TASO UGANDA - THE INSIDE STORY

Participatory evaluation of HIV/AIDS
counselling, medical and social services
1993 - 1994

The AIDS Support Organization (TASO)
World Health Organization (WHO)
ACKNOWLEDGMENTS

People living with HIV/AIDS, family care-givers, and the caring community of neighbours, together with external funding partners, are the cornerstones of TASO. They have stood by TASO staff and management to work towards the TASO goal of restoring hope and improving the quality of life of people and communities affected by HIV/AIDS.

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PREFACE

TASO is an organization with eyes that see the needs of the most vulnerable, with a heart that opens to the joys and sorrows of those affected by HIV/AIDS, and with arms that welcome all those who want to be part of the TASO mission. Since its creation in Uganda in 1987, it has led the way down paths of the AIDS epidemic that most were reluctant to tread back in the 1980s, and that many still fear.

Now TASO is leading the way in courageously opening its doors to frank evaluation, not through external dissection of the organization, but rather through a participatory process involving TASO staff, those they serve, and a core evaluation team. The evaluation was guided by Uganda’s National AIDS Control Programme and major TASO donors, and benefited from GPA technical and material support, including an external evaluation consultant. However, it is important to stress that TASO initiated the evaluation, took the time to plan it correctly, supervised the data collection and analysis. Perhaps most important, they have been transparent about the findings both within the organization and with their outside supporters, thus permitting others to learn from their experience.

Countless organizations and programmes have already been inspired by the effective model offered by TASO. Although the contribution of all TASO staff, supporters and clients must be acknowledged, TASO’s Executive Director, Mrs Noerine Kaleeba, must be mentioned by name. She deserves recognition and praise for her vision of solidarity, her gift of hope, her strength in sharing, her leadership in inspiring all of us to always do more, and do it better, for HIV/AIDS care and prevention.

Under her direction, TASO has evaluated various components of the programme, including cost, training, and community initiatives. This particular report focuses on the evaluation of TASO’s medical, counselling and social support services.

While TASO is a Ugandan organization, its experience as captured in this report will surely have a helpful ripple effect beyond Uganda’s borders. The global questions about how to cope with HIV and AIDS are TASO questions, and TASO answers are often global answers.

With this in mind, we are happy to make this evaluation report available to all those who can profit from the lessons learnt and find inspiration in TASO’s successes, its commitment to comprehensive care, and its leadership in holding families and communities together in the AIDS era.

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EXECUTIVE SUMMARY

INTRODUCTION

TASO is a voluntary organization which was created in 1987 by Ugandans to provide psychosocial support to people living with HIV/AIDS. TASO was founded to contribute to a process of restoring hope and improving the quality of life of people and communities affected by HIV infection and disease. By the end of 1993, TASO had expanded into seven districts in Uganda and was providing counselling, medical care and social support to a cumulative number of over 22,795 people with HIV/AIDS and to their families. TASO currently operates in seven centres, and is also working with the National AIDS Control Programme and other organizations to carry out AIDS prevention and care activities throughout Uganda. In addition to providing a care package, TASO offers training in counselling, provides material support to clients and their families, and supports community efforts in responding to the AIDS epidemic.

To enable TASO to measure its effectiveness in meeting the needs of people with AIDS and their families, TASO decided to evaluate its services. Technical assistance was obtained in 1993 from the World Health Organization Global Programme on AIDS to carry out a participatory evaluation of TASO counselling, medical and social support services.

EVALUATION METHODOLOGY

Quantitative and qualitative methods were used in order to assess the different aspects of TASO care and support to clients and families. Specific TASO objectives and key evaluation questions were formulated for each of these TASO services: counselling, medical care and social support. People with HIV/AIDS who were registered with TASO between the period of January 1991 to March 1993 were sampled for the evaluation. Convenience and simple random sampling were used to select those to be interviewed from clients attending clinics, clients visited at home and their care-givers, and those who had ceased using TASO services. Qualitative data were obtained from clients, counsellors, community representatives and key informants. TASO records were also reviewed.

Data were collected using survey instruments developed by TASO staff. The instruments consisted of quantitative questionnaires for administration to clients and care-givers, qualitative guidelines for focus group discussions with clients, counsellors, counsellor supervisors and community representatives, and qualitative guidelines for key informants.

TASO staff were trained to use the various instruments in gathering information over a period of 3 months to allow for continued delivery of services to clients throughout the evaluation period. The interviews were primarily conducted by counsellors during counselling sessions, thus increasing the validity of the data. Data were analysed by
the TASO Core Evaluation Team and feedback of preliminary results was given to staff, clients and community representatives at the seven TASO centres prior to preparation of the final report of the findings.

PARTICIPATORY PROCESS

The TASO evaluation used a participatory process and included the major stakeholders, such as TASO staff, clients, community representatives and donors. Each contributed to the design, planning and implementation of the evaluation. A participatory process enabled TASO to own the evaluation exercise, and to build its own capacity in skills such as formulating questionnaires, interviewing, gathering information through interviews and focus group discussions, and analysing data. The participatory approach also helped TASO to define concepts related to living with HIV/AIDS and to discuss and accept failures as well as successes. The participatory process began with discussions among TASO staff on the need for an evaluation. An Evaluation Steering Committee was formed to provide guidance to the study and was composed of TASO members, TASO supporters including donors, and WHO staff. Key questions, service indicators, data instruments and data sources were discussed and agreed upon.

COUNSELLING SERVICES

_The evaluation investigated whether TASO counselling services were helping clients and their families to cope with HIV/AIDS_

Results

Coping with disease and related problems consists of acceptance of being HIV positive and having a positive attitude towards the prospect of a shortened life expectancy.

Counselling appeared to help clients to cope with HIV infection. Counsellors and clients discussed topics related to coping in almost half of the counselling sessions; 90% of the sampled TASO clients revealed their serostatus to someone outside of TASO, with 85.3% revealing to a relative. A high level of acceptance by their families (79%) and communities (76%) was also reported by the clients.

Recommendations

- TASO should critically examine its counselling service and identify components of emotional support that communities, if trained, could provide.

- The adoption of alternative means of transport by TASO centres, for example, motorcycles and bicycles should be explored. Such measures could enable counselling staff to offer independent home counselling services without increasing pressure on the shared transport used by the
different services. Emphasis should be on quality rather than on quantity of counselling to clients.

- TASO should broaden its programme, using counsellors, community workers and PWAs, to sensitize religious leaders about care and support to people living with HIV/AIDS (PWAs) and about positive living. Community gatherings, such as Resistance Council meetings, are other avenues of outreach.

- Counselling should emphasize revealing of serostatus to spouse/partner in order to enhance coping, make support possible, and enable behaviour change.

- Training of counsellors should include basic nursing care, an overview of HIV/AIDS medicines and when to seek help. Organised community and family education and information outreach activities should cover basic care of PWAs.

- Counselling the family about the HIV/AIDS diagnosis and educating about home nursing care should be commenced before the person is bedridden.

The evaluation explored whether TASO counselling services were helping to promote safer sex practices among clients and their families.

Results

The most commonly reported current safer sex practices adopted by TASO clients included abstinence (45%) and condoms (33%), with condom use adopted more by males (48%) and abstinence more by females (56%). Issues related to safer sex practices and prevention were discussed in 39 (79.6%) of the 49 observed counselling sessions. Of the 246 respondents who ever used condoms, 182 (74%) reportedly used condoms in the last sexual encounter prior to the interview.

There was generally a reduction in the number of sexual partners by clients after learning they were infected with HIV.

Recommendations

- Counselling should address myths about abstinence and support strategies to sustain clients’ choice for abstinence, for example, discussing other ways to attain sexual satisfaction.

- Counselling for infected people should reinforce consistent use of condoms, even in faithful monogamous relationships.
Sufficient quantities of condoms should be distributed during each counselling session (according to client needs) and recorded.

The evaluation investigated whether TASO counselling services enabled clients to formulate strategies for the present and future.

Results

Planning for self and family was observed in 55.1% of the counselling sessions observed during the evaluation. The plans discussed included starting income-generating activities (IGAs), making a will, building/repairing a house and continuing to work and educate children. Will making was discussed with 39% of the clients; 16.8% made wills. While 22.3% of the clients said they had nothing to pass on, 51.3% of the clients wished to make a will.

Recommendations

- Counsellors should encourage clients to discuss plans for the future with family members, including plans for survivors.

- Counsellor training should address how to deal with emotional fears about making wills and how to help women and children handle legal and social problems related to property.

MEDICAL AND HOME CARE SUPPORT SERVICES

The evaluation explored whether TASO clients receive treatment for opportunistic infections, and if they are satisfied with the treatment received.

Results

Care, comprised of medical treatment, counselling and nursing care, was found to be the most helpful service by 86% of TASO clients. TASO was cited as the major source of health care in the last month by 63.8% of the clients. Twelve out of 14 focus groups indicated satisfaction with TASO medical services. The vast majority of TASO clients sought early treatment, i.e. within two weeks of onset of symptoms. Of those sampled at home, 49.4% were on medications, and of those, 57% were taking them correctly. Care-givers knew in detail how to make sugar-salt solution (50.7%) and to use sachets to treat diarrhoea (78.6%).

Recommendations

- TASO should continue prescribing and supplying medicine according to the standard medication list, and should resist accepting medication not on this list.
• Continue to promote early diagnosis of tuberculosis among HIV positive people and compliance with treatment, in collaboration with the national tuberculosis programme.

• All TASO health care staff should be trained in counselling skills and in teaching clients and families about home care, correct use of medicines and when to seek help.

The evaluation explored whether TASO gives sufficient information, education and training to clients and care-givers concerning medications, home care and sources of additional help.

Results

TASO was the main source of information on AIDS care and prevention for family care-givers (31.8%) and clients (68%). TASO was also the major source of extra help for 71.3% of the family care-givers. The majority of community members believed that family members/relatives should be the major care-givers at home (57.1%), followed by community members themselves and by TASO staff.

Recommendations

• As TASO services are meant to complement other available government and NGO services, every health unit should provide basic AIDS care and counselling. TASO should provide training in counselling skills and positive attitudes towards PWAs to non-TASO health care workers and follow-up to those trained, as necessary, in order to help them support family care-givers in provision of home care.

• TASO should facilitate the capability of communities to contribute towards the care of PWAs, such as community contributions for medicines and enabling community members to provide emotional support to PWAs and their families.

• TASO should explore ways to lend support to home care-givers who are primarily women, and also to involve other community resources such as religious groups, community health/extension workers, and neighbours.

SOCIAL SUPPORT SERVICES

The evaluation explored whether PWAs and their families receive material support.

Results

On joining TASO, 34% of the sampled clients expected material assistance. Of these clients, 56.2% reported that this need had been met. Still, 48.1% of all the sampled
clients indicated that home care could be improved by provision of material assistance.

Recommendations

- TASO rather than the donor should decide on the mode and criteria of distribution of material assistance donated externally.

- TASO should assist communities to seek alternative resources, building on the capabilities and resources of the communities, e.g. visiting the sick and offering food.

- TASO should establish linkages with social welfare services and NGOs in order to refer clients for material support.

The evaluation examined whether TASO day centre activities benefit PWAs who participate.

Results

The 8.6% of the 730 sampled respondents who were regular members of the day care centre found the main benefits to be sharing experiences with one another (95.2%) and learning skills to earn a living (84.1%).

Recommendations

- TASO day centres should be used as learning facilities to equip clients with knowledge and skills to be shared in the community.

- The drama group should be assisted by professionals to develop skills to deliver information on HIV/AIDS and to enable them to earn an income at the same time.

The evaluation investigated whether income-generating activities funded by TASO promote self-reliance among clients.

Results

The majority of those sampled (59%) mentioned the need for capital to start IGAs. There was low over-all performance of IGAs in promoting self-reliance, mainly as a result of low start-up capital, lack of adequate supervision and a lack of a clear policy towards funding of projects. As a result only 12% of clients repaid the loan, although 81% successfully set up their projects.
Recommendation

TASO should carefully re-consider options (through a two-year pilot study in selected areas) for providing jobs and IGAs for PWAs, looking at management by TASO, health of clients, involvement of families, sustainability, feasibility and other resources in the community. The result of such a study should be used to establish policies on IGAs.

The evaluation examined whether clients' needy children benefit from the educational support provided by TASO.

Results

Currently 370 out of 1057 children assessed as needy receive school fees. No additional children have been provided with this assistance since April 1992 due to limited funds, although the numbers of needy children are increasing.

Recommendation

- Explore options for referral of needy children to other organizations, e.g. for school fees.

MONITORING SERVICES

An objective of the participatory evaluation was to design an ongoing monitoring and evaluation system for TASO services. A mixture of process and outcome indicators will be used. Indicators for counselling will include: centre client attendance for counselling, home visits, counselling sessions per counsellor and condom distribution. Indicators for medical care will consist of client attendance for medical care, medical home visits, medical visits per clinician and percentage of medicines available in TASO clinics based on a national standard drug list. Indicators for social support will include client attendance at day centres. Data obtained on a monthly basis will be analysed and used by TASO centres for improved service delivery.

Recommendations

- All centre staff should be trained in the completion of monitoring forms developed as a result of the evaluation and funds should be allocated for monitoring activities.

- A system should be devised to ensure the active participation of local centre Executive Committees in centre level decision-making and monitoring of centre performances.

- Ongoing monitoring of selected indicators should be used to identify problems and develop solutions for implementation on a monthly basis.
• Other indicators should be developed for periodic use in measuring, e.g. sexual behaviour, revealing serostatus, making wills etc. Cost analysis of TASO services should also be conducted.

• A major evaluation of TASO services should be carried out every three years, using the present evaluation study as a baseline.

CONCLUSIONS

The evaluation found that TASO has assisted clients and their families to live positively with HIV/AIDS. TASO has achieved this through a "package" of counselling and medical care as well as material support to clients and their families. Clients have been supported to reveal their serostatus; family and community acceptance of PWAs has been high and clients have demonstrated positive attitudes through their responsible sexual behaviour and seeking early treatment for opportunistic infections.
INTRODUCTION

In 1987 sixteen Ugandans who were affected by AIDS, because they or their family members were living with HIV/AIDS, decided to set up a voluntary organization to provide psychosocial support to people affected by AIDS. By the end of 1993, TASO had expanded into seven districts and provided counselling, medical care and social support to a cumulative number of over 22,795 people with HIV/AIDS and to their families. Efforts have been made to improve the services in quality and quantity in order to meet the ever increasing and changing needs. As TASO staff and administration have struggled to "build the boat while sailing", they have raised queries about the effectiveness of their work.

The TASO administration and staff often wonder whether objectives are being achieved, whether needs are being met, and whether services are being delivered in the most effective way. All they know is that more and more people are asking for their services. Although the impact of TASO's work on the epidemic is not quantified, most are certain that without TASO, and other similar efforts, the face of AIDS in Uganda today would be a different one.

A decision was therefore taken to evaluate TASO services. However, before requesting external assistance to develop the evaluation tools, TASO staff went into retreat in February 1993 to consider the objectives of the evaluation. The World Health Organization, Global Programme on AIDS subsequently agreed to provide technical assistance for a participatory evaluation of TASO counselling, medical and social support services, which is summarized in this report. The report provides background information on these services, the evaluation methodology and findings, the participatory process and makes suggestions on how to continue. The findings from this study will also serve as baseline data for future evaluations.

