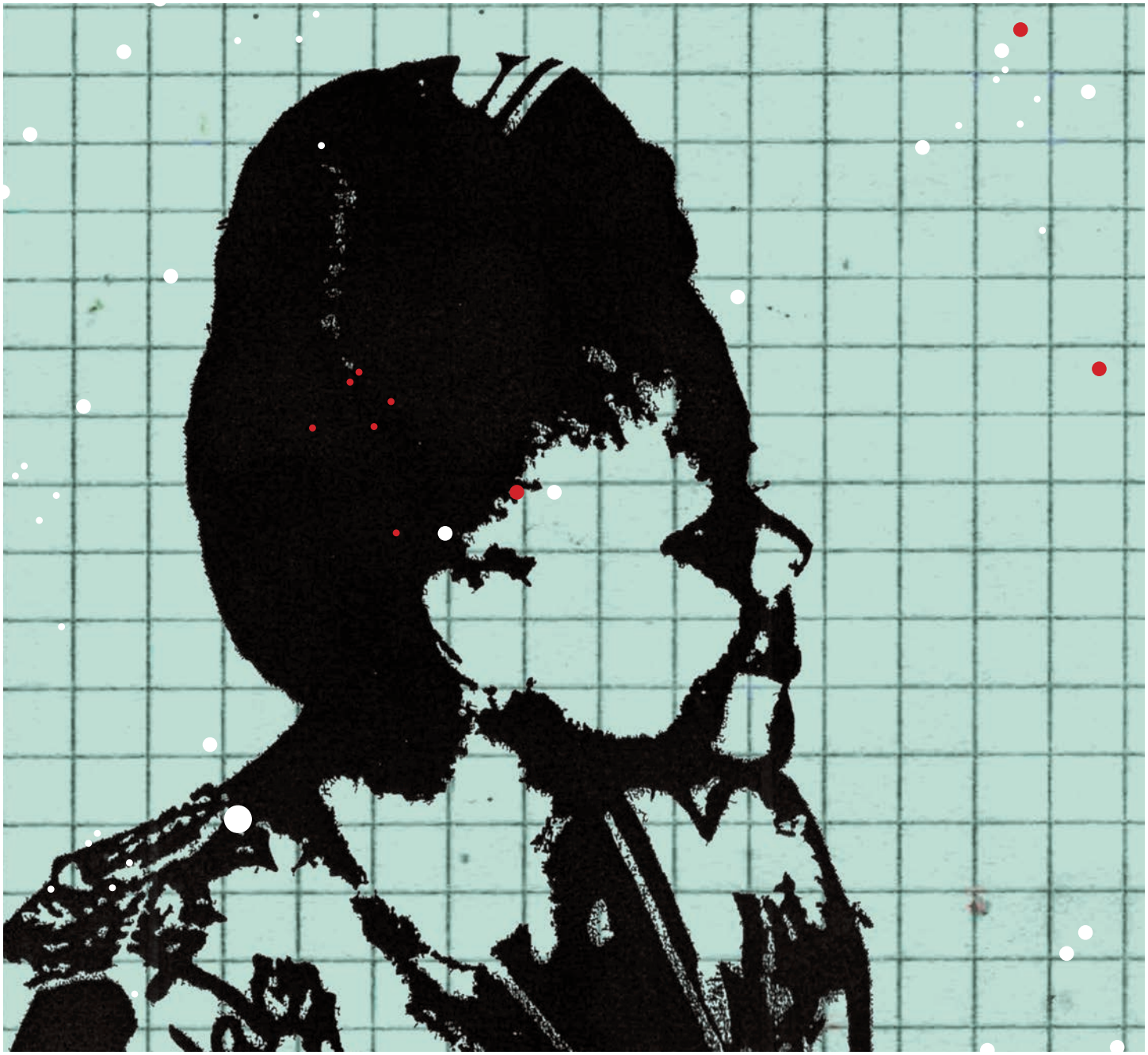
A QUALITATIVE EVALUATION



KIWAKKUKI

Women against AIDS in Kilimanjaro region **TANZANIA**

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Kvinnefronten / Women's Front of Norway

KIWAKKUKI

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KIWAKKUKI

Women against AIDS in Kilimanjaro Region, Tanzania
A qualitative evaluation

By Gro Th. Lie and Ellen Alexandra Lothe
Bergen/Moshi/Oslo, August 2002

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KIWAKKUKI

WOMEN AGAINST AIDS IN KILIMANJARO REGION
TANZANIA


ITEMBA
AFROSA
KIWAKKUKI

"We do not speak so much about 'risk groups' any longer, we know we are all at risk."

Photograph left: Dafrosa Itemba, project co-ordinator of KIWAKKUKI, Moshi.

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Acknowledgements

We, the evaluators, want to extend our warm thanks to all individuals who so generously shared their time and experiences with us during the evaluation mission. We are grateful for all frankness and co-operation, and for all inspiring discussions. Without these we would never have been able to acquire the deep insight into KIWAKKUKI's work and the Kilimanjaro region's serious HIV/AIDS related challenges that we feel we have at this point. The individuals and groups of women that we met, have for many years all been committed to fighting the AIDS epidemic and its impact, and this strong commitment seems to have become a part of their lives. We have been touched and impressed by the zeal with which they go on fighting, and the human warmth, understanding and attachment they show toward all the people they work with. The trustful courage with which they face problems and challenges is admirable. We hope they will find the motivation, inspiration and support necessary to continue this important work.

We also hope that the assessment, as well as the evaluation process, will provide useful insight and be a learning process for KIWAKKUKI as well as for the Women's Front of Norway and FOKUS, Norway.

Gro Th. Lie and Ellen Alexandra Lothe

Executive summary

The background for this evaluation was a request from Norad, through FOKUS to the Women's Front of Norway, to evaluate the work of KIWAKKUKI (Women Against AIDS in Kilimanjaro), a non-governmental women's organisation in Tanzania. KIWAKKUKI has received financial support from the Women's Front of Norway, through FOKUS, since 1998.

The main objective of the planned evaluation mission was to provide qualitative information on the reflections, lived experiences and visions for the future from participants, members and recipients at different levels of KIWAKKUKI's many core activities.

The evaluation mission was carried out in the Kilimanjaro region in Tanzania from May 21st to May 31st 2002 by a team of two independent consultants: Gro Th. Lie, Professor and Director of the Research Centre for Health Promotion (HEMIL), University of Bergen, and Ellen Alexandra Lothe, Lecturer at the Lovisenberg Deaconal University College in Oslo.

The evaluators managed to collect the data as intended. They interviewed individuals and groups, had interactive discussions, participated in several of KIWAKKUKI's daily activities, made field visits to local branches of the organisation, did home visits to patients, and interviewed AIDS orphans supported by KIWAKKUKI.

