CONSULTANCY REPORT

ON

SOCIAL SUPPORT STRUCTURES

TO

SUPPORT ART SCALE UP IN

TANZANIA

Dr. AG Coutinho
Mrs. Grace Oling
PO Box 10443
Kampala Uganda

6th July 2005
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cover page</td>
<td>1</td>
</tr>
<tr>
<td>Table of Contents</td>
<td>2</td>
</tr>
<tr>
<td>List of Abbreviations</td>
<td>3</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>4</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>5</td>
</tr>
<tr>
<td>Introduction and summary of situation of HIV in Tanzania</td>
<td>6</td>
</tr>
<tr>
<td>TOR, Objectives and Scope of Work</td>
<td>7</td>
</tr>
<tr>
<td>ART scale up in Tanzania</td>
<td>7</td>
</tr>
<tr>
<td>Social support packages for PLWHA</td>
<td>8</td>
</tr>
<tr>
<td>Models from Uganda</td>
<td>9</td>
</tr>
<tr>
<td>Methodology of Consultancy</td>
<td>13</td>
</tr>
<tr>
<td>Consultancy Findings</td>
<td>14</td>
</tr>
<tr>
<td>Recommendations</td>
<td>16</td>
</tr>
<tr>
<td>Stakeholders Workshop 4&lt;sup&gt;th&lt;/sup&gt; JULY 2005</td>
<td>20</td>
</tr>
<tr>
<td>Conclusions</td>
<td>21</td>
</tr>
<tr>
<td>Appendices</td>
<td>22</td>
</tr>
</tbody>
</table>
(i) List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACW</td>
<td>AIDS COMMUNITY WORKER</td>
</tr>
<tr>
<td>AIDS</td>
<td>ACQUIRED IMMUNE DEFICIENCY SYNDROME</td>
</tr>
<tr>
<td>AMREF</td>
<td>AFRICAN MEDICAL RESEARCH FOUNDATION</td>
</tr>
<tr>
<td>ART</td>
<td>ANTI-RETROVIRAL THERAPY</td>
</tr>
<tr>
<td>CN</td>
<td>COMMUNITY NURSE</td>
</tr>
<tr>
<td>CTC</td>
<td>CARE AND TREATMENT CENTER</td>
</tr>
<tr>
<td>DMO</td>
<td>DISTRICT MEDICAL OFFICER</td>
</tr>
<tr>
<td>FHI</td>
<td>FAMILY HEALTH INTERNATIONAL</td>
</tr>
<tr>
<td>HBC</td>
<td>HOME BASED CARE</td>
</tr>
<tr>
<td>HIV</td>
<td>HUMAN IMMUNO DEFICIENCY VIRUS</td>
</tr>
<tr>
<td>HR</td>
<td>HUMAN RESOURCES</td>
</tr>
<tr>
<td>IDC</td>
<td>INFECTIOUS DISEASES</td>
</tr>
<tr>
<td>MoH</td>
<td>MINISTRY OF HEALTH</td>
</tr>
<tr>
<td>OI</td>
<td>OPPORTUNISTIC INFECTION</td>
</tr>
<tr>
<td>OVC</td>
<td>ORPHANS AND VULNERABLE CHILDREN</td>
</tr>
<tr>
<td>PASADA</td>
<td>PARISH AIDS SUPPORT ACTIVITIES DAR ES SALAAM</td>
</tr>
<tr>
<td>PEPFAR</td>
<td>UNITED STATES EMERGENCY PRESIDENT’S PLAN FOR HIV/AIDS RELIEF</td>
</tr>
<tr>
<td>PLWHA</td>
<td>PEOPLE LIVING WITH HIV/AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>PREVENTION OF MOTHER TO CHILD TRANSMISSION</td>
</tr>
<tr>
<td>TASO</td>
<td>THE AIDS SUPPORT ORGANISATION</td>
</tr>
<tr>
<td>TOR</td>
<td>TERMS OF REFERENCE</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>UNITED NATIONS JOINT PROGRAMME ON HIV/AIDS</td>
</tr>
<tr>
<td>VCT</td>
<td>VOLUNTARY COUNSELLING AND TESTING</td>
</tr>
<tr>
<td>WHO</td>
<td>WORLD HEALTH ORGANISATION</td>
</tr>
<tr>
<td>ZACP</td>
<td>ZANZIBAR AIDS CONTROL PROJECT</td>
</tr>
<tr>
<td>ZAPHA</td>
<td>ZANZIBAR ASSOCIATION OF PEOPLE LIVING WITH HIV/AIDS</td>
</tr>
<tr>
<td>ZASO</td>
<td>ZANZIBAR ASSOCIATION TO SUPPORT ORPHANS</td>
</tr>
<tr>
<td>ZNA</td>
<td>ZANZIBAR NURSES ASSOCIATION</td>
</tr>
</tbody>
</table>
(ii) **ACKNOWLEDGMENTS**

We acknowledge and thank the following organizations and individuals
Ministry of Health, UNAIDS FHI, WHO, Pharm Access and World Bank for funding this consultancy.
Dr. Swai, Dr. Eric Van Praag and Mrs Olowo- Freers for their guidance
Ms. Mwanga and Ms. Msumi for the superb organization and logistics
The staff of NACP and UNAIDS for day to day support
Our hosts in Iringa – the DMO, AMREF and CARE staff for excellent field trips
The Zanzibar team we interacted with and had such memorable field visits
All the attendees of the Stakeholders workshop
All the clients and their families who gave us permission to interact with them and take photographs
The AIDS Support Organization for permission to share their documentation
Executive Summary

Since 2003 there has been a concerted effort by the government of Tanzania (GOT) to scale up care, support and treatment for its citizens and in an attempt to achieve universal access to ART an HIV/AIDS Care and Treatment Plan 2003-2008 was developed by the GOT in collaboration with the Clinton Foundation. Tanzania and the NACP and TACAIDS in particular have put together an impressive number of guideline and policy documents for care and treatment to provide a vision and leadership for the scale up of care support and treatment in Tanzania. In order to consolidate these gains, there is need to outline an essential social support package that can be rapidly instituted for all people starting ART so as to ensure adherence and prevent the emergence of drug resistance with its attendant complications to individual and health system.

In order to address this challenge a consultancy was requested with the following TOR

- a) Review the ongoing HBC and other community based social support services in the community so as to determine the existing linkages with Care and Treatment Clinics at hospital level.
- b) Outline a plan for strengthening the role of the community and home based care in supporting and monitoring adherence to life long medications

The consultancy involved field visits to Dar es Salaam, Iringa and Zanizibar. Overall we were impressed with the awareness and commitment to scale up ART. This was evident in all the sites we visited and terms like “CD4” were used with confidence. However we also observed a huge gap in knowledge about ART and the requirements needed to move to a scaled up model.

The findings and recommendations are detailed in the full report but the take home message is that current HBC models will not be able to deliver the social support package necessary for supporting adherence among clients starting ART. There will be need to identify a multi-sectoral partnership to deliver a social support.

Social support packages will become more important as the efforts shift from an enrollment phase to a sustained adherence phase. It is clear that there are many barriers to adherence and an effective social support package will go a long way to supporting clients adhere to medication.

However it is also clear that HBC is only part of a social support package and cannot be expected to deliver the whole package. There is urgent need to identify the additional players that can contribute to the national social support package and set up communication and co-ordination structures at district level with the client at the center of the planning process.