1.1 Overview of HIV/AIDS in Uganda

The first AIDS cases were reported in Uganda in 1982 among lakeside traders in Rakai District. In 1987 the National AIDS Control Programme was established with the help of the World Health Organization. By that time there were already many cases in the capital city of Kampala and in Masaka and Rakai districts. By mid-1991 an estimated 1.5 million Ugandans, or about 9% of the general population and 20% of the sexually active population, had HIV infection. By early 1994 there were over 43,000 AIDS cases reported to the National AIDS Control Programme, which estimates that this figure represents only one-sixth to one-fifth of the actual number of cases.

The AIDS epidemic has spread to all districts of the country, however prevalence of HIV varies widely from region to region. Infection rates are as low as 2% of sexually active adults in districts like Moyo in northwestern
Uganda. Rates are highest in Kampala and other urban centres and in some southwest districts.

The male-female ratio among those infected with HIV is about 1:1, with a mean age of 30 years for women and 34 years for men. In the 15-19 year-old age group there are six times more infected females than males. Data from sentinel surveillance shows that the prevalence of HIV infection among women attending antenatal clinic ranges from 5% in some rural areas to 29% in certain urban areas.

Within sub-Saharan Africa as a whole, the Ugandan communities, government and NGOs are perhaps the most open about the magnitude of the HIV/AIDS problem. Consequently many AIDS prevention and care activities are going on in the country. The majority of them have been developed as an emergency response to the AIDS calamity, but few of them have been evaluated. There is a growing need for further evaluation in order to plan new interventions and strengthen existing ones.

1.2 History of TASO

TASO represents one of the first organized responses to the AIDS epidemic in Uganda. Prior to 1987, AIDS care was provided in only a few places in Uganda. TASO came into existence in order to address the needs of people living with AIDS (PWAs) and their families through provision of counselling, medical and nursing care and material assistance, first in the capital city and, with time and experience, elsewhere, in response to requests from other towns to set up centres. TASO currently operates in 7 centres in the country and intends to open a new centre in 1994. In contrast to 1987, there are now special AIDS clinics in many government and mission hospitals. Other organizations have also taken on AIDS care. TASO has acted as a model, for some of these initiatives, in the care of PWAs.

1.3 TASO movement philosophy

TASO advocates and its work is guided by "positive living"; this has come to be recognized as the philosophy of the TASO movement.

The philosophy calls upon individuals, families and communities to uphold the rights and responsibilities of people affected by HIV/AIDS and their communities. These are:

- The rights of people infected or affected by HIV/AIDS to be supported emotionally, medically and socially.
• The responsibility of people infected or affected by HIV/AIDS to cultivate self-esteem, hope, respect for life, respect for and protection of their community, care for self, care and support for dependants.

• The rights of the community to protect itself and its responsibility to curb the spread of HIV.

• The responsibility of the community to support people infected or affected by HIV/AIDS so that they have access to emotional, medical and social services and can live responsibly with HIV/AIDS.

The philosophy of the TASO movement affirms that the above-mentioned rights and responsibilities should be fulfilled through education, counselling, dialogue, acceptance and togetherness, not through coercion and stigmatization.

1.4 Mission of TASO

TASO was founded to contribute to a process of restoring hope and improving the quality of life of people and communities affected by HIV infection and disease, and exists to offer:

At the personal level:

• One-to-one counselling which empowers the infected/affected person to make informed decisions which improve quality of life and achieve a balance between rights and responsibilities.

• Sensitive and compassionate care which provides early diagnosis and treatment of opportunistic infections, and enhances living positively and dying with dignity.

At the family level:

• Counselling for family members to dispel their fears of contracting HIV through casual contact, facilitate care of infected and affected people, and prepare the family for and support them during bereavement.

• Nursing and nutritional materials which facilitate home care.
At the community level:

- Community counselling which empowers the community to organise an appropriate response to the problems generated by HIV.

- Facilitation of community-planned responses, community evaluation of their responses and mobilization of community resources.

At the national and international level:

- Sensitisation of the public about "positive living".

- Training of appropriate personnel for service delivery.

- Mobilization of resources for achievement of goals.

- Joint international efforts for total defeat of HIV infection and disease.

Those who come to TASO are encouraged to live positively with HIV/AIDS. In practical terms, clients are encouraged to:

- accept their diagnosis
- seek counselling
- seek prompt medical care
- maintain a balanced diet
- practice safer sex
- have adequate sleep and exercise
- continue to earn an income
- continue with normal social activities
- plan for the families and dependants
- avoid harmful habits such as drinking alcohol and smoking.

For two personal stories of TASO clients see case studies in Appendix 1.
1.5 Organizational structure

TASO Headquarters

TASO headquarters are located in two houses in Kampala. One house serves as the administration centre, and the other as a training centre. The organizational structure of TASO (Appendix 2) consists of:

- a board of trustees
- a directorship
- three departments:
  - Planning and Development - project proposals, fund-raising, programme planning and support of new initiatives.
  - Services - counsellor training, counselling, community initiatives for training and community mobilization, medical service and social support.
  - Finance and Administration - budgetary control, disbursement of funds and general administration.

TASO Centres

TASO centres, located in 7 sites around the country, are the focus for services to clients and communities (Appendix 3).

*Mulago centre* - formed in November 1987, soon after the TASO idea was conceived, it is the oldest and model TASO centre. It started to function in Noerine Kaleeba’s previous office (as principal of the physiotherapy school) and later expanded into neighbouring rooms in the polio clinic provided by hospital administration. The centre now exists in its own premises erected by TASO on the Mulago hospital compound. This building was funded by ActionAid, Uganda.

*Masaka centre* - six months after the Mulago centre was set up, TASO’s influence was extended west of Kampala to Masaka hospital which serves Masaka and Rakai districts. Because one of the founding members of this centre was then chairman of the Masaka branch of the Uganda Medical Association, this association’s office was the first home of the TASO centre. Later the centre moved into one of the former laboratory rooms and now it operates in a former measles isolation ward, thanks to the reduction of measles in the district. The manager’s offices are housed in an old hospital maintenance workshop. Plans have been finalized to erect a building financed
by the United States Aid for International Development (USAID), the Government of Uganda and Redd Barna.

_Mbarara centre_- in early 1990 the first TASO sensitization workshop in Mbarara, west of Masaka, was held, followed by the founding of another TASO centre in one of the private patients’ wards of the maternity section in Mbarara government hospital. A piece of land was purchased adjacent to the hospital using Quaker funds and the building was co-funded by Jersey Overseas Aid Committee (JOAC) and USAID through the Government of Uganda. Prior to moving into their own building on a separate compound, the centre had expanded and had been using the garage of the hospital ambulance.

_Tororo centre_- having started in a small room, this centre which is in the eastern part of the country near the Kenya border, was expanded by building wooden walls around one section of the sheltered path connecting different wards in Tororo government hospital.

_Jinja centre_- from early 1989 an AIDS referral clinic in the hospital was conducted by a core team of volunteer health workers, supported by the AIDS Control Programme, Ministry of Health. Later TASO brought in counselling techniques and complementary medicines, and in December 1991 formalized it as a "TASO Jinja Counselling Centre". This centre is now situated on Jinja Hospital compound in a former polio ward.

_Mbale centre_- the only room available for this centre on the Mbale government hospital compound was a part of the mental ward which was partitioned in order to accommodate the centre’s office, day centre and clinical room. In December 1993 DANIDA funded a building erected on a plot offered by the Mbale government hospital.

_Entebbe centre_- starting from a small room in the Entebbe government hospital, it has now moved to a separate rented building outside the hospital.

Each TASO centre has a manager who is answerable to TASO Headquarters through the Planning and Development Department. The centre Executive Committees (Appendix 4), comprised of local opinion leaders, oversee the affairs of the centres. Other staff include an administrator, counsellor supervisors, a medical coordinator, a day centre supervisor, nurses, clinicians, counsellors, trainers and support staff (filing clerks, driver, secretary, cleaners). Table 1 indicates the number of paid staff, most of whom work full-time. Some medical staff work part-time.
Table 1: Number of staff (1993) and clients (end 1992) by TASO centre

<table>
<thead>
<tr>
<th>Centre</th>
<th>Counsellors</th>
<th>No of medical staff</th>
<th>No. of TCI trainers</th>
<th>No. of support staff</th>
<th>Total no. of staff</th>
<th>Cumulative no. of clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entebbe</td>
<td>8</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>13</td>
<td>25</td>
</tr>
<tr>
<td>Jinja</td>
<td>9</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>9</td>
<td>22</td>
</tr>
<tr>
<td>Masaka</td>
<td>25</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>21</td>
<td>54</td>
</tr>
<tr>
<td>Mbale</td>
<td>11</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>16</td>
<td>31</td>
</tr>
<tr>
<td>Mbarara</td>
<td>9</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>13</td>
<td>28</td>
</tr>
<tr>
<td>Mulago</td>
<td>27</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>16</td>
<td>53</td>
</tr>
<tr>
<td>Tororo</td>
<td>15</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>8</td>
<td>29</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>104</strong></td>
<td><strong>17</strong></td>
<td><strong>17</strong></td>
<td><strong>8</strong></td>
<td><strong>96</strong></td>
<td><strong>242</strong></td>
</tr>
</tbody>
</table>

Departments at each centre consist of:

- counselling services
- medical services
- social support services
- TASO community initiatives (TCI)
- administration
- day centre

An Executive Committee with the following roles exists at each centre:

- appointing certain staff at centre level
- monitoring centre activities
- planning
- controlling the budget
- raising funds

Programme management for service delivery:

- TASO programme inputs in service delivery include staff time, material assistance to clients and families, medicines and equipment. By far, the major input is in terms of staff time in counselling clients. External donations of foodstuffs and medicines are in effect beyond the control of the
organization, and are largely received on irregular intervals. However, donations of medicines have enabled TASO to provide treatment to clients. In recent months, TASO has adopted a fee-for-service policy in treatment, where each client pays a nominal fee of 300 Uganda shillings (29 US cents) per visit. This amount is minimal in comparison to the costs of medicines.

- The process activities related to delivery of services are training, counselling, treatment and referral, home care and child support. Delivery of services at TASO centres are supervised from TASO Headquarters. The management structures at centres require consistent managerial support with a flow of information through the key people for decision and policy-making purposes.

- Nevertheless, financial constraints limit intensive managerial input at centres. This limitation is offset by frequent meetings for all managers at headquarters level. Since its inception, TASO has grown into a large organization, employing full time staff for service delivery and administration. However, the pace of recruitment of staff and organizational structure and management has not kept up with the rate of expansion and registration of new clients into the organization.

- From the inputs and activities described above, the major programme outputs are counselling, treatment, client home visits and material assistance to clients and families. The effects of these outputs are believed to be positive living and behaviour change primarily among clients, and secondarily among families of clients and the community.

1.6 Objectives and Services

Objectives

In order to fulfill its mission, TASO has the following overall objectives:

- To offer counselling services to people with HIV/AIDS and their families;
- To train counsellors for TASO and other organizations and to ensure effective provision of counselling;
- To complement available medical services;
- To sensitize the public and to promote positive attitudes towards people with HIV/AIDS and their families;
• To minimise the social ills caused by HIV/AIDS through material support to clients and their families;

• To build and support community-based efforts initiated to respond to the AIDS epidemic.

**Services**

TASO carries out a number of activities in achieving its objectives, namely, counselling, training of counsellors, medical care, social support, sensitization of the public and also community outreach. Counselling and medical services are offered as a "care package". All services are delivered in TASO centres, and also in homes for people too ill to come to the centres.

*Counselling* - services are offered by trained HIV/AIDS counsellors at TASO centres, hospital clinics and wards and in homes of clients. Continuous counselling is given to clients who participate in day centre activities. Counselling is carried out in order to provide emotional and psychological support to people living with HIV/AIDS and their immediate families, and to reduce the rate of HIV infection.

*Training* - the TASO Training Division undertakes training of counsellors for TASO and for other AIDS-related organizations. Training is also provided to trainers and community voluntary workers. The main aspects emphasized in the training curriculum include knowledge about HIV/AIDS, positive attitudes, communication and counselling skills. To date, TASO has trained 142 counsellors for itself and 168 counsellors for other organizations (Table 2). TASO has also trained 24 counsellors for organizations outside of Uganda.

In addition, TASO has provided experiences and training in basic helping skills to participants from the following AIDS initiatives around Africa: WAMATA and UPENDO AIDS project in Tanzania; Catholic Secretariat, Nigeria; KENRI, Kenya; Project Hope, Manzini, Swaziland; AIDS/STD Unit, Gaborone, Botswana; KASAMA AIDS initiative, Zambia; and AIDS Control Programme, Accra, Ghana.
Table 2: Counsellors trained for TASO and other organizations

<table>
<thead>
<tr>
<th>Year</th>
<th>Counsellors for TASO</th>
<th>Counsellors for other organizations</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990</td>
<td>18</td>
<td>Uganda Catholic Medical Bureau</td>
<td>10</td>
</tr>
<tr>
<td>1991</td>
<td>63</td>
<td>National Resistance Army</td>
<td>18</td>
</tr>
<tr>
<td>1992</td>
<td>46</td>
<td>ACP/GTZ Kabarole</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td></td>
<td>ACP Entebbe</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Teso AIDS Project</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MAPSO</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Joint Clinical Research Centre</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mengo Hospital</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>All Saints Church - Nakasero</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nakasero Blood Bank</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>COBSEL - Lira</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Kumi AIDS Project (TASO)</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Uganda Catholic Medical Bureau</td>
<td>16</td>
</tr>
<tr>
<td>1993</td>
<td>15</td>
<td>ACP - Entebbe (Government Hospital)</td>
<td>22</td>
</tr>
<tr>
<td></td>
<td></td>
<td>National Resistance Army</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>CHIPS</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rubaga Hospital</td>
<td>14</td>
</tr>
</tbody>
</table>

Total 142 160

Medical support - TASO holds medical clinics at TASO centres twice a week. The average monthly attendance at TASO clinics has more than doubled in most centres from the period of January 1991 - March 1993 to the more recent average in early 1994, as shown in Figure 1.
Staff include part time doctors, nurses and a full time medical coordinator. In 1993 TASO clients started paying a service fee of 300 Uganda shillings (29 US cents), but medicine is provided free of charge. Medical support is also provided by TASO Mulago to immuno-suppressive syndrome (ISS) outpatients clinic for adults and children run by Mulago hospital once a week. TASO medical staff (doctors, medical assistants and nurses) and counsellors provide care and counselling to PWAs receiving in-patient care at the hospitals. However the tendency has been to increasingly rely on TASO to provide counselling and medical follow-up of clients in TASO clinics and at home. Patients who are too ill to come to the TASO centre send a message through a relative requesting to be seen at home. The home care team varies according to the situation, but usually consists of a doctor or medical assistant, a nurse and the client’s counsellor. They provide counselling, medical and social support services as needed, and also prevention education to family members. The medicines given are primarily to treat common opportunistic infections, but also include intravenous infusions for cases of severe dehydration. TASO uses a standard drug list in accordance with the national essential drug programme, and receives medicine supplies from international donors.

Social support - to minimize the social impact of HIV/AIDS, TASO provides material support to clients and pays school fees for some needy children of clients. Income-generating activities such as garment sewing, pig-farming, shop keeping and banana and vegetable cultivation are also undertaken by clients who are assisted by TASO.
Sensitization of the public and community outreach - activities include sensitization and AIDS awareness seminars and AIDS counselling orientation workshops for those working with AIDS patients. Awareness talks are given to the general public. Drama groups by clients also convey information and education on HIV/AIDS to the public. TASO also produces publications and promotional materials (brochures, T-shirts, badges).