This report addresses qualitative aspects of KIWAKKUKI's activities, HIV/AIDS related challenges and how these challenges are met, as outlined in the Terms of Reference. The report first aims at contextualising KIWAKKUKI's challenges (chapter 2). The contextualisations are based partly on information from interviews with key informants, partly on the various talks and discussions held during the mission, and also on studies of relevant documents. A description of KIWAKKUKI's many faces and methods of work follows in chapter 3. This description is based on the interviews and interactive discussions with the evaluation participants. In chapter 4 are some further findings acquired during the mission and observations from the field trips to the branches, with special reference to key points in the terms of reference. Conclusions and recommendations are found in chapter 5. The annexes 4 - 10 are meant to give an opportunity for studying some of the rich qualitative information gathered.

The evaluators will conclude that KIWAKKUKI is a strong organisation with clear visions and objectives and with very dedicated members at all levels. The evaluators will, however, make the following recommendations to KIWAKKUKI:

- Admit and permit needs to rest to minimize the risk of burn out.

- Strengthen access to updated AIDS transmission and medication knowledge. This can be done by linking KIWAKKUKI to international networks that might have updated knowledge on AIDS medicine and relevant new research related to prevention and coping.

- Strengthen counselling capacity and relevant counselling skills in talking with women and men about their sexuality.

- HIV Test-kits should be available in the KIWAKKUKI premises.

- Strengthen the knowledge on AIDS orphans' needs and the skills to counsel children. Children's grief processes and reactions to traumatising conditions are often different from those of adults. KIWAKKUKI needs more knowledge on children's basic needs at different age levels and on children's reactions to death and traumatising conditions.

- Intensify the incorporation of PLHA in the organisation.

- Strengthen the network for economic empowerment of financially disadvantaged women.

- Community-based anti-stigma work needs more efforts to develop more supportive and enabling communities. If people living with AIDS realise that they might receive sympathy and supportive reactions from their family and neighbours, it will be easier to come forward as PLHA.

- KIWAKKUKI's idea about a mobile information centre for use in the rural areas should be supported.

- Question Youth Alive's major strategies for HIV prevention.

- Strengthen the emphasis on condom use as a preventive strategy.

- Challenge political leaders and the Government on their views and behaviour with regard to HIV-preventive behaviour and norms for male sexuality.

The recommendations must be interpreted in the context of the overall impression: KIWAKKUKI is an impressive women's organisation which is leading the way in the fight against AIDS.


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1

Introduction

A brief background description of KIWAKKUKI

KIWAKKUKI (Women's Group Against AIDS in Kilimanjaro) is a grassroots initiated organisation in Tanzania. The initiative to form the organisation was taken in 1990, and KIWAKKUKI was officially registered as a Non Governmental Organisation (NGO) in 1995.

Today the organisation, with its 1400 members and 11 employed staff, is a member of the Moshi municipality NGO's Network, AIDS NGOs Networks of Tanzania and East Africa, and collaborates with Tanzania Gender Networking Programme, Kilimanjaro Women Information Exchange and Consultancy Co (KWIECO), the National AIDS control Programme and is supported by the local leaders (government, religious) as well as by the local business community.

KIWAKKUKI operates 8 core programme components and 2 specific projects inside the Programmes. The core programme components include:

- Empowerment and capacity building through members' meetings and various committees, monthly and quarterly meetings that are for experience sharing, activity reporting, planning and monitoring. This also includes annual training seminars to leaders and volunteers on community facilitation skills.

- Information, Education and Communication and BCC through Daily Education sessions at the Moshi AIDS Information Centre, Weekly Community Health Education Outreach programme and production of education materials.

- Counselling and Home based care, through Daily One to One Counselling, Weekly Home visits and Special Needs Care for ailing patients.

- People Living with HIV/AIDS (PLHA) Support through medical and social-economic provisions, monthly meetings at the Centre of Hope where they relax, share experiences, make consultations with their counsellors and discuss income generation.

- Children's and Adolescents' HIV/AIDS and Care Programme through School/ Out of school Youth Health Education, AIDS Orphans' school sponsorship, Children Counselling, social support, and supporting Youth Alive Kilimanjaro Club, which deals with, exchange programme.

- Extending existing services through establishment of KIWAKKUKI grassroots branches in new areas.

- KIWAKKUKI's Strategies of Self-Generated Funds, Sustainability and Members' Savings and Credit Scheme.

- Networking with other organisations whose objectives either are in line or complement with those of KIWAKKUKI's.

The specific projects include:

- AIDS Orphans School Sponsorship

- KIWAKKUKI Home Based Care

BACKGROUND FOR THE EVALUATION MISSION

The background for the evaluation mission was a request from Norad, through FOKUS to the Women's Front of Norway, to evaluate the work being executed by KIWAKKUKI. The organisation has received financial support from 1998 and to date from the Women's Front of Norway through FOKUS, Norway. The funding from the Women's Front of Norway has mainly subsidised the running of the KIWAKKUKI Head Office, sponsored female secondary school AIDS orphans as well as supported grassroots women's activities in the local branches of KIWAKKUKI and activities of Education Team Outreach. The Women's Front of Norway is but one of several donors who support KIWAKKUKI's diverse activities.

The evaluation mission was carried out in the Kilimanjaro region in Tanzania from May 21st to May 31st 2002 by a team of two independent consultants: Gro Th. Lie, Professor and Director of the Research Centre for Health Promotion (HEMIL), University of Bergen, and Ellen Alexandra Lothe, Lecturer at the Lovisenberg Deaconal University College in Oslo. The evaluation team worked together in the Kilimanjaro region to evaluate the KIWAKKUKI for six days on the evaluation objectives, and Lothe continued this work alone for another four days.

Prior to the evaluation mission, Professor Lie and Lothe met in Bergen with Agnete Strøm from the Women's Front, and Mette Moberg from FOKUS, to discuss the Terms of Reference, plan the evaluation, prepare data collection tools, and review background material. The terms of reference was subsequently reviewed by KIWAKKUKI and approved by FOKUS, the Women's Front of Norway and Norad.

OBJECTIVES

The main objective of the planned evaluation mission was to provide qualitative information on the reflections, lived experiences and visions for the future from participants, members and recipients at different levels of KIWAKKUKI's many core activities.

EVALUATION METHOD

The qualitative information gathered during the evaluation mission was explored through interactive interviews and discussions with key informants (Denzin, 1989). The interviews covered key topics listed in the terms of reference (please see Annex 1), but also invited the informants and participants to express their own concerns and reflections, good experiences, ideas and visions for the future, their perspectives on feminism and the empowerment of women, their hopes and aspirations for the coming generations regarding gendered relations, and their views on how KIWAKKUKI can contribute towards a better future.