It is also clear that PLWHA themselves are an essential part of the social support package and there is need to be supported to participate actively in ART scale up in several ways including as model patients, peer educators and HBC providers.
Introduction and summary of situation of HIV in Tanzania

The first case of AIDS was reported in Tanzania in 1983 and since then there have been 176,102 AIDS cases reported which is a huge underestimate of the actual number of cases. The 2003 HIV/AIDS/STI surveillance report estimates that by the end of 2004 there would be 1,810,000 PLWHA and a cumulative 2,000,000 AIDS deaths. (Other references talk of 800,000 deaths) The national HIV prevalence is now estimated to be between 7% and 10% of sexually active adults depending on the source of data. ANC surveillance data for 2001 showed Prevalence at 9.6% while Blood donors in 2003 had a prevalence of 8.8% and a more recent population based survey puts the prevalence at 7%. There is need for additional data from several sources including wider population based surveys to get an accurate picture of the current situation in Tanzania.

In Zanzibar the estimated prevalence is 0.6% with an estimated 6,000 HIV infected persons. To date 38 individuals have been started on ART in Zanzibar. Whatever the statistic one uses there is no doubt that HIV/AIDS is having a tremendous impact on all sectors of Tanzanian society. It is estimated for instance that 50-60% of all adults admitted in medical wards are HIV+.

Since 2003 there has been a concerted effort by the government of Tanzania (GOT) to scale up care, support and treatment for its citizens and in an attempt to achieve universal access to ART an HIV/AIDS Care and Treatment Plan 2003-2008 was developed by the GOT in collaboration with the Clinton Foundation. This ambitious plan aims to put 423,050 on ART by end of 2008. Currently as of June 2005 it is estimated that there are 8000 Tanzanians on ART from all sources with an estimated 400,000 in immediate need of ART. The 3X5 target for Tanzania was 220,000 people on ART by end of 2005. To date 92 sites have been identified and phased training and accreditation is taking place. The Minister of Health has announced this number of sites to be increased to 198 with an adjusted target of 100,000 people on ART by end of December 2006. It is recognized that once enrollment is achieved the major challenge will be drug adherence and while the facility based program does put in place some adherence programs there is urgent need to identify resources and a community based model to ensure life long adherence.

Tanzania and the NACP and TACAIDS in particular have put together an impressive number of guideline and policy documents for care and treatment to provide a vision and leadership for the scale up of care support and treatment in Tanzania and these include

- Revised guidelines for Home Based care services (2004)
Training plans and curriculums for home based Care providers (2004)

In addition Tanzania has managed to mobilize large amounts of resources to tackle HIV/AIDS from its own coffers, the Global fund, PEPFAR, The World bank, the UN bodies and other Bilateral donors. In addition a significant number of NGOs and research institutions are active in the country and in particular helping to scale up HIV testing and provide care and treatment including home based care.

Despite these impressive gains ART treatment is still taking place in a fragmented way with multiple providers who often take a very western medical approach and do not link to each other, to the public health system, to home based care initiatives or to other sectors that could provide the social safety nets needed. There is also need to outline an essential social support package that can be rapidly instituted for all people starting ART so as to ensure adherence and prevent the emergence of drug resistance with its attendant complications to individual and health system.

TOR, Objectives and Scope of Work

a) Review the ongoing HBC and other community based social support services in the community so as to determine the existing linkages with Care and Treatment Clinics at hospital level.
b) Outline a plan for strengthening the role of the community and home based care in supporting and monitoring adherence to life long medications

The scope of work included
- Inception meeting with NACP, UNAIDS, WHO, FHI, Clinton foundation, Pharmaccess
- Field visits to PASADA, Infectious Disease Clinic (IDC), AMREF and CARE - TUMAINI HBC in Iringa,
- Field visit to NACP, ZAC, ZAPHA+ and clients homes in Zanzibar
- One Day Stakeholders meeting to share experiences and outline a plan to strengthen social support services for ART in order to support life long drug adherence
- Consultancy report

ART scale up in Tanzania

Since October 2003 Tanzania has been committed to providing ART for its people. A detailed and ambitious scale up plan was put together with the assistance of the Clinton foundation and since then there have been urgent attempts to raise resources and operationalize it. When donor resources were not coming in time, Tanzania itself committed $2,000,000 to kick-start the program. While the program is way behind its targets it is clear that there is a determination to scale up ART and to do so in a
planned methodological way. A major challenge has been to identify, train and motivate the different cadres of human resources needed to launch and sustain this undertaking. Countries like Uganda and organizations like TASO in particular that have had a longer experience with ART are well aware of the important role of HR and the challenge to deploy committed and capable individuals.

In addition more experienced ART programs are aware that without an essential social support package it might be difficult if not impossible for clients to be able to adhere to the stringent adherence requirements for ART. The current Tanzania program while recognizing the need for social support envisages that this can be provided by its home based care program. This consultancy will examine this assumption and advise accordingly.

**Social support packages for PLWHA**

Care and Support of PLWHA has shown that apart from the medical and counselling needs, clients require further social support to assist them cope with their illness. As clients access ART, they undergo significant life changes that require a new set of support systems relevant to the new challenges they face and in turn require social support as they readjust.

A **Social support package in line with some of the needs displayed by clients on ART in both Uganda and field visits in Tanzania is proposed below:**

- Community awareness programs to address stigma and myths about ART hence provide a supportive environment for clients on ART
- Transport support to facilities (for the poorest) to initiate treatment and for follow up care
- Treatment assistants from the community for those households with no other adult who can assist client with drug adherence
- Home based care and other community based initiatives to provide medical care and psychosocial support at home to address medical challenges like side effects of drugs in addition to facility based services
- Strengthening messages on behavior change and adherence through Family support/ medicine companions and peer support groups (ensure messages evolve with evolving needs). Social support groups need to structure around a common ongoing activity of interest to ART beneficiaries if it is to be sustained over many years
- Reproductive Health services- PMTCT, Family planning and condom provision services with community distribution component to address emerging sexual
reproductive health needs. Also social negotiation skills to negotiate e.g. abstinence or condom use.

- Food security through initial food supplementation and then followed by improved agricultural practices, seeds and inputs like animals
- Economic empowerment – business start up skills and capital
- Support to overstretched families with OVC to enable them care for OVC, e.g. Elderly care givers etc
- Education support for children of the poorest
- Continuous ART literacy to address emerging issues
- Universal VCT including Home based/community based VCT initiatives
- Housing for some clients who may have no place to stay in the interim intensive ART initiation phase (1-3 months)

Models from Uganda

THE TASO HOME BASED CARE MODEL

When formulating this model, everybody who should care for the client was considered, and also the need to work hand in hand as a team. This model consists of 4 levels

**Level One**
This level consists of the client and the caregivers. The caregivers, who are usually relatives of the client, are given the basic knowledge on HIV/AIDS, First Aid, basic or general hygiene, how to recognize danger signs, and any other relevant facts. They are told to call the Aids Community Worker in their area [who are already trained by TASO], in cases where the client’s condition deteriorates and they need help.