TASO Community Initiative (TCI) - the TASO community initiatives began in 1990 when TASO staff realized that many of the clients who came for HIV/AIDS counselling had few options for follow-up support. TASO then began to recognize the urgent need to empower people at the grassroots level so that they could tackle AIDS-related problems themselves. After discussions with a number of community groups, TASO realized that community members who were given the basic skills needed for home care, counselling and AIDS education would go on to extend TASO’s services and eventually reach out to more people and communities. The objectives of TCI are:

- to provide AIDS education and to promote behaviour change at the grassroots level
- to involve the community in the care of people with HIV/AIDS
- to promote positive attitudes at the community level towards HIV/AIDS
- to set up a referral system for TASO and other AIDS services organizations
- to support community efforts to alleviate the socio-economic consequences of the AIDS epidemic.

Appendix 5 shows the TCI organizational structure in relation to TASO services and community activities. TCI is carrying out a combined formative, process and outcome/impact assessment. Field testing of the formative study has been carried out in two of the 18 TCI communities located in four TASO centres, (Masaka, Mbarara, Mulago and Tororo), resulting in modifications and re-mobilization of communities before further assessments.

1.7 TASO clients

A TASO client is one who is confirmed as being HIV-positive or having AIDS and is registered with the organization. The families of clients also receive services (not including medical) while clients are alive and after they die. By the end of 1993, the cumulative figure of registered TASO clients was 22,795. The yearly cumulative figures from 1989 to 1993 are shown in Figure 2.
Most TASO clients are women and the overall male:female ratio is 1:2. A small percentage are children below 12 years of age. Most TASO clients live within a radius of 30 km from a TASO centre.

1.8 Partners and supporters of TASO

A number of organizations fund TASO directly for its operations or provide material assistance. The majority of these are international funding agencies. Appendix 6 lists these agencies and shows TASO's funding position.

TASO has subscriber members who meet annually at the general assembly and elect members of the Board of Trustees. The majority of these members are people who live and work in Uganda. Subscriber members also include corporate members comprising corporations or organizations which subscribe to the TASO philosophy and pay membership fees as a contribution to the running of board activities and the TASO movement (Appendix 6).

1.9 AIDS-related organizations in Uganda

Over 50 AIDS care organizations currently exist in Uganda, and the number is increasing. They offer services such as home care, counselling, medical care, income-generating activities, and social support.

Efforts to coordinate AIDS-related organizations in Uganda are being made by the Uganda AIDS Commission. TASO and other organizations offering patient
care are members of a patient care sub-committee of the Commission. From the inception of TASO, the National AIDS Control Programme has been instrumental in providing support and recognition from the highest levels. The TASO director was a founding member of the National AIDS Control Programme.

TASO offers training of counsellors to many AIDS-related organizations in and outside Uganda (see Table 2). In addition, TASO works closely with three organizations:

- The AIDS Information Centre (AIC) provides AIDS information and carries out voluntary counselling and testing for HIV. AIC refers clients to TASO for counselling and care, while TASO refers potential clients to AIC for testing.

- The Philly Lutaaya Initiative is a collaborative project between TASO, AIC, UNICEF and others. The Initiative aims to educate the public by involving its members in sharing their personal experiences with HIV/AIDS in the spirit of singer Philly Lutaya, who set a courageous example of living openly and positively with AIDS.

- THETA (Traditional Healers and Therapies Against AIDS) and THEWA (Traditional Healers, Women and AIDS Prevention) are two collaborative projects between MSF (Medecin sans Frontier) Swiss and TASO to involve traditional healers in the care of PWAs.
2.1 Aims and objectives of the TASO participatory evaluation study

TASO initiated a participatory evaluation to assess its performance in meeting the needs of people with HIV/AIDS and their families for counselling, medical and social services. A participatory process was chosen in order to ensure involvement of all TASO "stakeholders", including administration, staff, clients, community members and donors. The evaluation also undertook to develop an ongoing monitoring system.

An Evaluation Steering Committee was formed by TASO to provide guidance to the evaluation process. A TASO Core Evaluation Team, assisted by a WHO consultant implemented the evaluation study.

Since TASO started as a grassroots effort to face an emergency situation, no baseline survey was carried out prior to the birth of the organization. Thus this study does not compare results with baseline data in order to assess programme impact, but rather, presents data on the existing situation. In order to present as complete a picture as possible, multiple groups and multiple data collection methods were used, including groups from outside of TASO.

The specific TASO objectives and the key evaluation questions are summarized in Table 3.

Table 3: TASO service objectives and key evaluation questions

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Key Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Counselling Services:</strong></td>
<td></td>
</tr>
<tr>
<td>To develop mechanisms to enable clients to cope with emotional problems related to infection/disease</td>
<td>Are TASO counselling services helping clients and their families to cope with HIV/AIDS?</td>
</tr>
<tr>
<td>To promote safer sex practices among clients and their partners in order to reduce the risk of transmission of HIV infection</td>
<td>Are TASO counselling services helping to promote safer sex practices among clients and their families?</td>
</tr>
<tr>
<td>To help clients and their families plan for the present and future</td>
<td>Do TASO counselling services enable clients to plan for the present and future?</td>
</tr>
<tr>
<td>Objectives</td>
<td>Key Questions</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Medical Services:</strong></td>
<td></td>
</tr>
<tr>
<td>To provide diagnosis and treatment of opportunistic infections</td>
<td>Are clients receiving treatment for opportunistic infections and are they satisfied with treatment received?</td>
</tr>
<tr>
<td>To provide client and family education on HIV/AIDS, medicines, home care and when and where to seek additional help</td>
<td>Does TASO give sufficient information, education and training to clients and care-givers concerning medications, home care and sources of additional help?</td>
</tr>
<tr>
<td><strong>Social Support Services:</strong></td>
<td></td>
</tr>
<tr>
<td>To supplement material needs of clients</td>
<td>Do PWAs and their families receive material support?</td>
</tr>
<tr>
<td></td>
<td>To what extent do TASO's material handouts meet the needs of PWAs and their families?</td>
</tr>
<tr>
<td>To promote self reliance of clients through income generating activities</td>
<td>Do income generating activities funded by TASO promote self reliance among clients?</td>
</tr>
<tr>
<td>To share personal experiences and to gain skills in living with HIV/AIDS</td>
<td>Do PWAs who participate in TASO day centre activities benefit?</td>
</tr>
<tr>
<td>To provide educational support to needy children of clients</td>
<td>Do clients' needy children benefit from the educational support provided by TASO?</td>
</tr>
</tbody>
</table>
2.2 Sampling

The sampling frames of clients consisted of people with HIV/AIDS who were registered with TASO between the period of January 1991 to March 1993 (Table 4).

Table 4: Sampling frames

<table>
<thead>
<tr>
<th>Sampling Frames</th>
<th>Planned</th>
<th>Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td>TASO clients (attendees)</td>
<td>358</td>
<td>324</td>
</tr>
<tr>
<td>TASO clients (drop-outs)</td>
<td>265</td>
<td>74</td>
</tr>
<tr>
<td>TASO clients (home-visited)</td>
<td>298</td>
<td>322</td>
</tr>
<tr>
<td>Home care client care-givers</td>
<td>298</td>
<td>232</td>
</tr>
<tr>
<td>Counsellors’ focus groups</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Male client focus groups</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Female client focus groups</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Community focus groups</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Counsellor supervisors’ focus groups</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Counselling session observations</td>
<td>70</td>
<td>49</td>
</tr>
<tr>
<td>Case studies</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Key informants</td>
<td>47</td>
<td>24</td>
</tr>
</tbody>
</table>

For purposes of the evaluation, an active client was defined as one who had received a service within the previous six months. Convenience and simple random sampling were used to select those to be interviewed. Convenience sampling allowed for data collection during normal service delivery. All clients within the sampling frame were randomly sampled to be interviewed when they came to the TASO centre to receive the various services. A client attendee was considered to be one who had registered with TASO and went to at least one counselling session and used TASO services or when home-visited for counselling and medical home care. Home-visited clients were those requesting and receiving TASO services at their homes. Drop-outs were clients who had registered and received counselling services at registration and no other TASO service.

As clients arrived and registered for services, a list was compiled. In order to sample from both early and late arrivals, specific time schedules were used (9.00 to 10.00 a.m. -10.00 a.m. to 12.00 noon). Simple random sampling was then used to pick those to be interviewed. Counsellors carrying out home visits also interviewed those clients and their care-givers who fell within the sampling
frame. Based on experience and records, each interviewer was expected to interview two clients per day. In addition to client and care-giver interviews, focus groups with counsellors, male and female clients and community members were held at each of the seven centres with a maximum of 12 participants in each group. Trained interviewers used a list of questions to guide the discussions.

All counsellors in each centre formed one group, except in Masaka and Mulago where there were two groups. The questions included topics discussed in counselling sessions, successes and failures of TASO services in meeting the needs of clients, and major difficulties.

The male and female clients met separately with not more than 12 in each group. The counsellor supervisor asked on a clinic day for those who were willing to participate in a group to write their names down. The questions for discussion were about the strengths and weaknesses of TASO services, expectations and their fulfillment, benefits and how to improve services.

The community members were invited by the centre manager to participate in a discussion group and were given an appointment to come to the TASO centre. The questions focused on the role of the community in providing care and support to PWAs and their care-givers, and the strengths and weaknesses of TASO services.

The key informants were contacted by letter, with the TASO director requesting an interview. Trained interviewers asked guiding questions about TASO in relation to other AIDS-related organizations and health facilities, the constraints in service provision and possible solutions.

2.3 Data collection

Instruments

The detailed indicators, data collection methods, data sources and data collectors are summarized in Appendix 7. Survey instruments consisting of questionnaires were designed for collecting quantitative data from clients and care-givers. Focus group guidelines were developed to collect qualitative data from clients, counsellors, counsellor supervisors and community representatives. Other guidelines were developed for key informants, information gathering by clients and observation of counselling sessions. A mixed method approach for data collection instruments allowed for comparison of evaluation findings during analysis.

Training

Training of interviewers was conducted for four days with the aim of equipping counsellors with skills in interviewing and guiding focus group discussions, and
enabling them to understand and translate interview questions into the local languages. Counsellors were considered to have a trusting relationship with their clients already, which would be more likely to lead to open and accurate responses. Interviewers and focus group moderators and rapporteurs were trained by the Core Evaluation Team and the WHO/GPA consultant.

**Procedure**

Quantitative and qualitative data were collected from 9 August - 10 December 1993. At each centre the Core Evaluation Team initiated data collection by first reviewing the questionnaires with the interviewers. The Core Team especially the TASO centre managers, continued to supervise the data collection exercise. A system of checking for all possible errors was put in place in all centres; interviewers cross-checked the completed questionnaires which were then verified by Centre Managers before transmission to TASO Headquarters for analysis. Key informants were interviewed by two people from outside TASO.

**Review of TASO records and design of monitoring forms**

The Core Evaluation Team examined existing TASO records in order to extract programme indicators for answering some of the key evaluation questions, and to streamline the existing record keeping system. Gaps and inconsistencies in record keeping were identified and revised standard monitoring forms were designed.

**2.4 Data entry and analysis**

The quantitative data were entered for computer analysis using Dbase III and imported into EPI INFO for analysis. Cleaning and double checking of all entered data were carried out to eliminate possible data entry errors. Analysis of data was in three stages: computation of simple frequencies, cross-tabulations and statistical significance analysis.

Qualitative data from notes and audiotapes were compared for accuracy and completeness. The data were entered for computer analysis using a word processing programme (WP5.1) and imported into Text Base ALPHA for further analysis, which included categorizing data, identifying variables and summarizing findings.

The plan for quantitative data analysis is shown in Figure 3.
Figure 3: TASO Evaluation Quantitative Data Analysis

- Manual checking of records
  - Duplication of records
  - Coding
- Computer programme plan
  - Variables to be entered
  - Ordered
  - Size of fields
- Screen image
  - Similar order and spatial arrangement as record
- Data Audit
  - Identify errors
  - Logical checks
  - Skip patterns
- Two clerks
  - Entered different variables
  - Checked on others records
  - Check of random records
- Frequencies of all variables
- Variables that answer evaluation questions
- Analysis of other variables
- Frequencies
- Cross-tabs
- Tests of significance
- TCI
- Duration as TASO client
- Link with qualitative data
2.5 Limitations of the study

Size of sampling frame of attending clients and client dropouts

The planned sample size was not achieved in the time available for the study. It was important to ensure normal service delivery during the data collection phase. Therefore priority was given to providing services to clients attending the TASO clinics. Difficulties were experienced in tracing client drop-outs either because they had moved to new locations, or had originally given incorrect addresses.

Bias

Using the participatory approach meant active involvement of staff and clients in the evaluation process and thus a potential decrease in objectivity. The interviewers were all TASO staff who also deliver services to the clients. There was a possibility of biased responses from clients in favour of the programme. In addition, the study was limited to those who were using, or had at one time used TASO services. No comparison of the data was made with other non-TASO PWAs. Neither was an attempt made to analyze data by comparing the 7 TASO centres, which differ in terms of time of commencement of services, locations (some are more urbanized than others) and size of operation and presence of TCI. Attendance at TASO centres tends to fluctuate throughout the year and is influenced by farming seasons and availability of material handouts; nevertheless for convenience purposes data were collected during three consecutive months.

Intervening factors

There are a number of other AIDS-related organizations providing services similar to those of TASO. Thus, some TASO clients may be receiving services from several organizations at the same time. The results obtained by the programme may not all be attributable to TASO intervention.

Validity

As in all studies on sexual behaviour, this study was aware of the possibility of inaccuracy of respondents concerning their sexual behaviour. In addition, the respondents may have biased their responses towards what TASO promotes. For example, clients may have reported a higher level of condom use or lower numbers of sexual partners than the reality. An attempt was made to address this concern during the training of interviewers. The trainers emphasized using "the counselling approach," that is asking the interview questions during the counselling session in order to minimize inaccurate responses. Feedback sessions were used to validate findings from the different data sources.
Reliability

The study attempted to standardize the structured questionnaire and to reduce error through a process of translation and back-translation into the six languages used during client interviews (Ateso, Luganda, Kiswahili, Padhola, Lumasaba, Lunyankole). External independent assistance was obtained in verifying the translations, which were then re-checked with interviewers for comprehension and accuracy. A number of terms, particularly those referring to sexual behaviour, which may have multiple meanings in different contexts were identified and translated correctly into the various vernaculars. Nevertheless, some concepts, such as abstinence, seem to have many definitions.

Data Gaps

A major consideration in interpreting results from the evaluation was the lack of TASO baseline data and a comparison population. Attempts have been made to make comparisons within the study subjects where relevant.

The study originally intended to make extensive use of TASO records. However, an early review of available data revealed inadequacies in the TASO record keeping system. Study areas which were modified as a result included:

- tracing client behaviour change over time (revealing serostatus, condom use and number of sexual partners) using TASO records. Instead, two case studies of TASO clients were carried out (Appendix 1).

- condom distribution among TASO clients. Data on condom use were therefore limited to those obtained from questionnaires alone.

- STDs among TASO male and female clients. Since the objective of TASO focused on AIDS care, STD-related symptoms were managed without being specified or identified. Some were referred to appropriate government hospitals. Hence no information on STDs among TASO clients was available at the time of the study.