Key informants were women who are involved in and central to KIWAKKUKI's eight core programme components and the two specific projects (AIDS Orphans School Sponsorship and KIWAKKUKI Home Based Care). Women at all levels of the organisational structure were selected for interviews and interactive discussions, and included representatives of all groups of stakeholders, whether they were defined as 'beneficiaries' (People living with HIV/AIDS PLHA, and families of PLHA), 'Service Providers' (activists, volunteers, paid staff), members of the Education Team, Home Visiting Team, the users of the Centre of Hope, the Committee for Orphans' Identification and Monitoring. Members from the rural branches of KIWAKKUKI were also involved in the evaluation process. Thus, the selection of participants aimed to reflect both the range of KIWAKKUKI's activities, the range of levels of active/passive membership, the range of roles in the decision-making structure (e.g. women in the Management Committee, the Board of Trustees, employed personnel, volunteers, members) the range of rural/urban diversity, and different age groups of KIWAKKUKI members and beneficiaries. KIWAKKUKI stakeholders were called upon to assist in selecting individual and representative evaluation participants from the different core program components

and specific projects. Group discussions and focus groups were also performed in order to obtain insight regarding the visions, impressions and experiences of members of the organisation.

KIWAKKUKI sends annual reports and audited financial accounts to the Women's Front of Norway. These reports contain statistics of activities with brief descriptions. The annual reports also describe planned activities and activities performed, and provide explanations for deviations from planned activities (whether positive or negative). KIWAKKUKI's financial report systems and format for auditing have already been assessed by other evaluators. The annual reports and audited financial accounts are quantitatively oriented in an input–output format, thus fulfilling the requirements that most donor agencies expect from a recipient.

During the 10 days of the evaluation mission, a number of persons and groups were met and interviewed (see Annex 2 for evaluation mission programme and time table for field work, and Annex 3 for list of names of people met and places visited. *It should be noted that names of AIDS patients and AIDS orphans have been anonymised unless the evaluation team knows explicitly that they are public about their situation*). Field trips to selected rural branches gave valuable opportunities to see how the rural branches conduct their meetings, and how they discuss with their members. The evaluation team also met rural branch executive committees and officers as well as representatives of the various respective district governments. These visits gave some insight into the decentralisation process of the KIWAKKUKI and how it works in practice. We also had the pleasure of meeting with the whole group of the Centre of Hope, and participate in the Candlelight service of a local Ward.

The evaluators had the opportunity to collect impressions and reflections from a variety of persons representing the various users' groups and activists connected to KIWAKKUKI. Besides learning about the methodology applied by the organisation, the team also presented the informants with the purpose of the evaluation mission. The timetable for interviews, meetings, visits and discussions was tight. In addition, every opportunity for communication and informal discussions was utilised to discuss relevant matters during breaks, meals and transportation. Valuable information was also gained from studying KIWAKKUKI documents, annual and semi-annual reports, a variety of literature published on the HIV/AIDS situation in the Kilimanjaro Region, plus both research literature and surveillance literature from the National Aids Control Program of Tanzania (see Annex 11).

ABOUT THIS EVALUATION REPORT

In this evaluation report the reader will not find statistics from KIWAKKUKI's activities, economic discussions or organisational models. Information on these issues will be found in other documents (for reference, see Annex 11). This report, however, addresses qualitative aspects of KIWAKKUKI and HIV/AIDS related challenges as outlined in the Terms of Reference (see Annex 1). The report first aims at contextualising KIWAKKUKI's challenges (Chapter 2). The contextualisations are based partly on information from interviews with key informants, partly on the various talks and discussions held during the mission, and also on studies of relevant documents (see Annex 11). Subsequently follows a description of KIWAKKUKI's many faces and methods of work (Chapter 3). This description is based on the interviews and interactive discussions with the evaluation participants. In chapter 4 are some further findings acquired during the mission and observations from the field trips to the branches, with special reference to key points in the Terms of Reference. Conclusions and recommendations are found in chapter 5. The annexes 4 - 10 are meant to give an opportunity for studying some of the rich qualitative information gathered on the impact of KIWAKKUKI on individuals' and groups of people's lives in the Kilimanjaro region of Tanzania.


THAILAND


KIWAKKUKI

2

Contextualising KIWAKKUKI's challenges

Extent of the epidemic and how it is met

"We as women have to set an example so that the men can learn from us: we give aid and support, we help with our own hands. We know it is our duty to do it."

The number of people living with HIV and AIDS has tripled from 1990 to 2000 in Sub-Saharan Africa. The vast majority of HIV infections are caused by unprotected sex between men and women. The proportion of adult women living with the virus has steadily increased. In Sub-Saharan Africa 55 % of the infected were women in 2000. Girls are five times more likely to be infected than boys, according to WHO reports. In Tanzania a total of 11.673 AIDS cases were reported in the year 2000. This adds up to a cumulative total of 130.386 cases since the first AIDS case was diagnosed in Tanzania in 1983. (Many cases are however not reported). The prevalence of HIV-infection among adults is estimated to be 8% in 2000. The Kilimanjaro region is among the hardest hit regions in Tanzania. In the age group 15-24 years females represent 69% of those infected. HIV prevalence among pregnant women varies from 4 % to 44% in different sentinel sites in Tanzania.

The founders of KIWAKKUKI in 1990 first concentrated on giving information on HIV/AIDS, in order to raise awareness of the problem and change people's sexual behaviour. They hoped in this way to be able to contribute to the prevention of the spreading of the AIDS epidemic. The vision they shared was that KIWAKKUKI was going to take responsibility in the Kilimanjaro region and lead the fight against HIV/AIDS. However, in spite of the amount of information given in the Kilimanjaro region in the 1990s, people were still being infected at a horrendous rate. One of the challenges to face is the large geographical area KIWAKKUKI is dealing with, and the poor infrastructure for transportation. As the HIV/AIDS related problems grew, and many more people got AIDS, more people saw the necessity for action. As the epidemic has expanded, the organi-

Photographs left: From a KIWAKKUKI membership meeting in Mowo.

sation has also grown. Challenges regarding the never ending expansion in terms of membership and number of groups, volunteer fatigue accompanied by mixed expectations have therefore also had to be met. Visions, strategies, organisational structure and action plans have also developed in this historical process.

