative.

5.1.5 Voluntary Counselling and Testing (VCT)

According to the findings, VCT was another area of capacity building in Sseeta-Nazigo. The discussion in Chapter Two revealed that capacity building was critical in establishing and enhancing the competencies of the service providers. In Chapter Three (3.2.2), VCT was discussed as an area of capacity building and the findings proved that TASO has built such a capacity in the community in a number of ways.

Capacity built in VCT assisted the CCA and ACW to offer counselling and refer clients to testing centres, which had established a working relationship with the programme. The findings also suggested that although the testing centres were outside the community, this never affected the utilisation of services. These findings are consistent with a study conducted in Mukono district, Uganda, which found that the location of testing centres did not affect the utilisation of VCT services (Alwano 2000: 75). It was established that community volunteers continued offering voluntary counselling to clients at the community clinic or in peoples’ homes.
In summary there was agreement between theory and practice on the role of capacity building in VCT in CHBC. As earlier mentioned in Chapter Three, capacity building in VCT constituted skills development, improving procedures and institutional building. This was also confirmed by the practice in Sseeta-Nazigo. However, the volunteers disagreed on the notion that capacity built in counselling alone was enough to enable the community to cope with the problem. They were also of the view that capacity built in VCT coupled with the availability of drugs enabled the community to offer quality CHBC services.

The absence of regular refresher courses for counsellors was also a concern. This was mentioned as critical because the programme implementers were required to continue performing their roles despite the increase in the number of families and clients in need of care and support. Overall, the focus of VCT on skills development was achieved. This enabled the programme implementers to offer counselling in the community and refer clients for testing.

5.1.6 Networking and Collaboration
Networking and collaboration were defined as significant in capacity building in CHBC. Chapter Two mentioned the importance of cooperation with other partners at the grass roots level to improve delivery of services. Consistent with this, networking and collaboration were examined in Chapter Three where a relationship between the hospitals, clinics and welfare institutions was regarded as significant in the success of a CHBC programme. The components of networking and collaboration were stated as: sharing ideas and tasks with organisations involved in different activities (thematic networking); exchange visits; and the existence of an enabling system as a mechanism to support initiatives at the grass roots level.

The case study established a number of approaches through which TASO built the capacity of the community in networking and collaboration. This was evident in skills development through exchange visits and referral systems. It also included promoting the participation of the programme implementers in TASO events, mobilising support and introducing the programme implementers to potential donors. These efforts
facilitated building the skills and confidence of the programme implementers. It also enabled them to access support from international and national organisations.

However, collaborative efforts were limited to medical care, provided by TASO and Mulago hospital, counselling by TASO and HIV testing by MASO and AIC centre. These are known organisations involved in HIV/AIDS activities. In other words, networking and collaboration in a multi-sectoral manner left much to be desired. There was no evidence of networking and collaboration on economic, childcare or legal issues. The findings are similar with a study by Mojapelo et al (2001: 55) which revealed lack of structure and capacity to manage CHBC activities in a multi-dimensional manner in Kweneng district, Botswana.

There was also a discrepancy of theory related to the support of an enabling environment as a prerequisite for networking and collaboration. As highlighted in Chapter Three (3.2.6), the enabling system was deemed essential to cater for the interest of CBOs at the grass roots. There were no records of Seeta-Nazigo being affiliated to other organisations outside HIV/AIDS. This could be an area for serious consideration.

Overall, capacity built in networking and collaboration facilitated the development of a referral system, which was used by the community for medical and psychosocial support. This contradicted the findings of a study by Lindsey (2000: 35) on CHBC in Botswana where many problems related to the referrals for medical and social welfare support were identified. Nevertheless, in a study conducted on Primary Health Care (PHC) in South Africa by Van Rensburg et al (2000) the majority of health workers expressed satisfaction with the referral system and corroborated the researcher’s findings.

The study also concurred with the findings by Russell and Schneider (2000) in South Africa where several CHBC projects had established a relationship with clinics and hospitals, which provided care, access to prescriptions and medication for patients. Some programmes negotiated CHBC supplies from hospitals and clinics in exchange for providing care to patients discharged in the community. These findings were also
in agreement with a study by Johnson et al (2000: 55) in Mamelodi, South Africa. The study found a well-established referral network to access medical and social services by the Tateni Home Based Care Services. This ensured the quality of care for PLWH/A.