Cost analysis was not conducted, however this evaluation helped to identify services offered, which can contribute toward future cost studies. Present and projected TASO budgets are found in Appendix 6a.
3.1 Planning and conducting the evaluation

The TASO evaluation used a participatory process and included the major stakeholders, such as TASO staff, clients, community representatives and donors who contributed to the design, planning and implementation of the evaluation. A participatory process enabled TASO to own the evaluation exercise, and to build its own capacity in skills such as formulating questionnaires, interviewing, gathering information through interviews and focus group discussions and analysing data. The participatory approach also helped TASO to discuss and accept failures as well as successes.

Preliminary discussions were held among TASO staff on the need for an evaluation. An Evaluation Steering Committee to provide guidance to the study was formed and was composed of TASO members, TASO supporters and WHO. Key questions and programme indicators were discussed and agreed upon and data instruments and sources identified.

TASO staff and clients gathered data and took part in interpretation of the findings and formulating the way forward. Since the evaluation study was participatory, it was important to share the results in order to:

- discuss and define concepts related to living with HIV/AIDS
- validate the evaluation findings with what the clients knew and had experienced
- enable staff and clients to interpret and make recommendations on the evaluation findings

3.2 Collecting data: a profile of the respondents

Among the 730 client respondents interviewed, the majority were women (68% women, 32% men) as approximately reflected in the total TASO client population (61% women; 36% men and 3% children). The mean age of respondents was 32.3 years, and 41% were widowed, with 29% married or cohabiting, 19% separated or divorced and 11% single. Of those who were married, 72% reported being in a monogamous relationship. Slightly over half (51%) of the respondents obtained primary level education, 29% secondary education while 13% had no formal schooling. A negligible number (2 clients) had university education. The major occupational groups were peasant farmers (26%) and business or skilled workers (26%); 23% were unemployed. The majority of the clients (71%) lived within a radius of 10 miles from a TASO centre.
With some difficulty, 74 clients (62% females and 38% males) who had dropped out of TASO were located and interviewed. The stated reasons for dropping out were as follows:

- moving away from the area, for example, going back to their village
- fear of stigma if seen in a TASO centre
- seeking care in other organization, hospital or private clinic
- dissatisfaction with TASO facilities, for example, counselling under a tree in the open
- unhappy to mix with clients of different social status.

Most of the 232 care-givers who were interviewed were women (86.2%). Half of the care-givers (50.5%) had primary level education, and were farmers (37%), unemployed (21%) or unskilled workers (16%).

A number of variables were examined in relation to clients from a TCI area and those from a non-TCI area for comparison purposes. Forty-eight (6.6%) of the total number of respondents were from TCI areas. None of the variables were found to be statistically significant. It must be noted that the sample size of 48 clients from TCI areas is small in comparison to the total sample size of 730 who were interviewed.

The duration of clients being in TASO was divided into one year intervals from 1 January to 31 December for each year. There was no significant difference between the older and newer clients for almost all of the variables examined, including knowledge about HIV transmission, attitude and practice on revealing serostatus, condom use, adoption of safer sex practices, planning and making wills. The earlier registered clients sampled in the study were few because TASO was young and had few registered clients. In addition, most of the clients registered at the beginning had died by the time of the interview period. Analysis of the main indicators by the seven centres did not yield any significant differences.

3.3 Discussing the evaluation findings

Following preliminary findings, the core evaluation team presented the findings to centre staff, clients and care-givers. The team spent one week at each of the seven centres and held in-depth discussions on the findings with clients and care-givers. Group members consisted of those who were interviewed, as well as those who had not participated in the interviews. Some of the clients had taken part in the client information-gathering exercise. The mixed group of participants in the feedback exercise did not however appear to influence interpretation of results. The observation was that in all centres, clients were free and willing to discuss the evaluation findings.
In general, the staff were positive about discussing and interpreting the evaluation findings. Where there was concern about conflicting results, the core evaluation team went back to the original data for verification. The feedback and interpretation of findings enabled staff in individual centres to identify their weaknesses and to strategize for improvements. They were able to ask questions and to obtain answers regarding their concerns over services offered to clients.

The joint interpretation of results with clients fostered a feeling of belonging and ownership of TASO by clients. Staff appeared to be regarded as friends during the feedback sessions, leading to free sharing of information. Staff felt rewarded by clients expressing their appreciation and were thereafter encouraged to continue giving services.

On average, 20 clients participated in each discussion feedback for men and women. Clients were positive about the evaluation and were willing to discuss pertinent issues, including sensitive issues on sexual behaviour.

During the feedback sessions, the relevant vernacular language was used in order to cross check clients’ comprehension of interview questions; secondly, responses from clients assisted the Evaluation Team to check the quantitative data results and to validate the qualitative data.

In addition, clients were able to share personal experiences and learn from each other during the feedback sessions. Concepts such as marriage, safer sex, client/counsellor contact, counselling sessions and coping were clarified and defined, which was important in interpreting results.

The core evaluation team made recommendations based on the evaluation results. The team was assisted by representatives of TASO service departments (counselling, medical, social support, training and TCI). The recommendations were then discussed with the evaluation steering committee and afterwards with a group of WHO staff and representatives of international and national organizations from several countries. And finally they were again discussed with the TASO Steering Committee and TASO staff.
COUNSELLING SERVICES: RESULTS AND DISCUSSION

The evaluation study sought to answer the following questions about counselling services:

- Are TASO counselling services helping clients and their families to cope with HIV/AIDS?
- Are TASO counselling services helping to promote safer sex practices among clients and their families?
- Do TASO counselling services enable clients to formulate strategies for the present and future?

4.1 Overview of counselling services

When TASO started, "counselling" was in the form of companionship with those affected by HIV/AIDS. Later it was realized that counselling skills were needed to effectively provide support. TASO staff were trained to listen, to help clients cope with fear and stress and to identify options and find solutions. This new approach was in contrast to the more traditional style of giving direct advice. When home care was started, counselling became an integral part of medical support.

Presently, there are many demands on counsellors in addition to the registered clients. For example, included in the workload is counselling the families of clients, both while the client is alive and during the bereavement period. They counsel clients of high social status who prefer to be counselled in places away from TASO centres. Counsellors also provide counselling services to non-registered PWAs who are referred from AIC, hospitals or are self-referred. The additional services, although not recorded, increase the workload of counsellors.

For the purposes of the evaluation, a "counselling session" was defined by the evaluation team, staff and clients as the dialogue between a counsellor and client during which issues are discussed, options are examined and possible plans related to the client’s HIV infection are made. As a result, the client and his/her family are empowered to continue with a meaningful life. The counsellor helps the client to understand and appreciate his/her situation so as to decide on the best ways of dealing/coping with the situation or problem.
A "contact" was defined as an interaction with a client during which a TASO service (counselling or medical treatment) is provided. On average, each client received one counselling session per month. Counsellors suggested that the maximum number of clients that can be effectively counselled is five per day. Thus, on average one counsellor can counsel 100 clients per month. Figure 4 presents a comparison of the number of clients per counsellor for two periods, January to December 1992 and January to March 1994. Focus group discussions with Counsellor Supervisors revealed that the workload is particularly high on clinic days, which does not allow for effective counselling.

Figure 4: Number of clients per counsellor in 1992 and from January to March 1994

4.2 Coping of clients and families

The evaluation sought to find out whether the content of counselling offered to clients at the different stages of their interaction with TASO services addressed the following:

- coping with disease and related problems
- safer sex practices
- planning for the present and future.

In addition, the evaluation sought to determine whether TASO counselling had any effect on clients’ knowledge and practice, and whether clients and their families were coping with HIV/AIDS. Coping was defined by the evaluation team, staff and clients to be an acceptance of being HIV-positive and having a positive attitude towards the prospect of a shortened life expectancy. A positive
attitude is manifested in "positive living" which includes avoiding re-infection and infecting others, revealing ones serostatus, seeking counselling, seeking prompt medical care, having a balanced diet, avoiding harmful habits such as drinking alcohol and smoking and maintaining hope in life (a will to live). The results are discussed below.

**Content of counselling**

A total of 49 observations were made of counselling sessions. Focus group discussions were held with counsellors and with male and female clients. From these data sources it was found that the major topics discussed in counselling were:

**Medical**

- Information given on symptoms
- Use of medicine and how to obtain if not available in TASO
- Persistent symptoms
- Medical problems for children

**Emotional/family**

- How to convince spouse to test for his/her own serostatus
- Refusal of spouse to register with TASO
- Spiritual issues
- How to reveal serostatus to spouse and others
- People's attitudes towards PWAs
- What to tell children

**Positive Living**

- Having a balanced diet
- Using TASO services
- Seeking prompt medical care
- Prevention of infection

**Education/prevention**

- Information about HIV/AIDS
- Prevention of spread of HIV
- Education of family members
- Problems of introducing condom use to spouse
- Issues related to pregnancy
Material Assistance/planning

- Lack of money and how to gain more income
- School fees for children
- Land ownership
- Successes and failures of income-generating activities
- Job seeking
- Who will take care of children in future
- Problems of relatives grabbing property after husband’s death
- Making wills
- Planning for self and family

In 23 (46.9%) of the 49 counselling observations, topics related to the coping mechanisms (such as accepting diagnosis, sharing serostatus with spouse/family, continuing to work, and self-care) were discussed between counsellors and clients. Clients appreciated TASO’s emotional support as illustrated by their comments during focus group discussions:

"TASO has helped to reduce thoughts and helped me to realise that I am not alone ... and I am still useful".

"When I came to TASO in February 1990, I was very weak but I was warmly received by counsellors."

"TASO was brought by God to help people. May the Lord bless TASO and its workers."

Drama groups were also mentioned by clients as having enabled them to gain a sense of fellowship and to share experiences.

The content of counselling is dependent on client needs, and differs from visit to visit and the findings reflect TASO’s attempt to assist clients to cope with their particular situation.

Sources of information about HIV/AIDS

TASO was reported by a majority of the respondents (68.1%) as the major source of information on HIV/AIDS. (Figure 5).
The churches/mosques, which are major places of social interaction, reflect a very low percentage (1.4%) as a source of information on HIV/AIDS. Discussions with clients revealed that religious leaders tend to stigmatize those with HIV/AIDS.

The health and extension workers also rank low (2%) as a major source of information on HIV/AIDS, indicating that TASO clients rely heavily on TASO for their HIV/AIDS information.

Regarding dissemination of information in the future, the clients and community focus groups suggested that:

- TASO should devise programmes to sensitize religious leaders through changing attitudes, giving information and education;
- TASO staff should reach out to communities in places of worship and other communal meetings, such as those of the Resistance Committees.

Revealing Serostatus

One of the important coping methods which was discussed between counsellors and clients was sharing HIV serostatus with spouse, family and community members. This enabled the family to better understand and accept the client’s condition and give appropriate help and care.
Of the 717 who responded to the question on revealing serostatus, 90% (88% of all TASO male clients and 91.5% of all TASO female clients) had revealed their status to somebody, as shown in Figure 6. There was no statistical difference between men and women in revealing serostatus (p-value=0.14). Counselling may have enhanced the sharing of serostatus among both the men and women.

Figure 6: Clients revealing serostatus (n=717)

Not revealing 10%

Revealing 90%

Figure 7: People to whom serostatus was revealed (n=648)

- Other relative: 85.3%
- Household member: 67.7%
- Friend: 55.7%
- Spouse/regular partner: 36.0%
- Public: 35.3%
- Others: 5.3%
Figure 7 shows that the vast majority (85.3%) revealed their serostatus to relatives other than household members or spouse/partner. Case study 1, which describes a client telling his sister before telling his wife and others in the village, confirms a common pattern of gaining confidence in revealing serostatus to other relatives before telling those closest to the individual.

The comparatively low percentage of sharing serostatus with spouse (36%) may be accounted for by the high percentage of widowed clients (41%) among those interviewed. Neither marital status nor gender influenced revealing of serostatus.

**Fear of revealing serostatus**

A number of reasons were given by the 69 (9.6%) clients who had not revealed their serostatus to anybody with the predominant reason being fear of shame (Figure 8).

![Figure 8: Fears about revealing serostatus amongst those not revealing to anyone (n=69)](image)

The fear of revealing one’s serostatus still prevails and needs to be continuously addressed. One client said:

"*When I discovered that I had AIDS, I cried for two months and I was chased away by my in-laws, but my coming to TASO has helped me to understand and become firm about my situation.*"
A member in a community focus group also expressed fear of revealing serostatus:

"TASO offices should not be in the open ... should be in a place which is not very open. People are still stigmatized. People fear to come to TASO centre because they fear identification."

Discussions with counsellors also revealed that they had clients of high social status who preferred to be counselled in places away from TASO centres.

**Family and community response to PWAs**

Both the community (76%) and family (79%) responses toward PWAs as shown in Figures 9 and 10, indicate a high level of acceptance, perceived by clients, which may be attributed to the level of AIDS awareness among the communities. TCI (the TASO Community Initiative) and other AIDS-related organizations carry out community educational activities which may have influenced AIDS awareness and acceptance in the community.

![Figure 10: Family response to PWAs (n=706)](image)

![Figure 9: Community response to PWAs (n=703)](image)

The high level of acceptance of PWAs among the communities may also be due to TASO counselling given to PWAs and their families. A member in a community focus group capturing the tendency to discuss AIDS freely in public, said:
Clients also reported that family members were providing physical care to them, which is an indicator of acceptance. The physical care provided included changing of bedding, giving medicine at the right times and providing food. Specific family members reported to have provided physical care and met needs of clients were: mother (17%), spouse/partner (12%) and sister (9%).

**Are TASO counselling services helping clients and their families to cope with HIV/AIDS?**

**Summary**

Counselling appeared to help clients to cope with HIV infection. Counsellors and clients discussed topics related to coping in almost half of the counselling sessions; 90% of the sampled TASO clients revealed their serostatus, with 85.3% revealing to other relatives. A high level of acceptance in families (79%) and in communities (76%) was also reported by the clients.

**Recommendations**

- TASO should critically examine its counselling service and identify components of emotional support that communities, if trained, could provide.

- The adoption of alternative means of transport by TASO centres, for example, motorcycles and bicycles should be explored. Such measures could enable counselling staff to offer independent home counselling services without increasing pressure on the shared transport used by the different services. Emphasis should be on quality rather than on quantity of counselling to clients.

- TASO should broaden its programme, using counsellors, community workers and PWAs, to sensitize religious leaders about care and support to people living with HIV/AIDS (PWAs) and about positive living. Community gatherings, such as Resistance Council meetings, are other avenues of outreach.

- Counselling should emphasize revealing of serostatus to spouse/partner in order to enhance coping, make support possible, and enable behaviour change.

- Training of counsellors should include basic nursing care, an overview of HIV/AIDS medicines and when to seek help. Organised community and
family education and information outreach activities should cover basic care of PWAs.

- Counselling the family about the HIV/AIDS diagnosis and educating about home nursing care should be commenced before the person is bedridden.

4.3 Safer sex practices among clients

Client knowledge about HIV transmission

Of the 730 client respondents, 498 (68.2%) knew all four major modes of transmission: unprotected sexual intercourse, infected pregnant mother to unborn child, transfusion with infected blood and sharing infected unsterilized skin-piercing instruments. Almost all clients (98%) knew about HIV transmission through unprotected sexual intercourse.