As one of the founders of KIWAKKUKI expressed it: *"We do not discuss so much about our own visions any more, neither about the support we give each other… because all of us have been affected by the epidemic in some way or the other..… We do not speak so much about risk groups any longer, because we know that we are all at risk. So we just give each other support without talking too much about these details… It is a challenge for our Tanzanian government to recognise how deep a problem this epidemic is, and that it is a problem for everyone in our nation, not only the infected… and then to fight against it. We as women have to set an example so that the men can learn from us: we give aid and support; we help with our own hands. We know it is our duty to do it"* (see Annex 4).

Thus, KIWAKKUKI faces today many challenges. Intensive work is done to meet these challenges, at different levels and from different points of departure. Tanzania is divided into regions. Each region is divided into districts. And each district is divided into wards. Wards are divided into ten-cells, which in theory each consist of 10 households. KIWAKKUKI has seen that the epidemic has impact at all of these entities - family, community and at national levels. Social, cultural and economic factors play their parts in the spreading of the virus. As a consequence of the impact of the epidemic, the cultural rites concerning burying and mourning in Tanzania are changing. Traditionally the mourning period stretches out over several days. The religious leaders have suggested that the mourning process should now be cut down to one day only, so as not to have too many days for mourning per death (see Annex 4). The cultural challenges deal with the position of women in this part of Tanzania, heritance laws and traditions regarding wives and children. The decision-making within family and community has changed in this AIDS era, and this also represents a challenge to the KIWAKKUKI work. The material and economical poverty in the area increases the need for care on many levels, both for the AIDS-patients and for the AIDS orphans.

Young men and women, and children with HIV/AIDS, have to face symptoms of the disease, terminal illness and death among age groups that are normally not linked with these phases of life. This burden can be even heavier to carry because the child or youth might experience the culture of silence surrounding these issues and thus feel that he or she cannot talk with anyone about them.

Challenges related to gender issues

"Whenever the long distance commuting husband comes home to visit, which might be once a month, or very often only once a year, then the wife is in no position to say 'No' to having sexual relations with him. So women are like a dustbin to carry on this burden of HIV/AIDS."

KIWAKKUKI, being a women's organisation, views HIV/AIDS in a gender perspective, and makes an effort to analyse factors that influence the lives of Tanzanian women today.

WOMEN'S STRIVE TOWARDS EMPOWERMENT REGARDING THEIR OWN SEXUALITY

"Therefore it is high time we empower these women to be strong enough to say 'NO' to their husbands."

One of the core problems related to HIV/AIDS has to do with family life and sexuality. There is therefore a need for openness on these issues. KIWAKKUKI feels that people ought to be able to discuss sexuality and has done important work in this respect. The organisation has focused on giving sex education at all levels in society. Especially there has been a focus on the importance of training teachers and health personnel. Assertiveness and empowerment of women have particularly been in focus, and KIWAKKUKI has worked towards having these aspects included in sex education and HIV/AIDS information for girls.

Women in Tanzania do not traditionally have power and control over their own sexuality. This is still true for many Tanzanian women today. However, the various impacts of the HIV/AIDS epidemic have actually seemed to have a paradoxical, positive effect on women's process toward empowerment in the region. Initially the women were quiet, silent and submissive, without experience in standing up for their own rights. Today they are more open about sex related issues, HIV/AIDS transmission, they volunteer to do home visiting to AIDS patients, they perform role-plays and help communities to make informed decisions regarding safe sex and prevention of HIV transmission. Women living with AIDS are more active today than before in giving testimonies, advocating for voluntary counselling and testing, and encouraging positive living. KIWAKKUKI provides examples of women taking command over this important aspect of their lives and bodies. These stories help give a more nuanced picture of women's sexuality (see Annex 7). However, the topic of women's sexual life is still covered with taboos. This is why it appears important to problematise it. If women are able to talk about this part of their lives, they might also improve their capacity to support each other.

Adult women often ask KIWAKKUKI members: *"What do we tell our husbands when they come back home after 10 months away for work? They bring presents, and want sex, although we know they have had girlfriends in these other cities. Husbands are rude, they want to be obeyed."* KIWAKKUKI members teach these women different methods in which they can talk with their husbands, and emphasise the importance of openness.

Women who are active as health professionals and counsellors at KIWAKKUKI some times have to counsel young women who "ought to" have been virgins, but are found to be HIV positive. Some times they must also counsel older women, of 50 years plus, who are not "supposed to" have sex, and are found to be HIV positive. This is a challenge for the KIWAKKUKI counsellors. Another challenge is to counsel a couple where it appears that the husband is HIV positive while his wife is negative. The wife is often willing to stay with her husband in these cases, and to nurse him whenever he gets sick, provided he consents to wearing condoms when they are having sex. A bigger challenge is often, however, how to counsel in a situation where the wife is the HIV positive one in the matrimony, and to try to make the husband stay with his wife under those conditions.

According to KIWAKKUKI counsellors, women often do not know their rights, so the counsellors have to teach them how to be assertive and stand up against their husbands. The women who come for counselling say that their biggest problem is that they are not able to say *"NO"* to having sex with their husbands. So a big challenge for KIWAKKUKI is to find a way of maintaining peace in the families and at the same time to work on the gender issues. The objective of KIWAKKUKI is that the women must be empowered in this matter that is so crucial to their lives. *"This is not the time for being shy!!"* as one counsellor put it. Being able to say *"NO"* to sex is related to the degree of the women's economic independence. This is why it becomes even more important to assist women in being able to have income so they can be able to live on their own. *"We cannot force men to change, it is difficult. However, if all the women can say 'NO', then all the men would run off to the forest and be ashamed, and hide their faces,"* says one woman. One of the counsellors put it this way: *"The husbands in our society and in our culture use their wives as their tools of some sort, and believe that they can do whatever they like with their wives. It is a challenge for us to try to change this attitude."*

Within the Tanzanian society there are common attitudes about gender differences and an acceptance of double standards for men and women when it comes to sex. This double standard tends to normalise, or excuse, the men who seek new partners without committing themselves to safety in sex. Alcohol and drugs are also more commonly used for men than for women, and increase sexual risk behaviour. Some men also mistakenly believe that having sex with a virgin can cure HIV. In the Kilimanjaro region there is no organisation for men as of yet

which approaches this theme, but in KIWAKKUKI, in the churches and in some local workplaces, men's sexual behaviour is being addressed.

KIWAKUKKI invites church and mosque congregations to send young couples to the organisation for pre-marriage counselling well in time before the engagement is being announced publicly and wedding plans finalized. The couples who do come, mostly do it when the wedding date is already fixed and is due to take place in two-three weeks time. However, the couples most often do not want to come for pre-marriage testing at all. Instead, they come when the wife has become pregnant. *"By then,"* says one counsellor, *"by then there is nothing that can be done except to marry them or bless them."* At the KCMC hospital some pregnant women who are tested HIV positive come back later for counselling with their husbands, but the majority do not come back with their husbands. However, if the pregnant woman is tested negative, her husband gladly comes for testing.