**Level Two**
This level consists of the Aids Community Workers [ACW]. These are volunteers from the community who are trained in basic counseling skills, First Aid, how to recognize danger signs and in case they do, to refer the client to the third level. They are also required to visit all clients in their area, and to supervise Direct Observed Therapy for patients who are on anti-TB treatment and soon to also visit clients on ART for drug adherence support.

**Level Three**
This level consists of a trained Nurse/Counsellor, referred to as the Community Nurse. We recruit retired nurses who are already based in the communities, often running their
own business and whom we provide a volunteer allowance. These Nurses get training in management of Opportunistic Infections [OI] and Septrin Prophylaxis and ART. They are entrusted with essential drugs, which they administer in simple cases. They also follow up clients especially the bed-ridden ones and those on TB and ARV therapies. They support the ACWs and Caregivers. They are answerable to the TASO team and are required to give a report of their work every month. The Home Care Team supervises their work every week, and gives them support as required. They refer clients to

- The TASO centres
- The TASO Home Care Team
- The nearest Government Health Unit
- The TASO Outreach Clinic if near

**Level Four**

This consists of the TASO centre Home Care Team whose activities are:

- To provide Support and Supervision to the Community Nurses [CN] and ACWs
- To visit and give treatment to the very sick clients who have been identified by the CN. The CN gives the direction and all the information required about the client
- To link up the Caregivers, the ACWs, CN, the govt. health facility and the TASO Field Officers, so that they work hand in hand as a team.
- Identify the neediest of the needy and give them home care kits

TASO Mulago Centre (one of 10 centers) has 11 communities each with one Community Nurse. TASO also runs a number of outreach clinics in different districts but this does not still meet the demand for services. Home care will remain the most demanded service by the community. Referrals can be done up the ladder i.e. from level one to two three and four, or vice versa.

**Objectives of the strategy:**

- To improve on the quality of care given to PLWHA by involving everybody at all levels
- To reduce stigma by involving the Community. If the community realizes that the problem is theirs and they have a part to play in fighting the stigma, their attitude changes and the stigma reduces
- To improve the referral system
- To reduce on the cost of caring for clients
- To reach more clients who cannot afford to reach the centres
- To empower the community to handle situations
- To make it easier to reach bedridden clients
- To improve contact between clients and the centres
- To reduce on the workload at the centres
- To help improve adherence in case of clients on treatment for long periods of time

**Advantages of the strategy**
• Provides a wider coverage of those who need home care
• Decreases the demand on the hospitals and health facilities
• Since it involves the community, it is more sustainable
• It improves collaboration with other service providers

Challenges
• Many clients join TASO every day due to various reasons. This leads to an increased work load and more TASO registered clients in the community who need home care
• New programmes which come on board also increase work in the community e.g the ART programme is home based as more and more clients are put on ARVs, and these are monitored by CNs and ACWs, the workload increases and yet the workers are volunteers who have to attend to their personal problems as well.
• Most TASO clients are women and are unemployed. They live under very unfavourable conditions and the hope of their coming up to live a better life is not there.
• There are many child – headed families which cannot support themselves; there are very helpless clients who live alone ; there are very young children who are sole attendants to their parents; all these are encountered during home care and yet home care has a limit to what it can offer.

TASO ART PROGRAMME

This programme was introduced as an additional service to the increasing TASO clientele.
It was to be integrated into the existing services, and not to be implemented as a separate entity. This was a big challenge, but the only plausible way forward. It had its own goals and objectives

Goal :
Its goal was to reduce mortality and morbidity of the clients, and to help them become healthy members of society again.

Objectives
1. By the end of 2008, 90% of all PLWHAS registered with TASO, and whose CD4 cells are less than 200, will have had access to ARVs
2. All TASO Medical staff will have been trained comprehensively in the management of clients on ART by the end of 2004 [this was implemented]
3. All TASO Counsellors will have been trained in ART related counseling by the end of 2004 [implemented]
4. By the end of 2005 all TASO Centres will have been upgraded to provide ART services,[on the way to success]
Model of the ART Programme

- The Programme is home based, with the exception of a few cases who collect their drugs from the center due to various reasons, in most cases because they are working during the day so they are not at home to receive the drugs.
- All the eligible clients and their HIV positive Family members will receive free ARVS.
- The programme will be in line with the National guidelines on ART.
- Phased preparedness and capacity building.

Components of Home based ART Programme.

1. Field Officers deliver drugs to the clients at their homes.
2. The clients must have their medicine companions before starting the drugs.
3. VCT for household members to be done by Field Officers.

FIELD OFFICERS.

These are dedicated men and women with a degree or diploma who are trained comprehensively to spear head the TASO Home based model for ART Programme/community component. Their one-month training covers the following areas:

- Basic facts about HIV infection and disease.
- Clinical skills for home based care.
- Basic counselling skills.
- Behavioral change communication.
- Community mobilization.
- Principles of adult learning.
- Principles and practices of ART.
- Finger prick VCT.
- Motorcycle riding skills.
- Monitoring and evaluation.

The role of Field Officers [F.O] in implementing the TASO Community ART Programme.

- The F.O. distributes ARVS to clients in the communities and also monitors and encourage adherence. They have different methods they use to assess adherence.
- They offer Counselling to clients on adherence and give any other care and support in their means.
- They do home visits for clients on ART to monitor their progress.
- They liaise with the Community Nurses, ACWs, PAC to ensure support to the clients.
- They facilitate the setting up of peer- support groups [this mobilization is left to clients as far as confidentiality is concerned].
- They provide home based finger prick VCT to consenting family members.
- They refill drugs for 5-10 clients a day serving a client load of 100 clients a month.
They carry out mapping of the clients homes.
They are responsible to refer clients with problems to TASO clinics at the center.

**Advantages of ARVs being delivered by Field Officers.**

- It is cheap and convenient to the clients.
- It increases support from the family members.
- It encourages disclosure.
- It reduces on the work load for the facility
- It creates room for Home Based VCT.
- It reduces the degree of stigma and discrimination.
- It is acceptable to the community so it can last.
- It improves on adherence to ARVs.

**Methods used by Field Officers to measure adherence:**

- Client self report.
- Pill counts
- Checking of empty pill packages
- Client and medicine companion check scorecards.
- Well being e.g. weight gain, physical appearance and reduction of opportunistic infection.
- Social monitoring, psychosocial assessment, and Nutritional monitoring.
- Checking on behavioral change - both risky and safe behaviors.

**Challenges**

- Wrong Addresses or client not found at home.
- Difficult terrain:- hilly and muddy roads.
- Theft of the motorcycles.
- Stretched manpower in carrying out VCT and refilling drugs at the same time.
- Clients shifting to different places of residence
- Long distances to clients homes.
- Monitoring adherence
- Expensive model at a national level

**Methodology of Consultancy**

The consultancy was carried out over an 10 day period within Tanzania. The consultants reviewed key documents from Tanzania related to care, treatment and support. An inception meeting was held with the head of NACP, Dr. Swai, Country coordinating representative for UNAIDS, Mrs. Bernadette Olowo- Freers as well as representatives of the MOH, WHO, FHI, AMREF, Pharmaccess and the Clinton foundation. The TOR were reviewed and the situational analysis clarified. A number
of site visits were undertaken in Dar es Salaam, Iringa district and Zanzibar and details of these visits and discussions are in the appendices. Finally a stakeholders meeting was convened in Dar es Salaam where the findings were presented together with some models from Uganda. A discussion and way forward for appropriate models for Tanzania was initiated. This report summarizes the processes.