228 (97.4%) of the men and 468 (94.9%) of the women knew that an infected person could be healthy-looking and could infect others. There is a high level of knowledge of the modes of transmission among both male and female clients.

Knowledge of safer sex practices

Clients reported knowledge of various safer sex practices. The most frequently mentioned method, as shown in Figure 11, was using condoms (85%), followed by abstinence (39.4).

Figure 11: Knowledge of safer sex practices (n=726)
Safer sex practices

The most commonly reported current safer sex practices by all sampled clients included abstinence (45%) and condoms (33%). Figure 12 shows that all the most frequently reported safer sex practice among male clients was condom use (48%) and abstinence was more highly reported by female clients (56%). Interpretation of these figures is, however, limited by the fact that data concerning the duration of abstinence were not collected. Case study 2 describes a woman who chose abstinence after her husband died.

Figure 12: Reported current safer sex practices by gender

Issues related to safer sex practices were discussed in 39 (79.6%) of the sessions of the 49 observed counselling sessions, which indicates that the topic of prevention of sexual transmission is well-integrated into the majority of sessions with clients.

The perception of most clients is that having fewer sex partners and "zero-grazing" (having sex with one's own partner only i.e., monogomy) without a condom are not safer sex practices. One may still be exposed to infection as it is very difficult to ensure faithfulness amongst partners. A female client commented:

"I got married to my husband in 1962 and I have never had sex with any other man, but here I am infected with HIV from him."

Abstinence is not viewed as a safer sex practice as it is not sex, however, clients regard abstinence and having fewer sex partners as positive behaviour changes.

Focus group discussions with counsellors and community members expressed concern over low levels of preventive behaviour, particularly among rural communities. TASO services are mainly confined to urban areas and cover a radius of 30 km from each TASO centre. A member from one community focus group commented:
"TASO should come out with programmes of educating the public instead of waiting for people to get infected and counsel ..."

As TASO doesn’t provide services to rural communities located outside its operational area unless communities organize themselves into outreach groups, it was suggested in a focus group discussion with community members to reach communities through training of community representatives in AIDS prevention.

**Number of sexual partners**

Clients were asked about the number of sexual partners before knowing their serostatus and in the previous 3 months before the interview. Figure 13 shows that the majority of clients (67%) reported zero partners in the 3 months prior to interview, while in the period before knowing serostatus only 18.4% reported zero partners. It is likely that TASO may have influenced the reduction in the number of partners as it is only after knowing serostatus that one is registered with TASO.

![Figure 13: Number of sexual partners of clients before knowing serostatus and during 3 months prior to interview](image)

**Use of condoms**

Of the 493 who responded to the question on condom use, 246 (49.9%) had ever used a condom (Figure 14). The reported period when the majority started using condoms was after joining TASO.
Figure 14: Ever use of condoms according to when clients started use (n=246)

1 month ago 4.1
2 - 4 month ago 14.2
5 - 11 months ago 14.2
12 - 23 months ago 48.8
More than 24 months ago 18.7

Of the 246 respondents who ever used condoms, 182 (74%) reportedly used condoms in the last sexual encounter prior to the interview.

Comparison was made of condom use for two periods: in the previous year and within the previous three months (Figure 15).

Figure 15: Regularity of condom use

Last year (n = 239)

Last 3 months (n = 229)

Always
Sometimes
Never

% 60
50
40
30
20
10
0

57.2
49.8
12.7
23.4
30.1
26.8

38
There was a marked increase of 7.4% in the number of people who reported consistent use of condoms in the previous year (49.8%) and those who used condoms consistently within the previous three months (57.2%). Additionally, there was a drop of 10.7% among those who sometimes used condoms, from the previous year to within the last 3 months.

Discussions with counsellors and clients revealed that consistent condom use, especially among married couples was very difficult. A resigned female client stated:

"I took the condoms and my husband refused to use them and when I insisted, he threatened to chase me out of his house. Since this meant leaving my children, which I could not afford to do, I gave in despite my knowledge about the negative implications of not using a condom."

Another female client reported:

"After being counselled I took the condoms to my husband who refused to use them and refused even to be counselled. He argued that since I am infected, as he too is (infected), there is therefore no need for condoms and even taking a test. So I gave in because I do not have any other source of financial support."

It was apparent from discussions with clients that clients with irregular sexual partners have a higher bargaining power for condom use than the married/regular sexual partners. However, for clients who are consistently using condoms, the main reasons for use of condoms were to prevent: HIV re-infection, infecting others, pregnancy and STD infection.

Data from the structured questionnaire indicated that of the 14 female respondents not using a condom the last time they had a sexual encounter, only 2 reported asking their partners to use a condom.

A case was cited of an elderly HIV-infected man married to a young woman who refused to use condoms because she wanted a child as it is a cultural disgrace to die without a child.

Other reasons given during focus group discussions for non-use of condoms included feelings that condoms reduce pleasure and that a partner may think one is unfaithful.
Are TASO counselling services helping to promote safer sex practices among clients and their families?

Summary

Abstinence was reported by 56% of the female clients. Condom use was reported by 48% of the male clients. Issues related to safer sex practices were discussed in 79.6% of the observed counselling sessions, and 57.2% reported consistent condom use in the previous 3 months and 74% in the last sexual encounter. It was noted that irregular sexual partners have a higher bargaining power for condom use than married/regular sexual partners. The number of condoms distributed in counselling sessions was not recorded.

Recommendations

- Counselling should address myths about abstinence and support strategies to sustain clients’ choice for abstinence, for example, discussing other ways to attain sexual satisfaction.

- Counselling for infected people should reinforce consistent use of condoms, even in faithful monogamous relationships.

- Sufficient quantities of condoms should be distributed during each counselling session (according to client needs) and recorded.

4.4 Planning by clients for present and future

In 27 (55.1%) of the 49 counselling sessions observed, planning for self and family was discussed between clients and counsellors. The plans discussed included starting income-generating activities (IGAs), making a will, building/repairing a house, continuing to work and educate children. Figure 16 summarizes multiple responses regarding plans made by clients. Feedback sessions with clients revealed that poverty was the main reason for not making plans.
While 276 (39%) of the respondents acknowledged having discussed making wills with their counsellors, only 119 (16.8%) had made wills. Clients’ feelings about wills are summarized in Figure 17. There were no significant gender differences in making future plans or in feelings expressed concerning wills. From the evaluation feedback sessions with male and female clients, it was observed that female clients view will-making as the man’s responsibility. An often repeated phrase among female clients was:

"I have nothing to pass on."

Figure 16: Future plans made for self, children and dependents (n=701)

<table>
<thead>
<tr>
<th>Plan</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No plans</td>
<td>43.1</td>
</tr>
<tr>
<td>Set up an income generating</td>
<td>26.5</td>
</tr>
<tr>
<td>activity</td>
<td></td>
</tr>
<tr>
<td>Construction or repair a</td>
<td>20.6</td>
</tr>
<tr>
<td>house</td>
<td></td>
</tr>
<tr>
<td>Make a Will</td>
<td>14.7</td>
</tr>
<tr>
<td>Buy property</td>
<td>13.2</td>
</tr>
<tr>
<td>Open a bank account for</td>
<td>7.8</td>
</tr>
<tr>
<td>children</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>18.5</td>
</tr>
</tbody>
</table>

Figure 17: Feelings about a will (n=701)

<table>
<thead>
<tr>
<th>Feeling</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Already made one</td>
<td>16.8</td>
</tr>
<tr>
<td>Wish to make one</td>
<td>51.3</td>
</tr>
<tr>
<td>Nothing to pass on</td>
<td>22.3</td>
</tr>
<tr>
<td>Don’t care</td>
<td>15</td>
</tr>
<tr>
<td>Bad omen</td>
<td>8.5</td>
</tr>
<tr>
<td>May disrupt family</td>
<td>2.3</td>
</tr>
<tr>
<td>Others</td>
<td>9.8</td>
</tr>
</tbody>
</table>
Making a will was a topic introduced early in the counselling relationship, and it usually arises many times. Fears about making wills were shared among both male and female clients, and included wills being viewed as a bad omen (implying imminent death) and as being potentially disruptive to families.

4.5 Challenges in counselling

Despite the major achievements of counselling, the counsellors during focus group discussions expressed some difficulties which they encounter in counselling. These include:

- emotional stress

  "Some clients break into tears ... so difficult to control... and death of clients."

- dependency syndrome of some clients, for example, they expect the counsellors to provide the service fee and transport.

- lack of general knowledge on medicine and basic nursing care whereas clients expect them to have this knowledge. Clients are more free to discuss their concerns about medical prescriptions with counsellors, rather than with clinicians or nurses.

- difficulty in counselling discordant couples and clients who say they are using condoms but who later become pregnant.

- inadequate transport for home visits.

- lack of privacy during counselling of clients due to inadequate office space. In some centres, counselling services are offered in the open under trees. This lack of privacy in counselling partly explains why people of high social status are reluctant to use counselling services at TASO centres.

- high workloads on medical clinic days.

TASO has an open door policy towards registration of clients, hence the trend of increasingly heavy workloads for counsellors will continue.
Do TASO counselling services enable clients to plan for the present and future?

Summary

Planning for self and family was observed in 55.1% of the counselling sessions observed during the evaluation. The plans discussed included starting income-generating activities (IGAs), making a will, building/repairing a house, continuing to work and educate children. Will making was discussed with 39% of the clients, with 16.8% having made wills. While 22.3% of the clients said they had nothing to pass on, 51.3% of the clients wished to make a will.

Recommendations

- Counsellors should encourage clients to discuss plans for the future with family members, including plans for survivors.
- Counsellor training should address how to deal with emotional fears about making wills and how to help women and children handle legal and social problems related to property.
MEDICAL AND HOME CARE SUPPORT SERVICES: RESULTS AND DISCUSSION

The evaluation set out to answer the following questions on TASO medical care:

- Are clients receiving treatment for opportunistic infections, and are they satisfied with treatment received?
- Does TASO give sufficient information, education and training to clients and care-givers concerning medications, home care and sources of additional help?

5.1 Overview of medical services

In a climate of neglect of AIDS patients, TASO initiated medical services in clinics and homes with a vision to encourage health care workers and families to also provide care. It became apparent that both counselling and medical care were needed by clients. Different approaches were tried in order to cope with the increasing numbers and the minimal resources, for example, prescribing based on the national essential drug list, educating clients and families on how and when to seek medical care and take medicines, and spacing appointments to not more than twice a month per client. Nevertheless, clinic days in most centres are long and heavy.

Clinic records among all TASO centres indicate that the average number of clients seen per clinic day ranges from 33 to 172. In focus group interviews clients confirmed that high clinic attendance caused difficulties:

"Clients from far leave very late."

"The time when the doctors start their work delays the whole system, at least if they start a bit earlier at around 8.00 or 8.30."

"At times the procedure of first come, first served is not followed and this leads to delay."

"Recruit more medical personnel (doctors) and counsellors to reduce on the fatigue."

"Change the system of keeping the appointments because some of us want strictly TASO services and usually have the 300 shillings."

When clients were asked about their expectation on joining TASO, the most frequently mentioned reason was expectation of care, which consists of medical treatment, counselling and nursing care (Figure 18).
Main needs of PWAs

Clients were asked about their main need related to HIV infection. Of the 706 respondents, 47% considered care as their main need related to HIV infection (Figure 19).

There was no significant difference between those mentioning care (47%) and those mentioning material assistance (28%) as a main need.

On the rating of TASO services, qualitative data however revealed that most clients view medical, counselling and material needs as being met concurrently
by TASO. On being asked about which service was most important for them, the responses were:

"Medical treatment, counselling, material assistance, all are equally good and work hand in hand like a chain or logs in a fire place..."

"All are equally important."

Care was cited as the most helpful TASO service by 86% of the clients (Figure 20).

5.2 HIV-related symptoms and treatment

Symptoms

From all clients interviewed, the most frequently mentioned symptom was fever (60%), followed by cough (45.5%), continuous diarrhoea (32%), sores on the inside of the mouth (18%), weight loss (14%), swellings on the side of the neck (10%) and herpes zoster (6%). Other symptoms mentioned were skin rash, headache, stomach pain, vomiting, genital sores and vaginal itching (Figure 21). Of all clients interviewed with various symptoms experienced in the previous month none reported being hospitalized.
Main source of medical care

TASO was the major source of health care for its clients, followed by health centres, private practitioners and government hospitals (Figure 22). Unlike other sources of medical treatment, TASO offers a care package of medical, counselling and social support services to clients. In addition, TASO carries out home visits to bed-ridden clients, a factor which may minimize the need to use hospital services.

In Figure 22, 11.5% of clients indicated having gone no-where for treatment of herpes zoster, a very painful condition. The focus group discussions revealed that some clients may have used self-medication or traditional herbalists to treat this condition.
Qualitative data from clients similarly indicated high use of TASO health services. From a total of 14 focus groups, 12 groups (85.7%) mentioned satisfaction with TASO medical services. Reported feelings included:

(TASO medical services are)..."very good";
"Doctors are available."
"You get right treatment."
"Can now live longer because of TASO treatment."

Two negative factors mentioned by clients were the burden of service fees and the shortage of some medicines.

Of all clients interviewed concerning provision of care for the various illnesses experienced in the previous month, the most frequently mentioned source of care was TASO (63.8%), followed by private practitioner (18.3%) and health facilities (16.2%), as shown in Figure 23.

Figure 23: Who provided care in the last month? (n=655)

<table>
<thead>
<tr>
<th>Source</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>TASO</td>
<td>63.8</td>
</tr>
<tr>
<td>Private practitioner</td>
<td>18.2</td>
</tr>
<tr>
<td>Health facilities</td>
<td>16.2</td>
</tr>
<tr>
<td>Family member</td>
<td>10.5</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>9</td>
</tr>
<tr>
<td>No one</td>
<td>4.9</td>
</tr>
<tr>
<td>Traditional healer</td>
<td>4.1</td>
</tr>
<tr>
<td>Other</td>
<td>4.4</td>
</tr>
</tbody>
</table>

TASO was also cited by 75.2% as the most helpful source of medical care. The observed preference for TASO services, while commendable, indicates future heavy demand by clients for TASO services which the organization may not be able to meet adequately. While TASO is a major source of care for its clients, the public health service and the community (family/household, traditional healer) are reported to be used far less.

Although the number of traditional healers reported to be providing care is low, clients may be reluctant to reveal use of healers when they also receive care
from TASO. TASO is undertaking a collaborative study with traditional healers which may shed some light on this matter.

Other sources of medical care

Clients were asked about other sources of medical help apart from TASO. Of the 373 respondents, 159 (42.6%) indicated obtaining medicines from other sources. Since clinics held by TASO occur two days per week at TASO centres, clients who need medical help on other days may seek it elsewhere.

Focus group discussions also sought information on where else clients receive medical help. Of the 14 focus group discussions, most groups mentioned the private clinic. Other sources of care: dispensary/hospital, medicine shop/pharmacy and traditional healer.

In conclusion, TASO provided medical treatment to the majority of its clients, although some clients used other sources of treatment such as private clinics, pharmacies, government facilities and herbalists.

The use of both traditional medicine and shops/pharmacies indicated that clients make use of both conventional and traditional treatments. Clients who used traditional medicine as well as TASO services saw the two sources as playing complementary roles.