One experienced counsellor says: *"Many young men who work in far away regions bring lots of money back to this region whenever they come home for a visit. They are able to pay a big dowry for the girl they want. The wedding is then often settled in a hurry, before the young man has to go away again for his work. Ten months later the couple comes to our office with a baby, and the young mother is tested HIV positive. This is a problem we face often"* (see Annex 7).

The KIWAKKUKI counsellors wish to counsel spouses and sexual partners to be open to each other, able and willing to discuss even delicate matters and taboos. They feel it is also so important to be open about having been infected, and be able to admit faults to each other, and understand each other.

SOCIAL, CULTURAL AND RELIGIOUS BARRIERS

There are social and cultural barriers to overcome. In some village meetings in the rural areas the men say they want their women to be circumcised, so that their sex desire will diminish and they will remain faithful to their husbands. In some areas in the region it is actually considered outcast for a woman not to be circumcised. She will not even be allowed to serve her father-in-law food if she is not circumcised.

There are quite different rules for men and women regarding sexual life and behaviour. Men often say that they want to use condoms in order not to be infected by the HIV virus, but, *"…my wife must be faithful."* Abstinence is demanded from her. The men feel that it is quite OK to have sex outside their marriage, and act accordingly. But they demand full obedience and faithfulness from their wives. *"So we have a long way to go",* as the KIWAKKUKI Executive Coordinator puts it.

If people believe or suspect that a person is HIV positive, they often believe that witchcraft is behind it and they will invest a lot of resources on witchdoctors who will give them certain answers. HIV/AIDS is a spirit, which can be removed

with witchcraft. Religious doctrines can say that if you pray a lot, you will not have to go to the hospital, take medicine etc.

A 17-year old HIV positive AIDS orphan living in a foster home completed Standard 7 last year. A teacher in her school believed in prayer, and carried the young girl from her foster home to another place where she told her: *"Don't take medicines, just pray."* KIWAKKUKI people were finally able to trace her, and told her that if she wanted to study more, KIWAKKUKI would provide the resources for her. She said, *"I will have to ask God"*, and finally declined both the school offer and other presents. In the end KIWAKKUKI asked the police for help in order to stress the seriousness of depriving the girl of help. The girl agreed to come to KIWAKKUKI, and came back to her foster parents.

MEN AND SEXUALITY

"A man, however, believes that if he does not have sex every day, he becomes weak and soft and loses his virility. So he must have sex every day in order to be strong. In Kilimanjaro, where many men have work outside the region, this has proven to be quite serious."

Men's attitudes to sex are obstacles for safe sex. KIWAKKUKI works on how to overcome such obstacles. A man believes that if he does not have sex every day, he becomes weak and soft and loses his virility. So he must have sex every day in order to be strong. In Kilimanjaro, where many men have work outside the region, this has proven to be quite serious. This is a special challenge for women, and a predicament where women often find themselves cornered. *"Men are the stubborn group. They feel that their sexual desires are there to be met at any time they want,"* as one women put it. Another woman had a solution to the problem: *"We must meet them on the highest level, from the President of the nation downwards. We must start from the top!"* KIWAKKUKI has tried to run couples' seminars, but the husbands never came. Fortunately quite a number of men come for the pre-marriage counselling, where being faithful is a crucial topic. Especially young couples have often come for this kind of counselling.

There is a pressure on men to prove their masculinity, and this can lead to the spreading of the virus. A widower who has lost his wife from AIDS will often feel the need to take up new sexual relations, or even start a new family with a second wife. In order to get a new wife, normally a much younger one (who is hopefully a virgin and not infected, so that she will not represent a risk for him) the widower can not admit publicly that he has lost his wife from AIDS and might himself be HIV positive. He might not see that the danger is actually that he might infect his new young wife and not vice versa. There is on the other hand often a pressure on women to prove their fertility and value as women by having children before marriage. This can also lead to spreading of the virus.

ECONOMIC ASPECTS

"A woman who previously used to work in prostitution said: 'I became HIV positive only because I worked to sustain myself and my child'."

Men often find themselves in need of migration for economic reasons, and this increases the risk for HIV transmission and the spreading of the epidemic. Women, on the other hand, often live with a lack of economic freedom and independence. This gives them little or no perceived power to negotiate the practice of safe sex or prevent unwanted sexual relations with men. Concerning the uncertainty that many people feel about their own sero status, many women are actually ready to test, but have no economical resources to do so, according to one KIWAKKUKI informant.

GROWING NEED FOR CAREGIVING SERVICES

"As a woman I feel that I have a responsibility of caring, not only for my own children and immediate family, but also for my in-laws and my extended family as well."

KIWAKKUKI was prepared from the very beginning that many people would get sick and that home care would be in high demand. The organisation was also prepared that there would be AIDS orphans. However, it has been difficult to foresee the enormous increase in these needs and the consequences of this. Women in Tanzania often have multiple care burdens, within the family, among the in-laws, and within the community. If a woman is HIV positive, she must also seek to care for herself. The HIV/AIDS symptoms weaken the body and diminish the energy of the person. If this person is a caregiver, the consequences can be heavy for the whole family. Girls often become caregivers at home, which some times includes that they are taken out of school to perform their caregiving tasks. Girl orphans are at risk for being exploited as house girls, both in terms of the caregiving workload and in terms of risk for sexual exploitation.

Challenges related to the AIDS orphans

A GROWING PROBLEM

In Standard 7 in a particular school, 3 out of 5 children were AIDS orphans. KIWAKKUKI reported it to the District Commissioner, who replied: "The basket is empty."

The number of AIDS orphans is growing quickly. In the Kilimanjaro region today KIWAKKUKI counts on a minimum of 50.000 AIDS orphans. The actual number is probably bigger, but because of stigma many of these children and their relatives are not open about AIDS related deaths in the family (see Annex 4). Out of these 50. 000 AIDS orphans, KIWAKKUKI supports 1570 of them. The Norwegian Women's Front sponsored 17 girls in secondary school in 2001. The Tanzanian government leaves the problem for the community to solve, according to KIWAKKUKI sources, giving only minimal help. In a certain Standard 7 in a particular school, 3 out of 5 children were AIDS orphans, according to the KIWAKKUKI Orphans' Project Officer. The KIWAKKUKI reported it to the District Commisioner, who replied: *"the basket is empty"*. The Mwanga district branch of KIWAKKUKI alone has been able to identify 4733 AIDS orphans in their district. Because of the stigma attached, this figure is probably also much higher. Out of these 4733 AIDS orphans in the Mwanga district, 64 are supported by different donors through KIWAKKUKI.