Consultancy Findings

These findings are based on a short consultancy visiting only a few sites. Validation of these findings has to be made by all those providing care and support and treatment in Tanzania. Overall we were impressed with the awareness and commitment to scale up ART. This was evident in all the sites we visited and terms like “CD4” were used with confidence. However we also observed a huge gap in knowledge about ART and the requirements needed to move to a scaled up model. Even at the highest levels of planning there is urgent need for appropriate “ART Literacy”. The situation on the ground is not reflected into a realistic ART scale up business plan and Tanzania may have over promised and under delivered on its actual ability to reach targets set by itself and its partners.

Key findings were as follows

ART ROLL OUT

• There is still a tremendous need for ART literacy at all levels
• Where quality ART services were provided like in the IDC and PASADA there was an increasing demand for ART that was overstretching resources
• Most programs were in the initiation stages and focusing on enrollment of clients with no clear plan for ensuring adherence when client numbers increased
• Most programs seen assumed that clients would be able to return for scheduled visits by their own means. In practice many clients could not afford the transport or were too sick to travel.
• While several HBC programs were actively referring clients to CTC we were not made aware of any process where the CTC staff and HBC providers did joint planning for patient care
• In both Iringa and Zanzibar there were delays to start treatment mainly due to lab result delays.
• All clients spoken to on ART or waiting for ART were asking for food supplementation

SOCIAL SUPPORT SERVICES

• There was awareness of the need for a social support package and this was most articulated by clients themselves
• Most programs visited could not provide all the components of an essential social support package
• Those providers meeting some aspects of a social support package were operating on a small scale and reaching only a few homes and clients.
• All homes visited were extremely poor with obvious food insecurity, many OVC and surrounded by stigma and fear.

HOME BASED CARE SERVICES

• The national guidelines and training package for home based care providers were of an excellent quality but the training package of the HBC does not cover some of the social support challenges they will face in the homes
• There has been good integration of issues of ART in the revised guidelines
• On the ground, home based care providers are still few and under capacitated. In addition the village HIV committees supposed to guide them are also ART illiterate.
• Apart from HBC providers of NGOs like AMREF and CARE the government supported HBC providers in the areas we visited will not be able to respond to many of the social support needs of clients e.g. food, transport, medicines
• It is not realistic to expect HBC to be the answer to all the social support needs to ensure drug adherence.
• HBC is part of a social support package and the other components and providers of social support need to be identified and linked to both CTC and HBC services
• HBC services in the past have targeted clients who were sick and probably dying. As clients start on ART and start the process of new life there will be new support needs and a need to reorient home based care services to support people living with HIV who are healthy but very poor.

HUMAN RESOURCES, TRAINING AND CAPACITY BUILDING

• This will continue to be the major bottleneck in rolling out ART. While there are plans to recruit and train the medical staff and counselors needed for scale up, we did not see any plans to train social support cadres including HBC volunteers, community HIV committees, District non – medical staff etc.
• There is need to evaluate the numbers and cost of these non medical staff needed to support ART scale up so that realistic resource mobilization and training plans can be developed
• There is a shortage of training institutions and training staff to respond to the huge gap in ART literacy at all levels. This is an urgent gap that needs to be closed soon.
• There will be need to train all health staff at facility in ART so as to have joint ownership of the programme
• Additional resources in the communities need to be identified like religious and traditional healers so there is buy in to the process of ART scale up.
• The potential of PLWHA to establish peer support and education groups exist but is not fully utilized
NATIONAL POLICIES AND RESPONSES

• Tanzania needs to examine those policies that may slow down or impede ART delivery e.g. whether HBC providers can carry and deliver ARVs to peoples homes
• Tanzania needs to support multi-skilling of personnel to carry out duties like HBC, home based VCT and ART adherence monitoring
• Tanzania has to invest more in HR for ART scale up including non –medical personnel
• There is need to examine the ART program to date, balance the needs for enrollment and adherence and re-determine realistic targets

Recommendations

The recommendations arising out of this consultancy are focused on social support systems to support drug adherence and in particular the role of HBC. The recommendations are divided into short term (6 months), Medium term (6-24 months) and longer term (24months+)

Short term (6 months)

The key resource for drug adherence is the client, their family and/or drug assistant. In the short term as clients are started on ART this has got to be the focus for education, motivation and social support. Since the clients starting on ART are scattered all over the country, it will not be possible to have HBC providers reach all of them in the short term. Therefore ART scale up programming must use the family as the greatest resource but also be prepared to support the family. The essential package needed in the short term for drug adherence would comprise

• Clear guidelines for clients and their families on ART with appropriate IEC materials in a simple and easy way to understand. Tanzania has the luxury that only one language – Swahili – can be used.
• As far as possible all sessions leading up to commencement of ART should be attended by client and family member/ drug assistant
• Support in disclosure and stigma reduction
• It may be necessary in the short run to provide a transport refund for those poor clients who cannot sustain monthly trips to CTC that are a distance away. This can be provided by community based organizations and is cheaper in the long run compared to treating drug resistance
• Food is an essential component of recovery from any chronic disease and AIDS is no exception. It will be necessary to urgently link with agencies like WFP to provide a complementary food supplementation for the client and their family so that both adherence can be supported and recovery accelerated
• Appropriate tools for drug adherence provided like pill boxes, pill charts, IEC materials
• Family based VCT provided to identify any other HIV+ family members who may need ART so as to prevent drug sharing
• Tracking system for defaulted clients and follow up to be carried out from facility

**Medium term**
The focus here is to build the capacity of the facilities and communities to support families where there is an HIV+ person or OVC regardless of whether or not they are on ART

• Scale up and ensure a network of HBC providers throughout the country. Scale up measures to reduce stigma and increase community engagement with PLWHA
• Support and develop as many HIV+ peer groups and engage them in both prevention and care and treatment. Provide the resources including allowances to make this worthwhile for them.
• Use the existing guidelines for HBC providers. These will need continuous refreshers on issues of HIV and ART
• Build the national capacity for training all cadres in care and treatment
• Map and rationalize the different providers of social support services and HBC in the country and establish a communication and co-ordination mechanism
• Move from food supplementation to food security programs
• Decentralize ART services to as close as communities as possible. Some dispensaries can be used to deliver pre-packed drugs for clients near them (75% of population is 5kms from a health facility)
• Put in place structures to deliver drugs to clients homes where need
• Put in place tracking systems that can alert when a client has defaulted
• Allocate more resources for social support

**Longer term**
Here the focus is on consolidating the short and medium term interventions but also moving on to greater client empowerment and independence. In particular the vision should be that clients on ART are reintegrated into the productive labor force, are able to raise their own money and if necessary pay for their own treatment. There will still be need for ongoing counseling and medication adherence but the immediate needs for food and transport etc should fall away. A framework for this process that is being used in TASO Uganda is described below.
The dual-epidemics of HIV/AIDS and poverty plague poor people in Africa. High unemployment, illiteracy, poor sanitation and meager education increase vulnerability to HIV infection. HIV/AIDS in turn worsens their already poor living conditions and can propel them from poverty to destitution. As people living with HIV/AIDS (PLWHA) become more impoverished, they are again more prone to opportunistic infections and other illness, perpetuating the cycle of poverty and disease illustrated in Figure 1. The downward spiral affects not only the PLWHA but also his immediate family, extended family, and community.