When treatment sought

TASO clients were counselled and given information on the importance of seeking prompt medical care. The TASO approach which includes "positive living", prevention, and early treatment of opportunistic infections had influenced over half of the clients to seek prompt medical care. The vast majority of TASO clients sought early medical treatment, i.e., within two weeks of onset of various symptoms (Figure 24). For example, 83% of the clients with cough sought prompt treatment which makes it possible to detect a serious but treatable disease like tuberculosis in a timely manner.

While counsellors were concerned about their inadequacy in basic knowledge of medicine and nursing care, the counselling they provided nevertheless appeared to have produced prompt health-seeking behaviour of clients.
Medicines

Information from qualitative data indicated that clients appreciate medicines supplied by TASO, in spite of the requirement of 300 Uganda shillings (29 US cents) as a service fee and the unavailability of some medicines.

"Drugs (medicines) are expensive but through TASO they are available."

"TASO has done more than a hospital could do for the AIDS patients."

Of the 251 home-visited clients interviewed, 123 (49%) were taking medication. Of those, 70 (57%) were taking the medicines correctly. This percentage is low in view of the fact that clients are visited at home by the medical team which includes nurses, medical assistants and doctors, depending on the situation. Compliance may be affected by patients obtaining and using medicines from a number of sources other than TASO, or patients may give up a course of treatment for various reasons.

Over half of the care-givers interviewed knew how to make oral rehydration solution for an AIDS patient who has diarrhoea and/or dehydration using either sugar-salt solution (50.7%) or sachets from the clinic (78.6%).

In summary, the results indicated that TASO was providing information, education and training on home care and medicines, particularly for home care of bed-ridden clients. Compliance by clients however could be improved through greater involvement of family members in the care of clients, as well as by increasing the knowledge of counsellors about course of treatment.
Hospitalization

The evaluation sought to find out whether TASO clients were recently hospitalized. Of all clients interviewed with various symptoms experienced in the previous month none reported being hospitalized. The most common reason for hospital admissions of PWAs was for severe dehydration after diarrhoea or vomiting. TASO clients and care-givers appeared to be managing diarrhoea through a variety of ways:

- prompt seeking of medical care from TASO
- use of oral rehydration solution
- use of other sources of medical help, such as health centres and private practitioners

TASO clients appeared to prefer care at home by relatives, with treatment from the TASO medical home visit teams. In addition to dispensing of medicines, the TASO medical team occasionally distributed home care kits when available. The kit consisted of: a pair of bed sheets, a rubber sheet for bed, soap and mouth wash when available. In contrast, hospital care entails transport costs and care of a relative, usually by a female. In addition medicines are not always available in hospitals.

Those clients who use pharmacists/medicine sellers or who take care of themselves may already be aware of treatments required for their illnesses, and thus minimize the need for hospitalization and utilization of other health services.

Are clients receiving treatment for opportunistic infections and are they satisfied with treatment received?

Summary

Care, comprised of medical treatment, counselling and nursing care, was found to be the most helpful service by 86% of TASO clients. TASO was cited as the major source of health care in the last month by 63.8% of the clients. Twelve out of 14 focus groups indicated satisfaction with TASO medical services. The vast majority of TASO clients sought early treatment, i.e. within two weeks of onset of symptoms. Of those sampled at home, 49.4% were on medications, and of those, 57% were taking them correctly. Care-givers knew in detail how to make sugar-salt solution (50.7%) and to use sachets to treat diarrhoea (78.6%).

Recommendations

- TASO should continue prescribing and supplying medicine according to the standard medication list, and should resist accepting medication not on this list.
• Continue to promote early diagnosis of tuberculosis among HIV positive people and compliance with treatment, in collaboration with the national tuberculosis programme.

• All TASO health care staff should be trained in counselling skills and in teaching clients and families about home care, correct use of medicines and when to seek help.

5.3 Information, education and training for care-givers

Profile of care-givers

A total of 232 care-givers were interviewed in their homes concerning care given to clients at home. Of these, only 32 (13.8%) were males and 200 (86.2%) were females. PWAs were mostly cared for by females (Figure 25) with the majority of care-givers being mothers of clients (26.3%) or other females (sister 18.5%, daughter 15.1%).

Figure 25: Caregivers’ relationship to person with AIDS (n=232)

Care-givers were asked to give their opinion on who should be the main care-giver of a PWA. 53.9% of respondents, who were currently taking care of PWAs believed responsibility belonged to the client’s mother, 12.9% believed the responsibility was TASOs and 10.8% believed it to be with the spouse of client. Data from qualitative analysis indicated that the mother was seen by care-givers and clients to be the right person:

"A mother offers everything for care."

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Even though mothers are viewed as ideal care-givers and are in fact providing much care at home, they do so in addition to many other household tasks and family responsibilities.

Community members had the general view that a PWA should be cared for by a close relative at home in order to:

"Avoid negligence in hospitals."

"Provide basic care to the patient"

"Avoid expenses."

Source of Information for care-givers

The care-givers interviewed reported receiving their information on HIV and AIDS from a variety of sources including TASO, radio, friends, colleagues and other people (Figure 26). TASO appeared to be reaching non-clients through home-visits made to clients. TASO was also the main source of information to care-givers concerning care of PWAs and prevention. Additionally, there are other sources of information on HIV in the community such as NGOs and the National AIDS Control Programme.

![Figure 26: Caregivers major source of information on HIV/AIDS (n=217)](image)

There was no significant difference in knowledge on HIV between clients and care-givers. TASO was equally reaching both clients and care-givers with information on HIV, prevention and home care (Figure 27). Care, including counselling, provided by TASO gives an opportunity to discuss prevention with
clients and care-givers in a personal way. Promotion of safer sex practices and infection prevention through hygiene can dispel fears of care-givers and family, and can serve as an entry point for care. Neighbours were also involved in discussions on AIDS prevention and care.

Figure 27: Who discusses AIDS home care and prevention with caregivers? (n=216)

Source of extra help

Figure 28: Source of extra help to caregiver (n=216)
The results in Figure 28 indicate that TASO was the major source of extra help beyond the household for care-givers in taking care of TASO clients (71.3%). The care-giver's other source of extra help was family members. This emphasizes the importance of support and skills to families in the care of PWAs.

**Community Response to Care of PWAs**

Community members advocated a community-based approach to care. When asked as to the place where a person with AIDS should be cared for, the community responses (expressed as a percentage of all the seven community focus groups) were: at home in own community (100%) and in hospital (42.8%). With regard to the person who should take care of PWAs, the responses were: family members/relatives (57.1%); community members (42.9%); TASO staff (14.3%). A number of reasons were given by community members for a community-based approach to care of PWAs, and these include:

- "There is social, spiritual and medical care at home"
- "The bedridden are living examples that AIDS is a danger. There is need to remain in their environment."
- "Care-givers will be able to do their normal work in addition to caring for PWA."
- "Cost sharing in hospitals may be very expensive."

However, the community members requested TASO to:

- assist care-givers by providing information on HIV/AIDS and training in home care in order to minimise infection
- provide patient care kits
- provide material assistance to clients.

The above requests indicated the community's acceptance of and expectation of TASO to provide the medical and material needs of clients.

Community members also realized the important roles that they themselves could play to assist family members in the care of PWAs, and these include:

- paying visits and giving emotional support, particularly by religious leaders
- offering immediate support in terms of basic provisions such as food (eggs, milk)
- contributing financial assistance for medicines
Does TASO give sufficient information, education and training to clients and care-givers concerning medications, home care and sources of additional help?

Summary

TASO was the main source of information on AIDS care and prevention for family care-givers (31.8%) and clients (68%). TASO was also the major source of extra help for 71.3% of the family care-givers. The majority of community members believed that family members/relatives should be seen as the major care-givers at home (57.1%), followed by community members themselves and by TASO staff.

Recommendations

- As TASO services are meant to complement other available government and NGO services, every health unit should provide basic AIDS care and counselling. TASO should provide training in counselling skills and positive attitudes towards PWAs to non-TASO health care workers and follow-up to those trained, as necessary, in order to help them support family care-givers in provision of home care.

- TASO should facilitate the capability of communities to contribute towards the care of PWAs, such as community contributions for medicines and enabling community members to provide emotional support to PWAs and their families.

- TASO should explore ways to lend support to home care-givers who are primarily women, and also to involve other community resources such as religious groups, community health/extension workers, and neighbours.
SOCIAL SUPPORT SERVICES: RESULTS AND DISCUSSION

The evaluation examined the following questions in relation to TASO social support services:

- Do PWAs and their families receive material support?
- Do PWAs who participate in TASO day centre activities benefit?
- Do income-generating activities funded by TASO promote self-reliance among clients?
- Do clients' needy children benefit from the educational support provided by TASO?

6.1 Overview of social support

When TASO began they wanted to meet all the needs of their clients, including adequate nutrition. They distributed food, such as eggs, rice and sugar to clients. In addition to food and financial assistance for school fees, TASO realized that clients needed an accepting environment where they could relax, be open and share the HIV/AIDS experience. A day centre was started. However, for many clients the underlying problem of poverty remained. Thus, in an attempt to be supportive to clients, TASO helped clients initiate income-generating activities.

6.2 Material support

The responses as to the most difficult need for clients to cope with at home are shown in Figure 29. In addition to financial assistance, material assistance (food and other items such as rice, oil) ranked high among the most difficult needs to cope with at home for both clients and care-givers.
On joining TASO, 34% of the clients expected material assistance from TASO. Of these clients, 56.2% reported that this need has been met and they were satisfied with TASOs social support (Figure 30). Focus group discussions further emphasized that material assistance was one of the strengths of TASO. Comments from clients on material assistance were:
"Material assistance is helping me as I am unable to work and earn money for food."

"Food handouts help much on positive living."

"We get food which some of us might fail to buy"

Of the 232 care-givers interviewed, 55 (23.7%) mentioned material assistance as being the most important type of care for their patients and 48.1% of the clients indicated that their care at home could be improved through provision of material assistance.

Clients appreciated the material assistance given but they also needed financial assistance which TASO does not currently provide. The distribution of available material assistance was not uniform in all TASO centres. Some centres provide material assistance to all clients while other centres assessed the most needy ones before distribution. The sporadic supply of material assistance contributed to problems of assessment and distribution. Some donors insisted on their own criteria for the distribution of materials, thereby leaving little room for assessments based on local needs.

Do PWAs and their families receive material support?

Summary

On joining TASO, 34% of the sampled clients expected material assistance. Of these clients, 56.2% reported that this need had been met. Still, 48.1% of all the sampled clients indicated that home care could be improved by provision of material assistance.

Recommendations

- TASO rather than the donor should decide on the mode and criteria of distribution of material assistance donated externally.
- TASO should assist communities to seek alternative resources, building on the capabilities and resources of the communities, e.g. visiting the sick and offering food.
- TASO should establish linkages with social welfare services and NGOs in order to refer clients for material support.

6.3 Day centre benefits

Out of the 730 sampled respondents, 63 (8.6% with 81% being female), were regular members of day centres. Members of the day centres are TASO clients who choose to participate in daily day centre activities, which entitles them to
share the proceeds from selling products, such as mats. The clients reported a number of benefits received from day centres, the main one being sharing experiences with one another (Figure 31).

![Figure 31: Benefits from TASO day care centre (n=63)](image)

From the focus groups, clients further emphasized the benefits from TASO Day Centres:

"(There is) change of life socially and getting new ideas from friends."

"(We) talk to friends and learn more about HIV/AIDS."

"We come together, share experiences, learn songs and forget (our) worries."

Others mentioned that coming to the day centre helped in generating income and also kept one busy, thus managing stress and worries.

Despite the many benefits of the day centre activities for members, it was only a very small proportion of the total clients who were the beneficiaries due to membership assessment, limited space and resources. The original aim of the TASO day centre was to augment and reinforce TASO counselling services. Specific objectives were formulated in order to address needs of those living with HIV/AIDS:

- to reduce stigma by inviting in clients and their relatives to sit together and have a common meal
• to share experiences about HIV/AIDS and support and comfort each other

• to share and gain some skills in order to earn some income for self support.

Some of these objectives have been achieved to date while others are better addressed at the community level, such as acquisition of income-generating skills.

**Do PWAs who participate in TASO day centre activities benefit?**

**Summary**

The 8.6% of the 730 sampled respondents who were regular members of the day care centre found the main benefits to be sharing experiences with one another (95.2%) and learning skills to earn a living (84.1%).

**Recommendations**

• TASO day centres should be used as learning facilities to equip clients with knowledge and skills to be shared in the community.

• The drama group should be assisted by professionals to develop skills to deliver information on HIV/AIDS and to enable them to earn an income at the same time.

### 6.4 Income-generating activities (IGA)

Clients were asked about how their care and support at home could be improved. The most frequently mentioned response (59.5%) was the need for capital to start an IGA, followed by requests for more material assistance (48.1%). The qualitative data from discussions with clients and care-givers also supported these findings. TASO has attempted to address these needs for IGAs with differing levels of success. Some centres (Entebbe, Masaka and Mbale) received funding for income-generating projects, but no clear policy existed on terms of distribution of these funds. Almost all of the requests for funds were met (16 of 16 in Masaka and 9 of 11 in Mbale). The percentage of clients who succeeded in setting up the funded IGA was 81%. At the conclusion 75% of the clients were capable of paying back the loans to the revolving fund; however, only 12% actually repaid the loan. Clients perceived the funds as either loans to be paid back to the revolving fund or as grants. This partly explains why some clients, though capable of paying back, were reluctant to do so. Some of the funding went to individual client projects in some centres (Masaka and Mbale), while in other centres (Entebbe), funding went towards a collectively owned project of day centre members. The amounts, whether grants or loans, were relatively small and were mainly projects related to agriculture. There was low overall performance of IGAs, mainly as a result of
low start-up capital, inadequate supervision and lack of a clear policy towards funding of the projects.

Do income-generating activities funded by TASO promote self-reliance among clients?

Summary

Almost 60% of sampled clients identified the need for capital to start IGAs. There was low over-all performance of IGAs in promoting self-reliance, mainly as a result of low start-up capital, lack of adequate supervision and a lack of a clear policy towards funding of projects. As a result only 12% of clients repaid the loan, although 81% did succeed in setting up their project.

Recommendation

TASO should carefully re-consider options (through a two-year pilot study in selected areas) for providing jobs and IGAs for PWAs, looking at management by TASO, health of clients, involvement of families, sustainability, feasibility and other resources in the community. The result of such a study should be used to establish policies on IGAs.

6.5 Needy children of clients

An additional stress for clients in coping with their situation was if their children were unable to continue with schooling due to lack of school fees. Hence an expectation of clients on joining TASO was to receive support towards the education of their children. Some clients received material assistance from other organizations in addition to those offered by TASO. A total of 8.4% of clients expected support for school fees. In addition, 25.4% of the clients reported that their care and support could be improved at home through provision of school fees to their children.

From TASO’s records, 1057 children (of clients) were assessed as needy in April 1992. Of these, 370 (35%) currently receive school fees and TASO intends to cover the fees until they attain seven years of education. The distribution of children currently benefitting from the educational scheme is shown in Figure 32. No additional assistance has been provided due to limited funds, although the numbers of those in need have continued to increase.
Figure 32: The TASO child support scheme (n=370)

Given the present funding level to the Child Support Scheme, TASO does not have the capacity to cope with the increasing numbers of needy children. Since the evaluation, Jinja has also started a child support scheme.

**Do clients’ needy children benefit from the educational support provided by TASO?**

**Summary**

Currently 370 out of 1057 children assessed as needy receive school fees. No additional needy children have received this assistance since April 1992 due to limited funds, although the numbers of needy children are increasing.