PREPARATION FOR ORPHANHOOD

"My mother was hospitalised because she was quite sick, and I went to visit her on a Sunday morning. After having spent some time with her, I went back home, and later on, that very afternoon somebody told me that my mother had passed away."

KIWAKKUKI realizes that an important task is to prepare young children and teenagers that they are going to be orphans. The organisation has many examples of children who have not been prepared by anyone about the dramatic destiny of their parents and the consequences this will have on their own lives. Several of the AIDS orphans that the evaluation team spoke to had not been aware of their parents' situation until after their death, in one case long after. "Ellinor", 17-year-old AIDS orphan, was not aware that her mother was terminally ill even if she knew she was hospitalised and quite sick. "Ellinor" and her three sisters had their lives dramatically changed when their mother passed away: Her mother had worked at a hospital and the family had lived in a house for hospital employees. Upon the mother's death the four sisters had to move out. The two youngest sisters are today being sponsored by the Women's Front of Norway (see Annex 8).

FUND-RAISING FOR AIDS ORPHANS

AIDS orphans who finish Form 6 and want to continue studying at the university, have a financial problem. They are entitled to 40 % of the costs covered by the ward they belong to, but 60 % of the cost has to be covered by government grants, and this has to be applied for. Normally, youngsters from poor families are not able to get these funds because they do not have anyone to lobby for them. This is true also, very particularly, for the AIDS orphans. They need a letter of support from a local leader. The relatives of the AIDS orphans have to walk from house to house with this letter from the District Commisioner, the letter asking for donations for the 40 % of the expenses that should be covered by the ward. In low-income districts, collecting this money is hard. KIWAKKUKI has often experienced that after the yearly budget is finalized and the resources distributed, new orphans with many needs appear. *"It is hard for us in those cases to tell them that they will have to wait for next year's budget"*, the Orphans' Project Officer says (see Annex 8).

KIWAKKUKI has come across orphans who have been stripped of their rights to inheritance after their parents died in AIDS, and is putting efforts into securing orphans' rights in this respect. KIWAKKUKI seeks to sensitise the parents in the school committees in order to create a fund for AIDS orphans. In some coffee producing districts a certain percentage is deducted off from the workers' salaries towards a fund for the AIDS orphaned children. "Terre des Hommes Foundation" in Switzerland has given a small amount of money in order to get this fund started. The money is earmarked for income generating activities for orphans.

The challenge of stigma

"My husband's parents never accepted the fact that their son suffered from AIDS. They believed me to have bewitched him, and asked me to leave."

GENERAL SITUATION

According to KIWAKKUKI sources, stigma is not as heavy in the Kilimanjaro region as it was in the early days of the epidemic. Many more people have been infected. Many more have dared to come out in the open about being infected. Many have died. So very many families are affected. The HIV/AIDS epidemic touches everyone and every family. As one of the founders of KIWAKKUKI put it: *"We do not speak about 'risk groups' any more. We are all at risk."* The Tanzanian government says, according to our informant: *"Now is not the time to be ashamed and hidden, we must start talking about this disease and of being infected."*

However, the stigma is still there, and it is a heavy burden for the individuals and families who are subjected to it. KIWAKKUKI is working hard at many levels

to fight stigma. It is especially heavy for children who have difficulty understanding what is going on and therefore have no rational ways of defending themselves. Some adults lose their jobs because they are open about being infected. Some women are still feeling the burden of the stigma, and therefore prefer caring for others than going to test themselves. According to KIWAKKUKI informants, in the same district the volunteering blood-donors have asked at the clinic whether the people who were going to receive the donated blood in the hospitals were HIV positive or negative. The blood donors said that if the patients have "that new disease", they would not want to donate their blood to them.

Upon questioning KIWAKKUKI activists about how they work to fight stigma, one person answered: *"We concentrate on continuous information, and believe that over a period of time, slowly but surely, we will succeed in fighting stigma. We strive to set a good example, being good role models, by treating all equally. Whenever necessary, we use gloves. When a patient is admitted into hospital, we talk with the relatives about the importance of being open about the disease and the condition. We encourage people who are HIV positive to visit us. One woman said that at home nobody wanted to be together with her, and that if she has touched something then nobody wants to touch that thing again. We went with her to her village and had a meeting there. It turned out very successful. Even the woman's father came to visit us in our office several times after that. The people don't know exactly how the virus is spread, and therefore they are afraid. Stigma is actually very high in the rural villages, and it is difficult to be a patient there. It is also very difficult to be an AIDS orphan there."*

A nurse activist in KIWAKKUKI shares with us a recent case from her practice: a child of approximately 10-12 years of age, whose mother died in AIDS a few years back. The child was born healthy but became sick last year. The father has remarried, to a young girl recently out of 7th Standard. If the father had told anyone that he is HIV positive, he would not have got a new wife. Therefore he passes as "healthy" in their neighbourhood, and he is now quite scared that people will start suspecting that his son is sick with AIDS. The boy has recently had a period of being quite sick with diarrhoea, but the father forces him to go to school. It is very important for the father to keep up appearances and go on living a normal life so that nobody will understand that something is wrong. Therefore the father denies that the boy is sick, and even refuses to let him take medicine (see Annex 4).

STIGMA IN A GENDER PERSPECTIVE

Women are particularly vulnerable to being stigmatised and ostracized because of their generally subordinated position within society. Some widowed HIV positive women are stigmatised and blamed for their husbands' death, as they are seen as guilty of having infected their husbands, whereas their husbands' active role in spreading the virus is often neglected. HIV positive women are generally also often considered to be promiscuous. For these reasons they are prone to be isolated

from neighborhood network. They might lose access to, or be deprived of the rights to inherit, their belongings, house and land because of this. In addition to this, KIWAKKUKI also points to the problem of women losing their legal rights as a part of the complexity. When a woman becomes a widow, she might lose access to her house, land and other material belongings.

STIGMA AND SOLITUDE

KIWAKKUKI is facing the challenge of solitude in relation to the HIV/AIDS stigma. Many people in the region have been left alone by their families, either because of death itself or also because other family members move away from the infected person. The evaluation team was able to visit several HIV positive persons together with the KIWAKKUKI Home Based Care team. Among the HIV positive persons visited, the evaluation team met two women in different neighbourhoods, but with the same fate: tested HIV positive, widows, living alone with only a young house-girl to come in and help from time to time, being visited in the weekends by a few family members (see Annex 3). Grown-up children are all married and have moved away. Both women are seemingly quite weak. They are given medicine and some food by the Home Based Team, and are read for from the Bible if and when they want to. One of the women says her house-rent used to be taken care of by one of the daughters and her husband, but her daughter's husband has recently passed away and the daughter is no longer able to provide the money for the rent.