5.1.7 Monitoring and Evaluation (M&E)
Chapter Three highlighted the main issues of capacity building in M&E such as action research, development of appropriate tools and data collection on care and support of PLWH/A and CHBC activities in the community. In the findings in Chapter Four, it was realised that TASO built the capacity of the community in M&E using a number of approaches. One approach was the training in reporting and record keeping, which enabled the community to understand and appreciate the M&E concept. Joint programme review meetings were conducted at the TASO centre to assess the viability and promotion of uniform implementation of the programme. These meetings were also held in the community, which enabled the programme implementers to share their experiences and support one another. This practice has continued and is a positive indicator of capacity building. In this way, there was consistency in theory and practice with TASO mainly as the convener.

A review of the training curriculum suggested that M&E remained an area of concern for capacity development in the CHBC programme. This was due to conceptual and methodological inadequacies. This problem was also acknowledged by Land (2000: 10) in his analysis of case studies in capacity development in ten African countries and confirmed by Khan and Stegling (2000: 19). In both instances, M&E remained a challenge to the projects. This case study established that the techniques used were suitable for those individuals who could read or write.

According to problems raised in the programme implementer’s reports, the authorities in the DHT and LC dealt with only a few issues. There was also no evidence of action research by TASO. Yet, as discussed in Chapter Three, this would have been the cornerstone of improving performance. Capacity building in this case focused only on intervention and as Udoh (1998: 8) observed, this left out regular and periodic reviews, lessons learnt and innovations, to link the efforts of research with the realities on the ground. However, such problems might be accommodated within the area of
HIV/AIDS as this is a crisis situation, which depends so much on trial and error. Nevertheless, the initiative set by TASO in Sseeta-Nzigo and its achievements could act as a springboard for improvement.

5.1.8 The Relationship between Capacity Building, Community Home Based Care and Development

From the case study there seems to exist a relationship between CHBC, capacity building and development. If development can be described as a series of activities aimed at improving the living conditions of a given community, capacity building could be considered to be part of the process. In Chapter Two (2.1.2), CHBC was described as concerned with enabling individuals and communities to take responsibility for the care and support of affected and infected people in the community. In this respect, activities in this context were highlighted.

Development involves improvement in people's lives in a number of areas such as increasing the level of literacy, socio-economic well-being, health and skills building to ensure sustained changes. Taken from the case study, the above tenets of development are also the major factors in CHBC. For example, the CHBC initiative in Sseeta-Nzigo had to tackle factors in CHBC. For example, the CHBC initiative in Sseeta-Nzigo had to tackle education for orphans and children in difficult circumstances. Income generating activities had to be integrated in the programme as a way of sustaining the initiative. This is another development aspect that merits praiseworthy consideration.

Since the process of development encompasses a number of factors, one would also believe that the concept requires a multi-skills strategy on issues orientated towards improvement in people's lives. The findings in Chapter Four demonstrated the importance of such a multiplicity of skills in CHBC. For example, in all the seven components of capacity building in CHBC, skills development of the programme implementers occurred. This implies that there is a relationship between CHBC and development.

According to the findings, it is apparent that capacity building in CHBC should culminate in improved living conditions of individuals and the community. For
example, skills development enabled the community to improve the following: counselling, mobilisation, provision of medical care, networking and IEC. These are also the precursors for sustainable development. Capacity built through the different interventions enabled community members to acquire life-long skills for dealing with problems. For development to occur there is need for a healthy population. As earlier mentioned, CHBC is also concerned about improving the quality of care at the household and community level. As in CHBC, in development people have to be informed and educated about pertinent issues that relate to their well-being.

Based on the above arguments, one can conclude that a relationship exists between the three concepts of capacity building, CHBC, and development as they involve improvement in people's lives. The three concepts constitute a triad of interactive factors when combined that could govern many aspects of efforts in improving the living conditions of people.

5.1.9 General Discussion and Observations

A clear overview of the findings indicated that capacity building in CHBC was interlinked and should be regarded so in order to ensure quality care for PLWH/A. For example, in all the seven components of capacity building in CHBC discussed, there was either skills development of programme implementers, improvement in procedures or strengthening of the programme. The study also revealed the interdependency of the seven components of capacity building. It was realised that capacity in one had an effect on the other. For example, capacity built in mobilisation led to participation of the local people in the programme. After the mobilisation process, the participants were trained in appropriate skills. Capacity built through skills development assisted the participants in mobilising and empowering the outreach communities with knowledge and skills in CHBC.