Counselors report that their clients’ greatest worry is the well-being of their families and the future of their children. Clients tend to be healthier when they have a consistent source of food, and they tend to be less anxious when their children are in school. The introduction of Anti-Retroviral Therapy at TASO has increased the hope of clients and as clients grow healthier and are living longer, they want to find their livelihoods again. Healthy clients want to move towards economic independence.

TASO clients are diverse in their capacities, skills, socio-economic backgrounds, and needs. Depending on their backgrounds and strengths, clients will benefit from different poverty-alleviation programs. There are, therefore, three flexible levels to a framework for economic empowerment: Social Welfare for the destitute, Jumpstarts for healthy dependent clients, and Financial Services (e.g., micro credit) for economically active clients.
For TASO’s poorest clients, food aid and social welfare will be a temporary and finite relief response to poor health and deep poverty, but stronger clients will graduate from food aid through jumpstart programs and may eventually be able to access loans and savings.

**Food Aid:** Most clients join TASO when they are very sick and many are malnourished. Poor nutrition has compounded the progression of AIDS. For very poor and sick clients, food aid is necessary for immediate emergency relief. Clients who receive food aid report that the food improves their health, lifts their spirits, and ultimately provides dignity to their lives. Food aid, however, is not a lifetime response to the poverty of clients. If and when health improves, TASO clients should graduate from food aid through sustainable economic empowerment.

**Jumpstarts:** Through jumpstart programs, clients can ‘graduate’ from food aid as they begin to earn their own living. They need initial training, guidance, and resources to begin their own income generating activities. A jumpstart is a one-time grant, training, and/or gift-in-kind with the ultimate aim of sustainable economic growth for the client. Examples include Heifer Project International, Trickle Up, and community projects.

**Loans and Savings:** Clients who earn an income and are relatively healthy and economically independent need financial services such as loans and savings programs to manage their income-generating activities. The program will not, however, act as a charity. Unlike the jumpstart programs, loans are best suited for clients who already have businesses and are capable of repayment. Loan schemes work best with strict policies. Interest and default penalties will apply.

---

**Figure 1: The Framework for Economic Empowerment**

For TASO’s poorest clients, food aid and social welfare will be a temporary and finite relief response to poor health and deep poverty, but stronger clients will graduate from food aid through jumpstart programs and may eventually be able to access loans and savings.

**Food Aid:** Most clients join TASO when they are very sick and many are malnourished. Poor nutrition has compounded the progression of AIDS. For very poor and sick clients, food aid is necessary for immediate emergency relief. Clients who receive food aid report that the food improves their health, lifts their spirits, and ultimately provides dignity to their lives. Food aid, however, is not a lifetime response to the poverty of clients. If and when health improves, TASO clients should graduate from food aid through sustainable economic empowerment.

**Jumpstarts:** Through jumpstart programs, clients can ‘graduate’ from food aid as they begin to earn their own living. They need initial training, guidance, and resources to begin their own income generating activities. A jumpstart is a one-time grant, training, and/or gift-in-kind with the ultimate aim of sustainable economic growth for the client. Examples include Heifer Project International, Trickle Up, and community projects.

**Loans and Savings:** Clients who earn an income and are relatively healthy and economically independent need financial services such as loans and savings programs to manage their income-generating activities. The program will not, however, act as a charity. Unlike the jumpstart programs, loans are best suited for clients who already have businesses and are capable of repayment. Loan schemes work best with strict policies. Interest and default penalties will apply.

---

**Figure 4: Breaking the Cycle of Poverty**
• The plight for TASO clients, and particularly those on ARVs, is far from hopeless. Many will live long and fruitful lives. As clients grow healthier on treatment they are eager to work and provide for themselves, but they continue to face deep poverty. TASO is already breaking the cycle of poverty through education, medical care, and psychosocial support, as illustrated in figure 4. Economic empowerment fits into TASO’s services to crack the last link on the cycle of poverty and AIDS.

STAKEHOLDERS WORKSHOP 4TH JULY 2005

The minutes of this very successful meeting are included in the appendices. The key comments and issues that were raised at this meeting are as follows:

“The context of ART scale up in Tanzania as well as the social support structures needed needs to take into context the following 4 key factors:

a) Tanzania is a huge country and difficult to cover adequately but 75% of the population is less than 5 kms from a health facility though ART ha snot yet reached those facilities

b) The majority of the people of Tanzania are poor but those with HIV/AIDS are often the poorest of the poor

c) Currently ART is available at CTC that may be up to 100 kms from where people actually live

d) Traditional HBC models have supported sick clients who are often on the road to death. With the advent of ART HBC programs need to adapt to support clients moving back to the path of life.”

“While we need to take ART closer to the people, it is not possible for a public sector model to either deliver drugs or provide a transport refund. Possibly some of the civil society partners can play this role”

“Since ART is life long, what guarantee do we have that NGO projects will continue to have ART for their clients and what sustainability plans are there”

“Current health insurance plans do not cover ARVs. This however is an avenue that needs to be explored as a rapid way to scale up ART in the private sector and civil service”

Tanzania has a historical ability to mobilize communities and this needs to be harnessed for ART scale up”

Use dispensaries in CTC catchments area as drug refill sites to reduce transport costs for clients”

Tanzania has been busy building systems for ART at a national level but now needs to focus down more on client centered issues”

“Most ART roll out has been focused on enrollment figures and we now need more emphasis on adherence”
**ART rollout is a multi-sectoral effort and this report needs to be disseminated to more partners who can support social support**”

“**PLWHA on the journey back to life need to be involved in the action and are good role models**”

“**Need to urgently look at models to provide transport support for clients enrolled onto ART**”

**Conclusions**

Tanzania has embarked on the road to universal access for ART for its people and this is very commendable. The path has however been more complicated than planned and numbers enrolled are falling below target. One of the reasons for this is the lack of a social support package to both support clients to enroll onto ART and also to subsequently support them with drug adherence.

Social support packages will become more important as the efforts shift from an enrollment phase to a sustained adherence phase. It is clear that there are many barriers to adherence and an effective social support package will go a long way to supporting clients adhere to medication.

Tanzania is developing a nationwide home based care programme that will support chronic care including HIV. The new guidelines and training manuals have done a good job to integrate HIV issues as well as ART issues. However there are not enough HBC workers on the ground and tremendous resources and training will be needed to reach the goal of two HBC volunteers per village.

However it is also clear that HBC is only part of a social support package and cannot be expected to deliver the whole package. There is urgent need to identify the additional players that can contribute to the national social support package and set up communication and co-ordination structures at district level with the client at the center of the planning process.

It is also clear that PLWHA themselves are an essential part of the social support package and there is need to be supported to participate actively in ART scale up in several ways including as model patients, peer educators and HBC providers.