One KIWAKKUKI counsellor says: *"Some times we see that the ones who have not been kind, or who have been rude, to their relatives when they were healthy, are the ones with the biggest problems when they are tested HIV positive. They find that only the KIWAKKUKI and the foreigners will help them."*

INVOLVING THE COMMUNITY IN FIGHTING STIGMA

"… slowly but surely, we will succeed in fighting stigma. We strive to set a good example, being good role models, by treating all equally."

Pressure is being put on infected people to be open about their situation. Some times the pressure comes out into the open; some times it is a hidden underlying attitude. One person suggested, when this question was raised at a public meeting in award: "Since AIDS is a problem and people who are HIV positive hide themselves, why *not put the names of the infected people on a blackboard in the village?"* However, the dilemma of the HIV positive persons is that they feel they are expected to be open about their status, but on the other hand they are actually risking being stigmatised, blamed and socially isolated if they do come out into the open. The KIWAKKUKI teaches a *"Don't judge"* doctrine, and argues that the problem involves so extremely many

people. Nobody can actually say that the problem does not concern him or her. Some times the problem is that many of those who are not yet tested are actually those who might also be HIV positive.

OBSTACLES IN PROMOTING OPENNESS

KIWAKKUKI is discussing how to improve the ability to share one's condition as HIV positive. One HIV positive person said to a counsellor: *"Come and visit me only at the KCMC hospital when I am a patient there, don't come home to me, because if the people at home, that is, my husband's family, come to know that I am HIV positive, they will accuse me of having been responsible for the death of their son. Then everything will be taken away from me."* Another woman came crying heavily to the KIWAKKUKI office, after having been chased out from her village, which is quite far from Moshi.

It is considered a shame to be open about one's positive sero status. HIV positive women are labelled as prostitutes. The children of the HIV positive women some times say to their mothers: *"Testify about your sero status any other place, but don't do it at home, in our village or in our neighbourhood. Otherwise no-one will ever talk to us again"* (see Annex 6). So often we see that openness about one's sero status comes when all other alternatives are exhausted, as a last resort in order to get help.

FIGHTING THE CULTURE OF SILENCE

KIWAKKUKI is constantly fighting the culture of silence and working towards openness on HIV/AIDS and sex related issues. There are, however, so many obstacles to face. Cultural constraints affect both men and women, and the children. Youngsters often have no one to speak to about what has happened when their parents are dead. The culture of silence on the one hand, and the pressure for openness on the other, are factors that influence each other and turn into a vicious circle, which is hard to break. The stigma of HIV/AIDS and the silence around sexuality are still real and existing hindrances for openness about the disease. KIWAKKUKI sees a need to work with the local communities, to make them open to receive HIV positive persons in their neighbourhood without stigma. Then the HIV positive persons might choose to be open about their status.

Photograph right: Children are also affected by the epidemic.

3

KIWAKKUKI'S many faces

The Information Centre

"The Information Centre is very useful. It is really a problem solver – when you walk in with a heavy heart, you walk out with a lighter one. I have experienced this myself."

The Information Centre is in a way KIWAKKUKI's "window" to the outside world. Centrally situated in downtown Moshi and with no entrance fee the centre attracts an increasing number of people who come in to be counselled, to receive written information, to watch the informative videos on HIV and AIDS on how to prevent oneself from getting infected, or to watch current videos of festive KIWAKKUKI occasions. There is room and time for questions and comments. Someone from the KIWAKKUKI office is always available for counselling. Especially the PLHA women who are affiliated to the KIWAKKUKI Head Quarters do an excellent job of informing. The information given in the Centre is also a very important part of the organisation's active anti stigma work. People who come in and fear they are themselves HIV positive will get psychological support and back-up to go and be tested. People who already know they are HIV positive will receive support and guidance. They will be encouraged to come out in the open with their status, and will be invited to join the Centre of Hope. People who visit the Information Centre will be encouraged to start speaking about the AIDS epidemic in a natural way, thus "coming out of the closet" with their thoughts and worries. Everyone who comes is asked to bring a friend next time. This provides a good opportunity for breaking the culture of silence regarding this burning issue which KIWAKKUKI estimates to be an urgently growing concern for every person, every family, every neighbourhood, ward, district and region in Tanzania.

The number of people who visit the Information Centre is registered, likewise how many have seen the information video. The level of knowledge of the visitors, and which questions have been asked, are also registered. The presentation of AIDS related themes and issues vary from day to day, and conclusions from discussions and evaluations of sessions with peer educators are registered.

A questionnaire form has been handed out to the users of the Information Centre, and representatives from the KIWAKKUKI staff are now faced with the task of analysing the answers. Medical students from the United Kingdom have come to help out with this analysis. They have expressed their preliminary impression that people who have used the Information Centre evidently have acquired a high level of knowledge about HIV/AIDS. There seems to be thorough knowledge on how the virus is spread, people are familiar with the most common symptoms, and seem to be quite informed about prevention. People seem to have knowledge also on the difference between having AIDS and being HIV positive.

Through the registration tool that is being used, it is not possible to detect whether the same persons frequent the Information Centre, or whether newcomers arrive. Each person is registered as a visitor each time. KIWAKKUKI activists sometimes are able to recognise people after they have visited the Centre several times. Such persons are gradually encouraged to take part in KIWAKKUKI's activities.

Education Team Outreach

Education Team Outreach is supported by The Women's Front of Norway and has 56 active members. Some belong both to the Education Team and the Home Visiting Team. Records of all meetings are kept for the statistics. Before people become volunteers, they have to complete a capacitating programme for volunteers. Peer educators are continuously being trained. The capacitating programme for volunteers can be completed both on grass root level as well as in the Head Quarters. It is a one-week training programme to learn about KIWAKKUKI's policies and AIDS-related challenges. The target audiences who receive this health education (work places, communities etc.) are also asked to evaluate the information sessions given by KIWAKKUKI volunteers. Typical feedback comments are: *"This is so good! We are so happy that you taught us about all this. Now you must come back and tell us about how we can talk to our youngsters."*

WORK METHOD OF THE EDUCATION TEAM OUTREACH

Letters of introduction to schools, religious congregations and other institutions are written from KIWAKKUKI, asking that representatives from the Education Team Outreach be invited to come and give information and health education. The team tries to be available whenever there is a group of people who would like to have a visit from them. In this way the team feels that they can sensitise important parts of the population and inform about KIWAKKUKI activities. KIWAKKUKI invited

itself to come and give information and health education at an early stage in the life of the organisation, when the epidemic was not as serious. The response was not very significant then. Nowadays, however, the organisation receives invitations and requests from all over the region, and from different groups and congregations. The choice of members of the Education Team to take on a particular educational visit is made while taking into consideration the characteristics of the individual institution that wishes to be visited, and activists are being assigned to the task according to the character of the particular target group – concerning age group, sex, social and economic background etc. In this way the team can provide each group that is to be visited with a team of educators who will be most likely to be listened to and get confidence from the group.