Pursuing the theme of interrelatedness, skills development cut across all the factors in capacity building. For instance, in networking and collaboration there was enhancement of skills of the programme implementers. Also, for the programme implementers to offer AIDS education they depended on the capacity built in mobilisation. Community residents had to be mobilised for AIDS events in the
community such as the World AIDS Day, AIDS Week to mention but a few. VCT in some instances also depended on networking and collaboration with other partners and also training. Clients were continuously referred to testing centres for HIV tests and to medical institutions for illnesses which could not be managed at the community clinic. Tools developed in M&E were essential in networking and collaboration for referral of clients from the community to support agencies.

A general observation of the findings further suggests that capacity building in CHBC was demand-driven. According to the findings, community mobilisation highlighted areas for capacity building, which was followed by skills development for the programme implementers in the respective areas. The need for community education and counselling led to training of ToT and CCA respectively. The demand for improved medical services necessitated the in-service training of the medical assistant and the donation of drugs to the clinic.

Similarly, the increase in the number of orphans and children living in difficult circumstances led to strengthening of the local school to handle more beneficiaries. Circumstances where capacity building was demand-driven also included the mobilisation and training of more condom distributors in the community. This was deemed essential after an assessment on the availability and accessibility of condoms. The assessment had recommended an increase in the focal points for distribution and sale of other brands of condoms in the community. Therefore, capacity built responded to the prevailing needs.

One of the pervasive themes that went through all the aspects of the study was the poverty experienced by the people of Sseeta-Nazigo community. KII s and FGD with TASO personnel raised considerable concern about the poverty of programme implementers, clients and their families. It should be noted that the structured interview schedule and the issues checklist used in this study never directly asked a question on poverty. However, it was raised when participants in FGD and KII s were

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44 As used in this context, demand driven means that in some situations the intervention on capacity building in the community depended on the request and assessment for the need of the required skill or support.
asked the question; "Is there anything that you would like to tell or discuss with us?" This is when the issue of poverty featured in the discussion. Although poverty was not one of the main themes of this study, the researcher feels that ignoring it could be a disservice to this dissertation. Studies by Khan and Stegling (2000: 12-13) and Mojaapeloe et al (2001: 16) on CHBC in Kweneng district in Botswana described appalling situations of poverty amongst clients and caregivers. Interestingly enough, if communities in a country like Botswana with an excellent Gross Domestic Product (GDP) face acute problems of poverty, the situation in Uganda could be beyond imagination. This could be an area for further capacity building to assist the community to mitigate the impact of the epidemic by integrating poverty alleviation in HIV/AIDS activities.

In summary, the findings have proven that capacity building in CHBC led to three major outcomes. Firstly, it resulted in the development of skills of the programme implementers in the seven areas of capacity building, that is to say: community mobilisation, IEC, support and supervision, VCT, networking, collaboration, monitoring and evaluation. Secondly, it resulted in improvement in the procedures of the delivery of service. In most cases, services became more accessible to the community members than they were before.

Thirdly, it led to the institutional development of the Sseeta-Nzigo community. Capacity built in this area was exemplified by the emergence of a community structure, the PAC, as a coordinating body for the programme at the local level. The PAC members were trained which strengthened their capacity to perform specific tasks such as community mobilisation, support and supervision and implementation of the programme activities. Thus the theoretical framework of capacity building in CHBC as summarised diagrammatically on page 98.

The framework indicates that for capacity building in CHBC to be successful, a superstructure is required with capacity in the seven components. It also must have commitment to build the capacity of the community. The framework presupposes existence of a structure at the community level made up of different programme implementers who are willing to work with PLWH/A, families, the community and the
outreach areas in order to implement CHBC activities at the grass roots. In the final analysis the capacity built at the community level will lead to skills improvement, a strengthened structure and improvement in the delivery of CHBC services.

5.2 Recommendations

Based on the study findings and the analysis that followed, the researcher recommends the following in six areas:

5.2.1 Community Mobilisation

From the findings it was evident that more clients are continually being registered. This is an indicator that the problem of HIV/AIDS is still prevailing in the community. On this basis, it is recommended that:

In view of the fact that the epidemic is still spreading, TASO should revisit its strategy of supporting old communities and assist them to cope with new challenges.