**Recommendation:**

- Explore options for referral of needy children to other organizations, e.g. for school fees.

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MONITORING SERVICES

A n objective of the participatory evaluation was to design a monitoring and evaluation system for TASO services.

The evaluation found that data collection forms in the seven centres were not uniform. In addition, there were many different forms some of which duplicated information. There were also inconsistencies within and between centres in completion of forms. Staff were spending considerable time completing these forms. Staff comments on records kept by the organization included:

"Forms keep on changing".
"...too much filling of forms".
"...tend to concentrate on reports and records to meet deadlines, therefore new clients are not attended to quickly".

An attempt was made to streamline these forms by carrying out a review and redesign of the forms in line with identified indicators to be monitored.

Examples of possible indicators for ongoing monitoring are:

Counselling

• Centre client attendance for counselling
• Number of home visits for counselling
• Number of counselling sessions per counsellor
• Number of condoms distributed

Medical

• Centre client attendance for medical services
• Number of home consultations for medical care
• Number of medical home visits per clinician
• Percentage of medicines available according to standard drug list
Social Support

- Client attendance at day centre

The steps for monitoring will be as follows:

- The staff will continue filling relevant forms as they provide daily services.
- TASO centre managers will organise and collect forms monthly.
- At the end of the month the consolidated data from the various centres will be submitted to the services department data office where it will be analysed, and trends will be generated. Results will be copied to respective centres and the HQ Executive Committee.
- Feedback of this data will appear as a regular agenda item at the Centre Management Committee meetings, the HQ Executive Committee and the Board of Trustees.
- Relevant information will be shared periodically with the Centre Executive Committee and with donors and others. (Figure 33)

Recommendations

- All centre staff should be trained in the completion of monitoring forms developed as a result of the evaluation and funds should be allocated for monitoring activities.
- A system should be devised to ensure the active participation of local Centre Executive Committees in centre level decision-making and monitoring of centre performances.
- Ongoing monitoring of selected indicators should be used to identify problems and develop solutions for implementation on a monthly basis.
- Other indicators should be developed for periodic use in measuring, e.g. sexual behaviour, revealing serostatus, making wills etc. Cost analysis of TASO services should also be conducted.
- A major evaluation of TASO services should be carried out every three years, using the present evaluation study as a baseline.
Figure 33
TASO Monitoring System

TASO Centre Staff fill in forms

Centre Management Committee Meeting

Centre Executive Committee → TASO Centre Manager collects forms from supervisor → HQ Service Department Data Office collects forms from centre manager and analyses and sends feedback

HQ Executive Committee

Donors Public and Other AIDS-related Organizations → Board of Trustees

Daily
Monthly
Monthly
Monthly
Quarterly

--- Feedback
CONCLUSIONS

TASO has demonstrated that people and their families are able to live positively with HIV/AIDS. Through counselling, medical care and material support to clients and their families, TASO has affected change in people’s attitudes, knowledge and lifestyles. In particular, TASO has demonstrated a strong capacity to overcome four problems that haunt AIDS care in most places: 1) revealing one’s HIV-serostatus to relevant others; 2) family and community acceptance of PWAs; 3) seeking early treatment; and 4) combining prevention and care.

A time has come for the organization to take the next step in its growth - to actively facilitate outreach to families, care-givers and communities in order to build their capacity for the care of PWAs, for example, by inspiring confidence in communities that they have the needed resources for living with PWAs and by training community representatives in various skills for transference back to the community level.

PWAs have lived positively with intensive TASO support. The test will be whether PWAs can also live positively within their own communities.

THE STRUGGLE CONTINUES.............
Appendix 1

Case Study 1 - His serostatus is not a secret
James Sekanyabo

James is a soft spoken man of 48. His ready smile, while revealing missing front teeth, betrays the burdens under which he lives. A man of strong faith (Seventh Day Adventist) he is the breadwinner, and the central pillar of strength for his household of 13 members.

The home sits in the middle of a cleanly swept compound shared with a few goats and chickens and surrounded by his carefully cultivated matooke and eucalyptus. Inside, the house is decorated with care and imagination. Typical Bahima geometric designs are complemented by mats and handicrafts made by his wife, Edith. Prayer books hold a place of honour on the table.

The days are full for James and his family. James arise in the dark of 6:00, wakes the 2 children who have to walk to school and then goes out to milk the 6 cows which he looks after. Milking done, he portions out enough for the family and, riding his bicycle, takes the rest to sell to regular customers at a marketplace 4 miles from home. With a bit of money in his pocket, he may stop to buy seeds or tools or other necessities for his vegetable garden and then cycle another 4 miles home. Now he must advise and supervise other members of the family who spend the day working in the garden - which is the primary food source for all of them. At this season of the year, they grow beans, millet and matooke. James admits to often needing a short rest at midday - and in this way, shyly acknowledges that HIV infection sometimes restricts his energy and his ambition.

Later in the afternoon, James is up and out and helping the younger boys look after cows. He milks them again and secures them in the kraal.

Then, family time. Before supper the entire family gathers for prayers. Night gathers, supper is enjoyed and sleep ends a full day.

The equanimity with which James and his family co-exist with the presence of HIV infection did not come easily. Nor does their accepting of HIV mean that life has become easy. Although holding off debilitating depression, the family nevertheless suffers anxiety, frustration, occasional poor health, and the worry for the future that is the natural partner of love of one’s children. Despite the hard work and long hours, the family
earns only about 20,000/= per month - hardly enough for soap, salt, sugar, oil, school fees, clothing, and transport for a household of 13 members.

James learned of his serostatus in 1991 - having previously gone through a period of concern and then relief when, after a VDRL test he was given treatment and mistakenly assumed that he need not worry about HIV. This misunderstanding led him to take a new wife who has since given birth to 2 boy babies.

James is a family man. His first wife died in 1980 after nearly 20 years of marriage which produced 4 children. He remarried again in 1982, but there were problems and this second wife left him in 1983 and went to Masaka. She returned in 1985 pregnant and the couple reconciled. She had a difficult pregnancy because she was weak. The baby, born by Cesarean section at the Mbarara hospital, died the same year. The mother died 6 months later in 1986. At no time during his wife's illness was James given any information about the nature of her illness.

James soon found that he was suffering more and more from fever. But having both the fever and syphilis treated, he felt strong again and married for the third time. This wife, Edith, is a smiling and welcoming woman who exudes a warm and gracious hospitality.

James learned of his HIV status only later when he donated blood for his brother who was to undergo surgery. When the process of screening blood was explained to him, he said that he would most definitely like to be told the results of the screening. Two weeks later, when his wife was pregnant with her second child, James was told that he was HIV+.

His face twists in memory of the emotions he experienced. "I was shaking. I was not in my senses. I was sweating. I don't know." The doctor who gave the results finally shook him by the shoulder until James came out of his daze. "Look here, don't mind too much. You're not going to die right now. God decides when it is time. Maybe God has prepared a different death for you." With such words, James calmed down a bit and was referred to TASO. He went immediately.

His most immediate concern was what to tell his wife, Edith. The TASO counsellor recommended waiting for a week - it was not necessary to tell her while he was still adjusting to the news himself. But James, terribly shaken, couldn't bear to be at home keeping the news to himself. He left the counsellor, returned home only to tell his wife that he had to go visit his sister and left for a trip to Mubende. There he greeted his sister with the words, "Yes, I've come here ... but I've come to die." Brother and sister shared tears and tried to console each other. After two days, James, driven by his need to talk to his wife, departed. Arriving home, he was consumed by his worry about his health, his family's future, his wife's future, the health of the baby she carried. He made a decision to tell Edith. A few days later, as she served lunch, James began to discuss things from the Bible. "All things have a beginning and an end," he started. Then putting the Bible aside, he told his wife what he had learned at the blood bank and TASO.

Now, looking up for the first time since he started this part of his story, he grins and says, "We didn't even eat the lunch she had prepared." Less than a week since James had learned his serostatus, he found himself in the role of a counsellor - talking quietly to his wife, giving her information and support.

Both James and his wife needed more help to understand what was happening to their lives. They went to TASO and observed that there were many other people apparently living and coping with HIV. They vowed that they would also cope. They could not let their people down. But they would need help. They needed long-term emotional support and encouragement and someone to listen and understand. They needed TASO counselling.

At this point, 3 years later, they are seeing their counsellor regularly - at least once a month, either at the TASO centre or in their home. And, although they are coping just as they vowed they would do, they clearly acknowledge their continuing need for the contact and sustenance they receive from their association with the TASO counsellor. (James sees the counsellor more often, because he rides a bicycle into the TASO centre. Edith, with 2 young children finds it more difficult to get into town. Thus, James continues his information-giving and counselling role with Edith after he returns from the TASO centre).
The process of TASO counselling has covered a wide range of needs and concerns. For example, the counsellor helped them break the news to the children and then later talked to the children about sex and AIDS. Condom use, another difficult issue, was also thoroughly discussed with the counsellor. Condoms are now an accepted and normal part of their lives and James articulates clearly their importance in preventing both pregnancy and reinfection.

James is equally comfortable about his decision to make a will - which was a new idea presented to him in counselling. He is pleased that planning for the future is an on-going part of his relationship with the counsellor. Such planning has included rethinking which children should be sent to school; having one daughter study tailoring so that she will have a source of income; selling 2 cows in order to buy metal roofing and make the house stronger; starting an Eucalyptus plantation in order to have another source of income; bringing his sister from Mubende to live with the family and including her in his will so that she will receive 1/3 of his land and thus stay in the village and look after the children. His counsellor has given him support for all of these ideas.

Basic home care techniques are also part of the legacy of TASO counselling. Last year when Edith was ill, James had the skills and knowledge to care for her first at home and then later during her hospital stay. Presently, the sister from Mubende, who also talks with the counsellor on home visits, is hoping to learn home care skills.

James has not kept his sero-status a secret. Because he himself had always been curious to see what an infected person looked like, he assumed that his neighbours harboured the same curiosity. Thus, he offered himself as an "exhibit" and educator to the village. People reacted with denial, but he insisted that yes, the virus had even come to him. He smiles in remembrance. "More and more, people aren't curious to only look. People want to know how to prevent HIV infection. They want to know more about AIDS."

James has become both an informal AIDS educator and counsellor in the village. He has encouraged several people to go for an HIV antibody test; he has taken others to TASO; he has explained the benefits of positive living; he has disarmed prejudice and vanquished stigma. James and his family want to break the cycle of fear and hiding that has given rise to the many ugly myths about HIV/AIDS. Thus, TASO benefits are spreading through clients such as James and Edith to the wider community in which we all live.

James’ energy is divided among his family, his neighbours and his fellow clients at TASO. As chairman of the client’s association, he goes to the counselling centre regularly and talks with, teaches and prays with waiting clients. He has been active in encouraging income-generating activities; he has helped write and act in a drama that has toured some villages; he has volunteered to do AIDS education in nearby schools; he has mobilized the people of his village and invited TASO staff to visit and discuss HIV/AIDS. In order to do these jobs, he has resigned from his position as Parish Chief and has rejected the community’s efforts to make him defense secretary. He only has enough energy to take on those tasks which he feels are most important.

His health is a concern and James watches it carefully. "Once a person has had counselling, he knows when to get treatment. And TASO assists with medicine." However, since the TASO clinic is only available 2 times a week, he has purchased some drugs from the chemist to have on hand for "an emergency." He does not see any other medical practitioner because he has complete confidence in the advice and treatment he receives at TASO.

Both James and Edith, as registered clients, receive material support from TASO each month. The food (rice, oil, and milk powder) makes possible a much more nutritious diet for their large household, they say. Nevertheless, both agree that even without such support, they would remain active TASO clients. The value they receive from TASO cannot be attributed to merely the material.
Kika is a 35 year old widow with 5 children who lives in the outskirts of Kampala. At present, only the eldest and the youngest children live with her - the others are in her mother's village about 15 miles away. Kika tries to visit them each month.

Living with Kika are her youngest, Aida, a 3 year old who is beginning to suffer from fevers and diarrhoea; and her oldest, Joseph who is a first year secondary school student. Also, her sister Rita and her infant share the house. A maternal aunt lives nearby and visits regularly.

Kika is a tall, straight and beautiful woman who admits only to an occasional headache or fever and tiredness. Grateful as she is for her good health, she nevertheless has great concerns. Chief among them is her young daughter who plays nearby as we talk. When she wanders over for a hug and then crawls onto Kika's lap for a short nap, love and worry transform Kika's face and the discussion changes course. The confident face transforms into that of a pensive and frustrated mother. She is, she now relates, simply desperate for work and money that will provide a future for the children. "I don't mind dying. Everyone dies. But I want to work. I have ideas for work. I have land. I can grow flowers to sell in the market, but I need money for seeds and to hire someone to dig the land." Holding her head and staring at the sleeping child in her lap, she again reiterates, "I don't worry for myself. I am free. It is for my children. Joseph needs books and shoes for school." This idea of work and what she is capable of doing returns again and again in her conversation.

Kika's husband died in 1990 of what she suspected was AIDS although she says that she really knew very little about the disease at that time. Soon thereafter her in-laws forced her out of their Entebbe road house and she was "re-trenched" from her job as a prison warden. She returned to Maganjo to her late father's house and land. Although the house is large and there are 3 acres of land, she, as a new widow, could not support all the children. Her mother took the middle children - 2 boys and a girl who are all now in primary school, years 4, 6 and 7. Soon the baby, Aida began suffering from fever and Kika took her to Mulago for a check-up. When the baby was pronounced HIV+, Kika was referred to the TASO clinic. She went only in the hope of obtaining medicine that would help Aida, but also found caring people who have helped her through the many difficult times of the past few years.
The financial burden of widowhood, an infant beginning to suffer, the loss of her job, and the knowledge of her own serostatus, dropped Kika into depression. She sat at home for a year. "I lost hope. I thought I would die. I didn't care."

Steady TASO counselling helped her regain the inner strengths that had sustained her in the past. Through counselling, she came to understand the course of HIV infection and eventually she began to focus on how to live. It was at this juncture that the need to be productive, to work, to support her children, to use her talents, became her number one concern. With the encouragement of her counsellor, she made plans for income generation. A first attempt at brick-making was not successful, but her current idea of growing flowers for sale in the market is beginning to take off. In neatly planted flower beds, the first healthy blooms are apparent. Nevertheless, because this plan has not yet fully succeeded, the specter of low income still haunts her. "If I have a little business, I don't fear. If I have a job I am not thinking, what will happen to my children? I want to buy clothes and books for them. If I have a job there is no problem."

She sees her counsellor about once each month - either at the TASO center or sometimes on home visits. She credits him with helping her think through possible income-generating schemes and giving her the confidences to actually begin. She gains more peace of mind with each counselling session. "After we talk, I feel free of worry."

When the counsellor makes home visits he arrives in a TASO vehicle, but Kika says that people in the area are not concerned and no one has shown any signs of fear or prejudice. Nevertheless, Kika has decided not to tell her family - mother and children about her serostatus. (She acknowledges that her mother may indeed know, but it is highly unlikely that they will ever discuss it). She sees no reason to burden others with her potential health problems. She has discussed her serostatus with only two of her sisters who reacted with strong and absolute denial at first and only reluctantly finally believed Kika. Now they are supportive and understanding and Kika knows that they will be with her if she needs them. The counsellor talks with Rita on his home visits and has helped her understand the situation and her important role in it. Even though the two sisters know Kika's serostatus, it is rarely discussed. It is a topic of conversation, only with her TASO counsellor and with one woman friend whom she met at the TASO clinic.