Finally to quote Dr. Swai – the head of NACP:

“**It is becoming clearer to me that ART rollout is a multi-sectoral effort and this report needs to be disseminated to more partners who can support social support**”

ART will not succeed without a multi-sectoral effort particularly to provide the social support package. Tanzania has the golden opportunity to incorporate this at the early stages of rolling out its ART plan if there is early buy in from all stakeholders.
Appendices

Appendix 1: Reference documents
Tanzania Documents

vi) Revised guidelines for Home Based care services (2004)
vii) Training plans and curriculums for home based Care providers (2004)

Uganda Documents

ix) TASO ART Strategic plan (2004)
ix) TASO home based care plan (2004)

xii) TASO community integration of ART: Draft (2005)

Appendix 3: List of organizations visited

- MOH (NACP)
- UNAIDS
- WHO
- FHI
- Pharm Access
- AMREF
- CARE- TUMAINI
- Alpha Dancing Group (Ilula)
- PASADA
- Infectious Diseases Clinic (Dar es Salaam)
- Zanzibar AIDS control programme (ZACP)
- Zanzibar AIDS Commission (ZAC)
- Zanzibar Nurses Association (ZNA)
- Zanzibar Association of People living with HIV/AIDS (ZAPHA)
- Stake holders meeting (see minutes)

Appendix 3: Site visit report

Sites visited in Dar es Salaam – 27th June 2005

PASADA
PASADA has 14,000 active clients and has started ART for 220 out of a funding target of 600 from PEPFAR funds. PASADA provides a full range of care and treatment services including HBC. It has trained 73 volunteers for 8 of the 40 parishes of Dar es Salaam. The training was for 2 weeks with a refresher at 4 months. Motivation is $20 per month to refund transport etc, as well as gumboots, umbrella. Clients to begin on ART receive 4 sessions of adherence counseling prior to commencement. The main social support needs expressed by clients are housing, food, and school fees. PASADA is trying to follow up clients on ART from other providers (WAMATA, CCBRT) whom they encounter in the field. PASADA is finding supporting adherence very challenging even though clients are becoming healthier.

Infectious Diseases Clinic
This was a brief visit as the clinic was busy. This is a collaboration of Muhimbili University, Dar es Salaam municipality, Harvard University (PEPFAR). So far they have enrolled 250 clients on ART and there is some follow up using health facility community workers. The clinic is overstretched.

Visit to IRINGA Region from the 28TH-29TH June 2005
This region was visited on the 28th and 29th respectively by the head of counseling and social support, Mrs. Zebina Msumi from MOH HBC programme, Dr. Alex Coutinho and Grace Oling. The inception meeting to spell out the theme of the visit was held in AMREF offices in Iringa, chaired by the DMO and moderated by The Project manager AMREF. Other members of staff both from AMREF and CARE Tumaini also attended the meeting.
Dr. Coutinho informed members that The Ministry of Health through The National AIDS Control Programme [NACP] in collaboration with UNAIDS, WHO, Pharm Access and Family Health International [FHI] organized a consultancy and invited him and his colleague from Uganda to visit a few Health units and projects which are delivering Health services especially to PLWHAS and produce a guide to delivery of social support services for this group of people in Tanzania.
The activities carried out by AMREF and Tumaini in collaboration with The Iringa Regional Hospital was outlined. The DMO outlined the progress to date in providing ART in the region. To date 80 people are on ART out of a target of 600. CTC is supposed to link to AMREF, CARE and CUAMM to ensure community follow up and support but this is informal and not followed up precisely. The DMO admitted that he himself was “very new at this ART”. Iringa is considered a high prevalence area due to a number of reasons. Thereafter a programme to visit the AMREF and CARE -Tumaini activities was drawn and planned for accordingly.

Kiponzelo Health based facility
A Medical Clinical Officer who was represented by Brown Mgunda, the Dental Assistant, manages the unit. It has 5 Nurses and there is a focal community home based staff. There are 10 community volunteers [one was around and took us to the
Home visits

The client Agnes, 25 years old HIV stays with her mother and has not shared her sero status yet with her mother. She had one child who died. She gets food from AMREF and has an IGA at home as - Pig rearing and Poultry and together with her mother processes and sells local brew as well. She has disclosed her sero status in a different community not near hers and gets an allowance from AMREF whenever she participated in these activities. She is not yet screened for ART

Child headed family.
He is called Ali 16 years old and goes to school supported by AMREF. Both parents are dead and another brother of his is mentally sick and his sister died due to Epilepsy. The house his parents left got burnt accidentally and he now lives with a family who accepted him to stay with them with contribution from AMREF. He prefers to continue staying there even if the burnt house would be repaired due to security purposes. He has harvested maize from a plot his parents used and the community has allowed him to use it only while he is schooling

MEETING WITH HIV/AIDS COMMITTEE MEMBERS IN ITENGULINYI VILLAGE
These were a group of community HIV/AIDS members about 25 of them attended the discussion and good gender balance was observed. The Director TASO U LTD thanked the community members for their cooperation in making the venue smart and for the good work done by helping the chronically ill patients in their communities and encouraged them to continue with the spirit. He informed them that the main aim of his visit is to ask them whether they can do an extra work of supporting their community members on ARVs. He informed them about the modality of providing ARVs and asked a few questions as copied below:
1) Have you heard of ARVs?
2) Are people in your community comfortable in talking about their sero status?
3) How easy is it for a woman who has tested HIV positive to tell her husband her sero status?
4) How many of you know how to teach someone how to use a condom.
5) If one doesn’t want to use a condom before an HIV test and comes to you for advise what would you tell him?
The community members seemed not to have had proper answers to the questions though they tried. They informed us they had received 3 days of training and needed more skills
building. They were reassured that the answers to such questions are usually difficult but that there is a training need. The members were very impressed and thank the visitors for the friendly discussion displayed. They asked for more assistance from AMREF.

Home visit to ILULA community
This is a project managed by CARE Tumaini through a sub grantee called Alpha Dancing group that cares for about 330 PLWHA and 5000 OVC.

M. W. 32 years old with no wife and child, with a main problem of persistent itchy skin condition on and off for about 3 years. He stays with his brother and his mother lives there too, he has not disclosed his status with anyone at home but assumes the mother knows. He has no job but was a farmer before. He looks weak and wasted. He rears a goat given to him by HEIFER project but no milk yet from the goat (plenty of fertilizer though) He was told about ARVS but it is not yet his turn to be taken to CTC for screening and he has no money to go on his own ($2). He will eventually be assisted by Tumaini project, which is also supporting him with food.

Female 58 years old, got relapse T.B on treatment but with persistent chest pain. Not yet on ARVS and doesn’t have transport money to go the care treatment clinic at the Hospital. (Looks stage 4 diseases) The client at the time of the visit had only 100.T.Sh. In the household were her 19-year-old daughter who dropped out of school and her 9-month-old grandchild. It was not clear if there was going to be any supper that day.

Z.K. 24 years old stays with her mother in their own home near a local bar. She had one child who died. She was brought back from her husband place because she was weak. She finished her T.B drugs and she has started attending care treatment clinic, but waiting for CD4 test and LFTs, which were not done because of no reagents. She disclosed her sero status to the mother. She was very uncomfortable with the session, which was then stopped, but she was told to have hope in ARVS if she starts.

COMMENT ON IRINGA VISIT

It was noted that Iringa Regional Hospital conducts a care and treatment clinic which gives out ARVS to clients who are supposed to be followed up by the community volunteers trained by AMREF and CARE as well as other HBC volunteers. The target for ART programme is 600 clients per year and so far 80 clients are on ARVS. Other services offered by AMREF include:
- Sensitization about HIV/AIDS by drama group.
- Supporting School children with scholastic materials.
- Giving drugs to 64 Hospitals.
- Giving bicycle to the home based care contact person.
- Training community volunteers.
- Giving garden fertilizers to the caregivers.
Poverty seems to be a roadblock in the way of starting ARVS, as most clients would not afford the many visits to the Hospital during the preparatory phase of ART as well as ongoing refills.