TASO and the community should devise strategies to promote the greater involvement of teachers in the programme in order to address the psychosocial and emotional needs of children living in difficult circumstances and to prepare them for the challenges of growing up, in order to reduce their vulnerability to HIV/AIDS. The emphasis is on teachers because of their availability as professionals teaching in the community, and as they spend more time with children.

5.2.2 Networking and Collaboration

The findings realised that there were a number of grey areas in networking and collaboration, therefore the study recommends:

Introducing the systems approach in training of programme implementers. The systems approach emphasises the role of partnership in care and support. This will
FIGURE 5.1

Theoretical Framework of Capacity Building in Community Home-Based Care (CHBC)

Outcomes of CHBC
- Building in CHBC
- Capacity of Caregivers
- Benefits in Communities

Beneﬁciaries (TARGETS)
- Caregivers
- Community
- Families
- Children (PLWH/A)

Components Distributed
- CCA
- PH
- NV
- PAC

Network and Collaboration
- Support and Cooperation
- Training (VCT)
- Volunteer Consultation/Coaching
- Information, Education and Communication (IEC)
- Multiple Skills in CHBC
- Community Mobilization
- Community Monitoring and Evaluation
- Monitoring and Evaluation

Improvement in the Care of HIV/AIDS Issues
- Improved and Organizational Capacity of the Caregivers
- Standardized Structure
- Consistent
- Care (e.g. in mobilization, Improvement/Development, Skills)

Medical Palliative Service Delivery (e.g. Procedures of CHBC)
promote more understanding of the concept of networking and collaboration in the CHBC context.

Advocating for the creation of an enabling system of organisations or formation of a federation of CBOs as an umbrella for initiatives involved in care and support at a community level. It is hoped that this will be responsible for nurturing the development and maintenance of grass roots community care through the provision of resources, incentives, education and advocacy and promote community problem solving and development.

Promoting thematic and cross networking as a mechanism of mutual support and learning for community based organisations like Sseeta-Nazigo CHBC. This would imply getting CBOs dealing with the same/related problem to share ideas and generate their own support system. The researcher feels that thematic and cross networking would allow cross fertilisation of ideas on care and support of the programme in a broader manner.

5.2.3 Support and Supervision

The findings identified areas that required more support and supervision, for instance material assistance, technical support and poverty amongst the programme implementers and the clients. The study therefore recommends that:

TASO and the community should address the problem of insufficient food supply amongst households through liaising with the department of agriculture and the district farm institute for effective social planning and technical assistance on this subject. In the long run, this may reduce the dependency on handouts for material assistance.

TASO and the DHT should facilitate exchange visits to successful organisations involved in other HIV related activities, for example, community care for orphans and IGAs to enable the programme implementers to gain more skills.

The DHT and TASO should ensure regular support visits to the programme implementers to address issues raised in the reports.
TASO should strengthen the capacity of the community to access poverty reduction programmes, for example, the Government poverty alleviation fund, UNDP and the churches. This could involve assisting the community to develop their own proposals that could be funded by donor agencies.

5.2.4 Monitoring and Evaluation (M&E)

The study identified several areas in the M&E approach used at the community level which may need strengthening. Therefore, it recommends that:

M&E should be strengthened by exploring other relevant data collection techniques such as the genogramme, which is easier to use, by both the semiliterate and literate members of the community. Genogrammes are pictorial presentations of data that could be used in collection of data related to patients. In this way the techniques would embrace both the needs of the volunteers who are literate and those who are illiterate.

The introduction of other M&E approaches should be explored for example, by integrating Participatory Rural Appraisal (PRA) and Triple "A" (Assessment, Analysis and Action) evaluation techniques that have been proven useful and easy to adopt at a community level. This will broaden the understanding and utilisation of M&E at the community level.

There is also need to develop family and client assessment tools in order to guide the programme implementers during home visits. This is based on the fact that there were inadequacies in the reports by the programme implementers.

There is need to promote action research at the community level in terms of studying effort, performance, efficiency, process and many other areas aimed at improving the delivery of CHBC services. This will benefit TASO to improve practice.
5.2.5 Skills Development of Programme Implementers

Study findings revealed a strong inclination in development of skills in psychosocial and medical issues. It was also found that refresher courses for the programme implementers had not been done despite the fact that the epidemic is dynamic. Based on the above, the study recommends that:

The DHT together with TASO should conduct refresher courses for the programme implementers. This should be done urgently to enable the volunteers to be updated on HIV/AIDS issues so that they can use the information in subsequent outreach trainings in community.