Occasionally, Kika and this woman meet and share food and talk. Kika says this is the only person who is really a friend and the only person (other than her counsellor) with whom she talks about her problems - HIV as well as economic problems. In a telling sign of her need to share, for the first and only time during the conversation, tears cloud Kika's eyes and she asks to stop.

Kika states that she has not played sex since her husband died. She knows about safe sex and condoms but says she doesn't need them since she doesn't play sex. She firmly states that she does not need a man to support her, she only needs a job. Condoms are not the answer for her. A job is!

She attributes some major behaviour changes to TASO. These are in the area of positive living which she describes in mostly dietary terms - greens, milk, no alcohol. She smiles when she talks about the days before HIV when she used to drink a lot of beer and whisky and eat whatever she felt like regardless of its nutritional value. She also understands the need to "not worry" and "be patient."

Kika does not have a will and although she understands the reason for one, she "doesn't have the heart for it." Working for the future has her full attention at this point - and that means a job, not a will. When pushed, Kika says that probably her sister Catherine will take the children since she has only 4 of her own.

Kika is happy to receive some material support from TASO in the form of 5 kg of rice and 1 litre of cooking oil each month. It appears that although this is welcome, it is certainly not the incentive that brings her to TASO. With or without such material aid, she would want to stay in touch with her counsellor and also seek medical reassurance for her headaches and occasional fevers. At this point, Kika says she does not have the time or interest to be involved with the TASO Day Centre. Yet, her attachment to her "TASO friend" makes evident her need for a sharing companionship.

Similarly, Kika has not yet had much need for use of the TASO medical services. However, she has always been pleased and grateful for the medical attention which she does receive and believes that the 300/= which is charged for a medical appointment and drugs is appropriate.
Kika, her son and daughter and her sister Rita and baby live in their late father's large house. The house, with concrete floor and iron roof, and numerous electrical outlets (but currently no electricity because of its expense) is large enough that rooms are rented out to 4 families. This income, plus the small market stall in front of the house (greens, sweet potato, cabbage, tomatoes which Kika buys early each day from a larger market nearby) plus the sale of the first few flowers, brings in about 30,000/= per month. Such financial constraints mean that there is little room for extras - whether that be an extra exercise book for student Joseph, a sweater for baby Aida, or an afternoon of companionship and food with Kika's friend from TASO.

Nevertheless Kika, often with help from her counsellor, is rising above these stark facts of her life. Her conversation reveals that the basis for this growing ability to manage lies in her confidence that TASO cares - that TASO understands and that TASO has and will continue to be there when she needs its strength.
Appendix 3

Map of Uganda
TASO Centres
Appendix 4

ORGANIZATIONAL STRUCTURE OF TASO SERVICE CENTRE

EXECUTIVE COMMITTEE

MANAGER

MEDICAL
ADMINISTRATION
COUNSELLING
DAY CENTRE
TASO COMMUNITY INITIATIVE (TCI)
Appendix 5

TASO HQ TCI ORGANIZATIONAL STRUCTURE

TASO HQ

TASO Centre

Community Initiatives

Social Support

Medical

Counselling

Village Committee

Community Workers

Education/Prevention Information

Condom Distribution

Referrals

Home Care
Appendix 6
Partners and Supporters of TASO

Major Donors

Donors who together contribute more than 30% of the TASO annual core budget:

ActionAid, UK
Australia International Development Agency Bureau (AIDAB)
DANIDA, Danish International Development Agency
Overseas Development Administration (ODA)
USAID, United States Agency for International Development through World Learning Inc.

Other Donors

Donors who have funded specific activities and together contribute less than 30% of the annual core budget:

Canadian Fund through Canadian High Commission
Care International
Catholic Fund for Overseas Development (CAFOD)
Comic Relief, UK
DanChurchAid
Food for the Hungry
Friends of TASO, UK
Germany Emergency Doctors (GED)
InterAid
Japanese Embassy
Jersey Overseas Aid Committee (JOAC)
Johns Hopkins University (JHU)
Quaker Services
Redd Barna
Soroptimist International
Swedish International Development Agency (SIDA)
UNICEF, United Nations Childrens Fund
World Food Programme (WPP)
World Health Organization (WHO)

Corporate Members

ActionAid, U
Associated Consulting Engineers
ESSO Standard (U) Ltd
Kakira Sugar Works
Magric (U) Ltd
Mukwano Industries Ltd
President’s Office
Total (U) Ltd
Uganda Travel Bureau
UNICEF (Uganda)
VSO (Uganda), Voluntary Services Overseas
Walusimbi’s Garage
World Learning (Inc)
Estimated TASO Core Income per Client

TASO Five Year Budget
Showing Funding Position

* Red purchasing power of the dollar per client income in constant 1991/1992 terms
Appendix 7
Key evaluation questions, indicators, data sources and collection

1) Objective for counselling services:

To develop mechanisms to enable clients and families to cope with emotional problems related to infection/disease

<table>
<thead>
<tr>
<th>Key evaluation questions</th>
<th>Indicator</th>
<th>Data collection method</th>
<th>Data source and size</th>
<th>Data collector</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are TASO counselling services helping clients and their families to cope with HIV/AIDS?</td>
<td>- Trends in attendance for counselling</td>
<td>- Content analysis of TASO counselling records</td>
<td>- Records at 7 TASO centres</td>
<td>- TASO Core evaluation team</td>
</tr>
<tr>
<td></td>
<td>- Percentage of clients reporting that they discussed their sero status with spouse, family</td>
<td>- Interview clients (client questionnaire nos. 21, 22, 23)</td>
<td>)</td>
<td>)</td>
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<tr>
<td></td>
<td>- Percentage of clients reporting being cared for by family members</td>
<td>- Interview clients (client questionnaire nos. 38, 39, 40, 41, 42, 43)</td>
<td>)</td>
<td>)</td>
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<tr>
<td></td>
<td>- Percentage of counselling sessions observed during which coping with infection/disease was discussed</td>
<td>- Observation of counselling sessions</td>
<td>- Survey of clients</td>
<td>- Survey of clients</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>- Attenders = 358</td>
<td>- Counsellors/ counsellor supervisors</td>
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<td></td>
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<td></td>
<td>- Home visited = 298</td>
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<td></td>
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<td></td>
<td>- Counsellors/clients/ caregivers (three sessions per centre)</td>
<td>- Counsellor supervisors from different TASO centres</td>
</tr>
</tbody>
</table>
Key evaluation questions, indicators, data sources and collection

2) Objective for counselling services:

To promote safer sex practices of clients and their partners in order to reduce the risk of transmission of HIV infection

<table>
<thead>
<tr>
<th>Key evaluation questions</th>
<th>Indicator</th>
<th>Data collection method</th>
<th>Data source and size</th>
<th>Data collector</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are TASO counselling</td>
<td>- Percentage of clients reporting sexual abstinence</td>
<td>- Interview clients</td>
<td>- Survey of clients</td>
<td>- Survey of clients by counsellors/ counsellor supervisors; case studies by TASO Core Evaluation Team</td>
</tr>
<tr>
<td>services helping to promote safer sex practices among clients and their families?</td>
<td>reporting sexual activity with steady partner only</td>
<td>(client questionnaire No. 18); case studies</td>
<td>(attenders = 358, home visited = 298); client case studies, 10 per centre</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Percentage of clients reporting consistent use of condoms with all partners/spouses</td>
<td>- Interview clients (client questionnaire nos. 13, 24, 25, 26); case studies</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>- Number of condoms distributed</td>
<td>- Content analysis of TASO records</td>
<td>- Condom distribution records</td>
<td>- TASO Core Evaluation Team</td>
</tr>
<tr>
<td></td>
<td>- Percentage of counselling sessions observed during</td>
<td>- Observation of</td>
<td>- Counsellors/clients/ caregivers (three counselling sessions</td>
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<tr>
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<td>which safer sex practices were discussed.</td>
<td>counselling sessions</td>
<td>sessions per centre)</td>
<td>- Counsellor supervisors from different TASO centres</td>
</tr>
</tbody>
</table>
Key evaluation questions, indicators, data sources and collection

3) Objective for counselling services:

To help clients and their families plan for the present and future

<table>
<thead>
<tr>
<th>Key evaluation questions</th>
<th>Indicator</th>
<th>Data collection method</th>
<th>Data source and size</th>
<th>Data collector</th>
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</thead>
<tbody>
<tr>
<td>Do TASO counselling services enable clients to formulate strategies for the present and future?</td>
<td>- Percentage of clients reporting making realistic plans for self, children and other dependents</td>
<td>- Interview clients (client questionnaire nos. 47, 48)</td>
<td>- Survey of client (Attenders = 358, Home visited = 298)</td>
<td>- TASO Core Evaluation Team</td>
</tr>
<tr>
<td></td>
<td>- percentage of clients reporting making wills</td>
<td>- Interview clients (client questionnaire nos. 44, 45, 46)</td>
<td>- Survey of clients (Attenders = 358, home visited = 298)</td>
<td>- Counsellors/counsellor supervisors</td>
</tr>
<tr>
<td></td>
<td>- Percentage of counselling sessions observed during which planning for the present and future is discussed</td>
<td>- Observation of counselling sessions</td>
<td>- Counsellors/clients/caregivers (three sessions per centre)</td>
<td>- Counsellor supervisors from different TASO centres</td>
</tr>
</tbody>
</table>
4) Objective for medical services:

To provide diagnosis and treatment of opportunistic infections

<table>
<thead>
<tr>
<th>Key evaluation questions</th>
<th>Indicator</th>
<th>Data collection method</th>
<th>Data source and size</th>
<th>Data collector</th>
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</thead>
<tbody>
<tr>
<td>Are clients receiving treatment for opportunistic infections, and are they satisfied with treatment received?</td>
<td>- Ratio of caregiver per client and average time spent with each client</td>
<td>- Content analysis of TASO records</td>
<td>- TASO clinic attendance records at 7 centres</td>
<td>- TASO Core Evaluation Team</td>
</tr>
<tr>
<td></td>
<td>- Number of medical home visits</td>
<td>- Content analysis of TASO records</td>
<td>- TASO clinic attendance records at 7 centres</td>
<td>- TASO Core Evaluation Team</td>
</tr>
<tr>
<td></td>
<td>- Availability of drugs and supplies according to standard treatment protocols (what is available, ordered, given, % of client visits that receive all medications as prescribed)</td>
<td>- Content analysis of TASO records</td>
<td>- TASO home visit records at 7 centres; survey of clients (Attendees=358, Home visited=298)</td>
<td>- TASO Core Evaluation Team; counsellors &amp; counsellor supervisors</td>
</tr>
<tr>
<td></td>
<td>- Satisfaction of clients with medical services as indicated in focus group discussions.</td>
<td>- Focus group discussion with clients on satisfaction with services and where else they seek additional medical care</td>
<td>Clients male, female at 7 TASO centres (2 focus groups per centre)</td>
<td>- TASO Core Evaluation Team</td>
</tr>
</tbody>
</table>
Key evaluation questions, indicators, data sources and collection

5) Objective for medical services:

To provide client and family education on HIV/AIDS, medicines, home care and when and where to seek additional help.

<table>
<thead>
<tr>
<th>Key evaluation questions</th>
<th>Indicator</th>
<th>Data collection method</th>
<th>Data source and size</th>
<th>Data collector</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does TASO give sufficient information, education and training to clients and caregivers concerning medications, home care and sources of additional help?</td>
<td>- Percentage of clients reporting that they understood the use of drugs as prescribed (how much, how long, how often)</td>
<td>- Interview clients questionnaire No. 55)</td>
<td>) Client attenders</td>
<td>) Counsellors/counsellor supervisors</td>
</tr>
<tr>
<td></td>
<td>- Percentage of families reporting following instructions for providing home care</td>
<td>- Interview family caregivers (caregivers questionnaire no. 29)</td>
<td>) - Survey of 298 caregivers</td>
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<td></td>
<td>- Percentage of families reporting sources of additional help not offered by TASO</td>
<td>- Interview family caregivers (caregivers questionnaire no. 25)</td>
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</table>
6) Objective for social support services:

To share personal experiences and to gain skills in living with HIV/AIDS

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<tr>
<th>Key evaluation questions</th>
<th>Indicator</th>
<th>Data collection method</th>
<th>Data source and size</th>
<th>Data collector</th>
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</thead>
<tbody>
<tr>
<td>Do PWAs who participate in TASO day centre activities benefit?</td>
<td>- Client attendance at day centres</td>
<td>- Content analysis of TASO records</td>
<td>- TASO day centre attendance records at 7 centres</td>
<td>- TASO Core Evaluation Team</td>
</tr>
<tr>
<td></td>
<td>- % of clients reporting benefits from attending TASO day centre</td>
<td>- Focus group discussions with clients on benefits; interview clients (client questionnaire no. 53)</td>
<td>- Clients male, female at 7 TASO centres (2 focus groups per centre)</td>
<td>- TASO Core Evaluation Team</td>
</tr>
</tbody>
</table>
Key evaluation questions, indicators, data sources and collection

7) Objective for social support services: To promote self-reliance of clients through income-generating activities

<table>
<thead>
<tr>
<th>Key evaluation questions</th>
<th>Indicator</th>
<th>Data collection method</th>
<th>Data source and size</th>
<th>Data collector</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do income generating activities funded by TASO promote self-reliance among clients?</td>
<td>- Percentage of income-generating proposals that receive funding</td>
<td>)</td>
<td>- Content analysis of TASO records</td>
<td>- TASO Core Evaluation Team</td>
</tr>
<tr>
<td></td>
<td>- Percentage of clients who complete the funded income-generating projects</td>
<td>)</td>
<td>- TASO records on income-generating project proposals funded by TASO</td>
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<td>- Percentage of clients with completed income-generating projects capable of paying back to the revolving fund</td>
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<tr>
<td>Key evaluation questions</td>
<td>Indicator</td>
<td>Data collection method</td>
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<tr>
<td>Do PWAs and their families receive material support handouts?</td>
<td>- Percentage of clients receiving some type of material assistance monthly</td>
<td>- Content analysis of TASO records;</td>
<td>- TASO day centre records on type of material assistance received at each of 7 centres</td>
<td>- TASO Core Evaluation Team</td>
</tr>
<tr>
<td>How much does TASO's material handouts meet the needs of PWAs and their families?</td>
<td>- Satisfaction of clients with social support services as indicated in focus group discussions</td>
<td>- Focus groups discussions with clients on satisfaction with services</td>
<td>- Clients male, female at 7 TASO Centres (2 focus groups per centre)</td>
<td>- TASO Core Evaluation Team</td>
</tr>
</tbody>
</table>
### Key evaluation questions, indicators, data sources and collection

9) **Objective for social support services:** To provide educational support to needy children of client

<table>
<thead>
<tr>
<th>Key evaluation questions</th>
<th>Indicator</th>
<th>Data collection method</th>
<th>Data source and size</th>
<th>Data collector</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do clients' needy children benefit from the educational support provided by TASO?</td>
<td>- Percentage of registered needy children of clients receiving educational support, reports on the types of needs met by TASO child sponsorship programme</td>
<td>- Content analysis of TASO records</td>
<td>- TASO records of educational support to registered needy children of clients</td>
<td>- TASO Core Evaluation Team</td>
</tr>
</tbody>
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