FIELD VISIT TO ZANZIBAR ON THE 1ST July 2005.

An inception meeting was held with representative from Zanzibar AIDS Control Programme (ZACP), Zanzibar Nurses Association, [ZAN] Zanzibar AIDS orphan support Organization (ZASO), Zanzibar AIDS Commissioner [ZAC] and a client representative from Zanzibar People Living with HIV/AIDS [ZAPHA]

Introduction about the purpose of the visit was done by the UNAIDS Country Coordinator who reminded them about the close collaboration between UNAIDS and ZACP in conjunction with M.O.H which made them to invite officials from TASO Uganda to come and share their experience on HBC. Dr. Alex Coutinho then outlined the basic information about HIV/AIDS, ART and HBC. Each represented organization then shared their HBC experience available at their center.

It was also noted that PEPFAR FUND is not yet known to most of the above mentioned organizations especially when it was mentioned that the ZACP programme on HBC ended on 30/6/2005. There was a lot of enthusiasm for more resources to support PLWHA through HBC but most of the organizations were reaching only small numbers.

Meeting with Zanzibar people living with HIV/AIDS [ZAPHA]

Rapid funding envelope is funding this dynamic group of PLWHAS. They are 85 clients in total and 45 of them are on ARVS. They have an IGA of making soap and have a tailoring project. When they meet they share experience and support one another. Their needs were food, loans and more sophisticated sewing machines, which can produce effective work. They were well informed and on the road to economic empowerment.

Mwembenjugu village
A. S. 25 years old is sickly wasted and weak has one child who is three and half years old and lives with her mother. She is a member of ZAPHA group, attends CTC and is awaiting for CD4 check (She is stage 4, needs admission and does not need a CD4 count to start ARVs) Dr Alex referred her in writing to Mnazi Mmoja Hospital CTC unit to be started on ART [to be followed up by the HBC Coordinator ZACP. The neighbors do not visit her due to fear and her own aunt is afraid of her. She has to be carried on a stretcher to and fro the nearest Dala Dala to go to hospital. Her biggest concern was lack of food.

S.B 36 years old a member of ZAPHA group, lives with his 75 year old mother in her home, has a 4 year old child [boy] his CD4 is 14 and being prepared for ART. He missed his appointment 3 weeks ago to start ART because he was weak and did not have taxi
fare. He was not followed up by the CTC to see why he had defaulted. He was due to go back on 5/7/2005. He lives on handouts from friends and their house is collapsing.

VB a 13 yr old boy has been started on ART but his guardian does not want him to know what is wrong with him. He was very intelligent, carried his Tri-immune around with him to school and was adherent with a good record of his drug ingestion. He is quite emotional when talking about his dead parents and needs ongoing counseling.

COMMENT OF ZANZIBAR VISIT
The people we met in Zanzibar were enthusiastic and committed. In particular the organization of PLWHA was active in home visits and referrals for ART but did not have an active collaboration with CTC. Again poverty was an overwhelming impression when we visited homes. The knowledge on ART at all levels was very scanty and there is a huge need for capacity building.

Appendix 4: Minutes of stakeholder meeting

MINUTES OF THE STAKEHOLDERS MEETING TO DISCUSS PRELIMINARY REPORT ON DELIVERY OF SOCIAL SUPPORT SERVICES FOR PLWHA.

Agenda:
1. Opening the meeting
2. Presentation: General observation
3. Presentation: Concepts
4. Presentation: Key findings
5. Wrap up
6. Closing

Attendance: Attached

1. Opening the meeting
The meeting was opened at 8.55am by Dr. Swai, the Programme Manager, National AIDS Control Programme by welcoming the members to the meeting. He informed the members that the meeting was about to discuss the preliminary report on delivery of social support services for PLWHA. The report has been compiled by two consultants from TASO- Uganda. They have visited Iringa, Dar es Salaam and Zanzibar. Further, he said that apart from the consultants presenting the findings, they will also share with the members their experience from Uganda. He let each member to introduce him/her self.

2. Presentation: General observation
The presentation on general observation during their visit was made by Dr. Alex Coutinho, Director, TASO- Uganda. He highlighted 4 things as general observations which were: Tanzania is big; people are poor but HIV +ve individuals are poorer;
CTC are existing but some are as far as 50-200 km from the clients; and HBC services in the past were provided to prepare patients to death but now is a reverse as patients are prepared to live again and not death.

He further elaborated on social support services for the infected and affected where he said that (to mention a few) poverty is overwhelming therefore need to empower clients economically through short, medium and long term IGAs, communities are committed but under trained, people are waiting for ARVs, ART literacy is needed and community volunteerism needs to be promoted. However, in Zanzibar Town, there is good structure for enhancing HBC services, clients visit each other; there is group income generating activities and HIV +ve individuals seem to be empowered.

**DISCUSSION:**

During the discussion it was recommended that we need to strategize on how to reach as many patients as possible as patients won’t come simply because drugs are available. Another point was that, we need to bear in mind the unit cost of HBC can be high but also other services like IGAs become very essential.

3. **Presentation: Concepts**

The first part of some key concepts that need to be considered for quality ARV services were presented by Dr. Alex Coutinho. The TASO critical path analysis for ARV delivery was shared. Further more, the presenter said that commitment, support, preparedness and good plan for ARVs are important for the programme to succeed. In social support system we need to strengthen involvement of PLWHA in addressing HIV/AIDS issues including ARVs.

The second part was presented by second consultant Ms. Grace who highlighted on the Uganda model of HBC. The model involves and addresses HBC at 4 levels namely relatives of clients who are care givers, community volunteers, community nurses, and TASO field officers. These are trained in various aspects of care and treatment. She also pointed out ART care pathway which is a road to ART. Various activities and procedures undertaken for each patient in each visit were explained. She concluded by cautioning that although the model has worked well, it might not be applicable to the whole Uganda and in other countries.

4. **Presentation: Key findings**

The key findings were presented by Dr. Alex by first of all mentioning the needs of clients on ARVs which include HBC volunteer, food support, family support, treatment, CTC reviews. Other needs to mention a few, are social support package which includes community awareness, transport facilities, treatment assistants, medical care and psychosocial, adherence and economic empowerment.

Some of the key findings included: There is high demand of ART services and sites are busy enrolling patients but no clear plan to ensure adherence; ART literacy is highly needed; CTCs are not linked with community structures; some clients delay to start treatment due to delay of lab results; clients are in big need of food; social
support packages need to be given. On the other hand, HBC service has good national guidelines; has few HBC providers; and is unable to provide social support needed. Moreover, the human resource training and capacity building may suffer due to shortage of training institutions and training staff and yet more health service providers need to be trained on HBC. Lastly, there is a need to examine policies that may slow ART delivery; support multi-skilling of personnel and invest more in human resource for scaling up ART. The presentation ended at 10.55 by giving short, medium and long term recommendations. This was followed by tea break up to 11.15.