As earlier articulated, ethical, legal and children issues were not incorporated in TASO training. It is therefore recommended that TASO should seek for technical support and integrate the above topics in the curriculum of programme implementers.

TASO should promote the concept of organisation-to-organisation mentoring by institutions of proven effectiveness not only in care and support for PLWH/A but also in legal and ethical issues, community orphan care and IGAs. This could be explored in a number of ways such as apprenticeships and skills clinics on different themes. It will involve identification of organisations with valid credentials in specific skills that are ready to work and assist CBOs, such as, in Sseeta-Nazigo those who are involved in care and support of PLWH/A. Such an arrangement could be started with mentoring of representatives identified by the CBOs who would in turn train others.

5.2.6 Information Education and Communication (IEC)

For IEC, the study recommends:

TASO, the DHT and MoH should promote establishment of a resource centre in the community and equip it with the necessary materials. The resource centre should target a cross section of people including the youth. This could involve identification of a common place acceptable by the different stakeholders in the community. Materials on HIV/AIDS could be mobilised from different organisations in Uganda.
The community should liaise with TASO and MoH, the DHT and other partners to document its "best practices" in the Seeeta-Nazigo initiative, in order to promote sharing of information between communities involved in CHBC activities.

TASO should strengthen the capacity of the community to produce more local IEC materials. More IEC is still needed in the struggle against HIV/AIDS. This could be through conducting skills building seminars for the programme implementers on how to develop IEC materials. The draft materials produced by the community could be edited by TASO before publication.

5.3 Conclusions

The main purpose of this study was to establish the importance of capacity building in CHBC. This was examined from the standpoint of the community taking responsibilities and performing tasks in CHBC. A number of secondary objectives were also set. These were: to explore the concept of capacity building in CHBC and also assess the critical factors that constitute capacity building in CHBC. Finally, the study endeavoured to establish a relationship between capacity building so as to improve practice in CHBC and lead to sustainable initiatives.

From the study the following conclusions could be made:

Community mobilisation is important in building the capacity of the community to deliver CHBC services. It was proven that community mobilisation led to ownership of the programme by its implementers and the community at large.

The study also established support and supervision as a critical factor in capacity building in CHBC. However, according to the findings it was evident that support and supervision is not just one diagnostic exercise, it is a process.

Development of specific skills in CHBC is important for effective quality service delivery and sustaining the programme. However, there is need to acknowledge that it
The Role of Capacity Building in CHBC

has to be done on a continuous basis. And in order to achieve long lasting results, skills enhancement in CHBC should be multifaceted and crosscutting in a number of disciplines.

Networking and collaboration are essential in sustaining a CHBC programme. Their impact depends on how the organisation reaches out to a number of multi-disciplinary organisations in order to ensure the delivery of services.

VCT is significant in building the capacity of CHBC initiatives and its success depends on availability of skilled personnel to offer services and access to testing facilities to the community members.

IEC strategies that are developed at a community level are a strong factor in capacity building in CHBC programmes.

Monitoring and evaluation is a principal key in building and sustaining a CHBC programme. However, for M&E to be effective, continuous research is required in order to link the initiative with the realities of what takes place during intervention so as to improve practice.

Finally, sharing the findings of this study will assist towards improving practice in CHBC. This is based on the fact that HIV/AIDS continues to affect many countries and more effort is required to deal with the epidemic. Therefore, the publication of this dissertation could make a positive contribution in improving the quality of care of PLWH/A and in empowering communities to mitigate the impact of the epidemic.
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APPENDIX I

CHECKLIST FOR KEY INFORMANT INTERVIEW (KII).

Please use this issues checklist for discussion with Key Informants such as the PAC Chairman, Medical Coordinator of TASO, Assistant Medical Officer at Sseeta-Nazigo Clinic and any other person well-informed about the programme.

Dear Sir Madam,

I am a Masters Degree Student interested in a research on Sseeta-Nazigo Community AIDS Initiative. You have been selected to participate in this study because of your experience about the Community Home Based Care programme in Sseeta-Nazigo. We have a number of issues that we would like to discuss with you for approximately one hour. Your response is important to us and we promise to treat it as confidential.

NB Introduce the Research team as well.

1. What have been some of the Community mobilisation activities carried out in Sseeta-Nazigo?

2. How has the community benefited out of these activities?

3. What are the community sensitisation activities that you recall being done in this village?

4. What was the impact of these activities?

5. What are some of the materials that the programme use in delivering information and educating the community on HIV/AIDS.

6. What are the different programme implementers of Sseeta-Nazigo community Home Based AIDS Initiatives?
7. What were they trained on and by who?

8. How did the training assist the programme implementers in delivering CHBC services?

9. What impact has it created in the community?

10. What mechanism is in place in form of support and supervision for the programme?

11. Who offers the support?

12. How has support and supervision assisted the programme and the implementers?

13. Could you please mention the organisations that Sseeta-Nazigo community Initiatives collaborates with.

14. Why do they collaborate with these organisations?

15. How has this assisted the programme implementers and the programme in general?

16. What is your opinion about the provision of Voluntary Counselling and HIV Testing services by the programme?

17. How has the community responded to the VCT services?

18. How do you monitor and evaluate the activities of the Sseeta-Nazigo Community AIDS Initiatives Programme?

19. Who are the people involved in the monitoring and evaluation?
20. How has the information generated assisted the programme?

21. Please give us the benefits of this activity to the programme and the community at large.

22. May you please make any suggestions that would strengthen the delivery of CHBC services in Sseeta-Nazigo.

23. Do you have anything in particular that you would like to discuss with us?

Thank you very much for your time.
APPENDIX II

CHECKLIST FOR FOCUS GROUP DISCUSSIONS WITH PROGRAMME IMPLEMENTERS AND TASO STAFF

This checklist is supposed to be used by the moderators as a Guide for Focus Group Discussions with ACW, PAC Members, Condom Distributors, TASO counsellors and Trainers at Headquarters.

Dear colleagues,
You have been selected to participate in this discussion because of your experience in working with the TASO community initiatives programme in general and the Sseeta-Nazigo community based AIDS Initiatives Programme in particular. Therefore your contribution is very important to us. The study is primarily for academic reasons however the findings could be utilized to strengthen the CHBC programme.

NB Start with self introductions for all the group members before the discussion.

COMMUNITY MOBILISATION

1) What have been some of the Community mobilisation activities carried out in Sseeta-Nazigo?
2) Who have been the key players in community mobilisation?
3) How has the community benefited from this activity?
4) What are the community AIDS sensitisation activities that you recall being done in this village? What was the impact of these activities?
5) What forums were used for informing and educating the on HIV/AIDS?

INFORMATION, EDUCATION AND COMMUNICATION (IEC)

6) What are some of the materials used by the programme implementers in community mobilisation, delivering information and educating the community on HIV/AIDS?

7) What were the sources of the materials? (Prompt for availability of local materials used).
8) How has the information, education and communication assisted the community in the struggle against HIV/AIDS?

9) What has been the impact of these activities?

**VOLUNTARY COUNSELLING AND TESTING (VCT)**

10) What is your comment on the VCT in the community?

11) Who offers the VCT services in the community?

12) Who are the major beneficiaries of this service?

13) How has the service impacted on the programme and the community?

**SKILLS DEVELOPMENT AND ENHANCEMENT**

14) What type of training did the following Programme implementers receive and who offered it?
   a. PAC
   b. ACW
   c. CCA
   d. Condom Distributors.

15) How did the training assist the programme implementers in delivering CHBC services?

16) What impact has it created in the community?

**SUPPORT AND SUPERVISION**

17) What mechanism is in place in form of support and supervision for the programme and its implementers? (Prompt discussion on areas such as technical and material assistance).

18) Who offers the support and supervision and how has this assisted the programme and its implementers?
NETWORKING AND COLLABORATION

19) Could you please mention the organisations that Sseeta-Nazigo community Initiatives collaborates with and the areas of collaboration?

20) Why do they collaborate with these organisations?

21) How has this assisted the programme implementers and the programme in general?

MONITORING AND EVALUATION

22) Could you please mention some of the M&E practices used in Sseeta-Nazigo Community AIDS Initiatives Programme.

23) What activities have been monitored and evaluated?

24) Who are the people involved in the monitoring and evaluation?

25) What are some of the factors that have facilitated M&E?

26) How has the information generated assisted the programme and its implementers?

OTHERS

27) What would you recommend in general to improve the delivery of CHBC services in Sseeta-Nazigo?

28) Do you have anything in particular that you would like to discuss with us?

Thank you very much for your time