**DISCUSSION**
Discussion resumed at 11.20 and some of the issues brought forward were:
1. Integration of TASO into public health services.
Response: TASO services are integrated into government health facilities. Some referrals are made from government facilities to TASO. TASO provides counseling and other support to the government such as capacity building in HBC and counseling.

2. TASO experience in adherence:
Response: There are challenges such as lack of knowledge; inadequate preparations of clients and poverty. In order to succeed in adherence, use of partners and PLWHA is important. Also need to invest in training counselors. The issue of ART literacy is important to the clients as well as care givers.

3. Criteria used for some clients to pay and others to get free ARVs:
Response: There is clear policy which allows anybody to bring in ARVs. There is coordination at both health facility and district levels. Uganda started provision of the drugs long time ago through government public hospitals and private practitioners. The poor clients were given free and rich ones were buying. However, in order to cover more clients there is a need to consider using health insurance agencies to cover PLWHA.

4. Arrangement on the ground for sustainability of clients under TASO:
Response: This does not apply to TASO alone because even those under the government are supported by the donors. However, TASO makes sure the agreement with any donor providing ARVs should not be less than 5 years.

5. TASO experience on food aid for clients:
Response: This is a big challenge. They work with WFP and some donors from US. The advice is that, the government should not involve in food distribution but encourage partnership with other organizations to do so.

6. Coordination of social support and HBC services from district to community levels.
Response: The use of existing coordination system is encouraged, but we need to make them understand the added advantages of this service.

7. Challenges on IGAs
Response: Not worked well so far as when clients get sick they spend that money and as such there have been diminishing returns. A special attention is needed to run such activities.

8. PEPFAR committees
Response: In Uganda there is a committee which is multi-sectoral in nature. In Tanzania we use partners’ group meeting to discuss such issues. The government is permissive to partners but they have to use the national guidelines.

9. Members agreed that recommendations given were relevant; need to strategize adherence; the issue of transport is a big challenge and needs to be worked out; issues recommended will be used in our plans; clients need to be assessed and prepared well; strengthen community involvement in ART programme; multi-sectoral approach has to be used; the report should be disseminated in a more multi-sectoral audience; involve more PLWHA in HIV/AIDS issues; all practitioners to be informed about ART issues; scale up ART literacy including adherence.

5. Wrap up

During the wrap up, Ms. Grace thanked the members for their kindness and contribution. She made a call that in order to succeed, the government should encourage and collect all players and discuss together what each partner could offer. Dr. Alex added that good leadership and motivation are needed for provision of good services; need to underline the social support system; need to re-focus and re-visit community involvement; and need a rapid capacity building.

6. Closing
Closing remarks were given by Ms. Bernadette from UNAIDS- Tanzania. She thanked the organizers of the meeting and congratulated the consultants for a good job. She called for government and partners to work together and use the existing structures such as regional and district authorities, NGOs, FBOs, CBOs to deliver the ART service down to the community where it is highly needed. We should also strengthen our prevention efforts. Dr. Swai closed the meeting at 1.13 pm by thanking the sponsors of the meeting namely FHI, WB, Pharm Access, WHO and UNAIDS.

List of Participants:

<table>
<thead>
<tr>
<th>S/no</th>
<th>Name</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Dr.E.Ndyetabula</td>
<td>UNDP</td>
</tr>
<tr>
<td>2</td>
<td>F.C Nchanila</td>
<td>HBC-Kinondoni</td>
</tr>
<tr>
<td>3</td>
<td>Edwin Macharia</td>
<td>CHAI</td>
</tr>
<tr>
<td>4</td>
<td>M.D. Machaku</td>
<td>Pathfinder</td>
</tr>
<tr>
<td>5</td>
<td>Carol Mushi</td>
<td>Pathfinder</td>
</tr>
<tr>
<td>6</td>
<td>Jonniah William</td>
<td>UNAIDS</td>
</tr>
<tr>
<td></td>
<td>Name</td>
<td>Organization</td>
</tr>
<tr>
<td>---</td>
<td>----------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>7</td>
<td>Emanuel Mziray</td>
<td>UNAIDS</td>
</tr>
<tr>
<td>8</td>
<td>Geert Haverkamp</td>
<td>Pharm Access</td>
</tr>
<tr>
<td>9</td>
<td>Bennett Fimbo</td>
<td>NACP</td>
</tr>
<tr>
<td>10</td>
<td>Tumaini Charles</td>
<td>NACP</td>
</tr>
<tr>
<td>11</td>
<td>Doroth Mandwa</td>
<td>PASADA</td>
</tr>
<tr>
<td>10</td>
<td>H.S. Khalid</td>
<td>NACP</td>
</tr>
<tr>
<td>12</td>
<td>Dr. M.Nyang’anyi</td>
<td>NACP</td>
</tr>
<tr>
<td>13</td>
<td>Zebina Msumi</td>
<td>NACP</td>
</tr>
<tr>
<td>14</td>
<td>Saumu Alli</td>
<td>ZACP</td>
</tr>
<tr>
<td>15</td>
<td>Amina Sleman</td>
<td>ZADHA</td>
</tr>
<tr>
<td>16</td>
<td>Ghanima Othman</td>
<td>ZANA</td>
</tr>
<tr>
<td>17</td>
<td>Grace Oling</td>
<td>TASO</td>
</tr>
<tr>
<td>18</td>
<td>Feddy Mwanga</td>
<td>WHO</td>
</tr>
<tr>
<td>19</td>
<td>Dr. Paul Waibura</td>
<td>AMREF</td>
</tr>
<tr>
<td>20</td>
<td>Dr. Msemo Diwani</td>
<td>ORCI</td>
</tr>
<tr>
<td>21</td>
<td>Dr. Eunice Mmari</td>
<td>CDC</td>
</tr>
<tr>
<td>22</td>
<td>Dr. Eric Aris</td>
<td>MNH</td>
</tr>
<tr>
<td>23</td>
<td>Mrs Theresia Hakili</td>
<td>NETWO+</td>
</tr>
<tr>
<td>24</td>
<td>P. Urassa</td>
<td>NACP</td>
</tr>
<tr>
<td>25</td>
<td>S. Akaniwa</td>
<td>TAWG</td>
</tr>
<tr>
<td>26</td>
<td>S. Saadat</td>
<td>ZAC</td>
</tr>
<tr>
<td>27</td>
<td>Dr. B. Shija</td>
<td>Kibaha</td>
</tr>
<tr>
<td>28</td>
<td>Mary Materu</td>
<td>COUNSENUETH</td>
</tr>
<tr>
<td>29</td>
<td>Adelina Kahwa</td>
<td>Kibaha</td>
</tr>
<tr>
<td>30</td>
<td>Zinat Fazal</td>
<td>PASADA</td>
</tr>
<tr>
<td>31</td>
<td>G. Mpangile</td>
<td>FHI</td>
</tr>
<tr>
<td>32</td>
<td>Dr. Ibrahim Kabole</td>
<td>AMREF</td>
</tr>
<tr>
<td>33</td>
<td>G. Decock</td>
<td>CCBRT</td>
</tr>
<tr>
<td>34</td>
<td>Josephine Komba</td>
<td>AMREF</td>
</tr>
<tr>
<td></td>
<td>Bernadette Olowo-Freers</td>
<td>UNAIDS</td>
</tr>
</tbody>
</table>

Appendix 5: Power point presentation to stakeholders