Some men take the challenge of information seriously. At work places men some times create their own information centres, and ask KIWAKKUKI to come and see, or to inaugurate them. KIWAKKUKI has sensitised the men at these centres, and now train peer educators there. They prepare seminars with these men, and share information.

The members of the Education Team Outreach, who have been elected to go to a particular institution to inform about HIV/AIDS, meet in advance to prepare their presentation. The team prefers to have one person who lives with HIV in each outreach group, together with one representative from Youth Alive whenever that is relevant. Normally three persons to each place are considered ideal, and sufficient for role-plays etc. One active PLHA who has already received peer education gives her testimony about her sero status etc. One of the peer educators is the leader of the group. An activity report form is afterwards filled out for the records.

ACTIVE ROLE OF PLHAS

The HIV positive women have an important role to play in KIWAKKUKI's health education activities. Several energetic, positive women who are HIV positive participate actively in KIWAKKUKI's daily life and activities. They often come along to meetings, information rallies and home visits, because it means a lot for people to be able to see for themselves that PLHAs are living positive lives and partake actively in society. It is of great importance in the anti stigma work that the "hidden" HIV positive persons can see these openly HIV positive women in action. It is also very important for the persons who tend to stigmatize PLHAs to see them and listen to them. Thirdly it is of utmost importance for the sick patients to see that it is possible to reach other stages of the disease and live positively even after long periods of serious illness. According to Education Team Outreach members, many people cry when they see a HIV positive patient. Others are puzzled to see

that PLHAs can be healthy looking. One man was told to have said: *"Can you bring to my village an AIDS patient who looks really sick, because people will not believe that this person we see now has the virus!"*

PLHAs in the education team are often asked about how they found out that they were HIV positive, and whether they are afraid to die quickly. The PLHAs explain, and answer, in a very direct and positive way. They assure their audiences that they are not afraid, and that the listeners do not have any reason to be afraid of them. They stress the fact that they can lead a socially quite normal life, just as long as they take care to live a healthy and regular life, and take preventive precautions.

PEER EDUCATION

The basic idea about peer education is that someone can educate their own peers, that is, someone from their own age group, friends, colleagues, etc. The responsible persons at the KIWAKKUKI Information Centre often have a good opportunity of observing the people who visit the Centre. From time to time they recognize someone among the visitors who has come repeatedly, and seemingly has acquired a high level of knowledge. If that person also gives the impression of being interested in taking a more active part in the work, she or he is asked to come for training to be a peer educator to others.

The Mwanga branch of KIWAKKUKI started peer education workshops last year, and have now 64 peer educators in the district. People from the local communities within the district choose their own representatives to come for peer education work. The ones who are chosen must be active people who are willing to work voluntarily. The first group session run by the branch was supported by the Faraja Trust Fund of Morogoro. There were only women present, but the Mwanga branch later considered that there ought to be a gender balance.

SCHOOL-WITHOUT-WALLS APPROACH

KIWAKKUKI has got the idea of the School-Without-Walls approach from Zimbabwe, although the concept originated in Canada. The point is to train role models belonging to certain sectors of society for use in information and awareness-raising campaigns. Changing the risk behaviour of the health educator must be done first, so that the health educator can actually be a good role model. Once that objective is obtained, the health educator can sit down with shoe-shiners, for instance, and talk with them about HIV/AIDS. The idea is to be taught by one's own peers. In this way risk groups and/or marginalized groups in whichever walk of life can obtain health education and information on HIV/AIDS. Role-plays and drama are also being used in this approach. If one member of the School-without-

Walls team feels that it is too difficult to change one's own behaviour, or that one feels he or she is simply not able to, the program allows for that person to step aside and let others take over.

CONDOM USE

The KIWAKKUKI point of view is that people should be made able to make informed decisions on AIDS preventive issues. Empowerment of women is important, to be able to act according to one's informed decisions for preventive strategies (e.g. condom use). The Women's Front of Norway has been in the forefront in giving support for the training of the grassroots women in this respect.

Since the culture in the Kilimanjaro region, for religious and other reasons, traditionally hosts resistance to condom use, the counsellors of KIWAKKUKI have therefore chosen to find diplomatic ways of introducing "behaviour change" and risk prevention to avoid HIV and AIDS. One way of speaking about prevention is to speak about the ABC *"Fleet of Hope":* with the elements A for sexual Abstinence, B for Being Faithful, and C, *"if you know that you will not go for the A or the B, it is better to be honest about it, and wear a Condom."* All of these three elements actually signify a risk preventive behaviour, but on different levels. KIWAKKUKI teaches how to use condoms, how to store them etc.

The members of the Education Team go out to teach as a team, so it seldom happens that anyone ends up feeling cornered or restricted about one's own personal beliefs concerning the use of condoms. If a Catholic on the team feels a bit awkward teaching people to use condoms, another person on the team will easily be able to take over.

A problem concerning the control of the quality of the condoms has arisen. Some national quality controls have proved condoms to be unsatisfactory. Such news quickly spread around, and caused many people to distrust condoms as a way of protection against HIV/AIDS. Promoting condoms therefore constantly meets challenges in the Kilimanjaro region.

WHAT PEOPLE WANT TO KNOW

The level of knowledge is already quite high on HIV/AIDS in the region. The most common questions on the information missions are about the use of condom, and how effective it is. People also express hopes and concern for the development of new medicines to cure AIDS. People are also often concerned about how the government can be challenged regarding the production of medicine, which can increase the life span of the infected persons.

In secondary schools the students often ask: *"What if we are abstinent until we are 30 years old, will that have negative effect on our fertility? Can we still have children at*

that age?" The Education Team answers that there is normally no problem having children at 30, and emphasises that other sexually transmitted diseases (STDs) can lead to infertility and that there is even prevalence of cancer cervix in women who are sexually active from an early age. The use of condoms can protect against HIV/AIDS, other STDs and unwanted pregnancies. The fact that in both the Christian and the Moslem religion it is forbidden to indulge in sex before and outside marriage is used actively and conscientiously in the KIWAKKUKI as an extra reminder of the positive aspects of being sexually abstinent before marriage and of being faithful when married.

EVALUATION OF KIWAKKUKI'S HEALTH EDUCATION

A small Education Team was formed in mid May 2002. One of the first tasks of the team is to analyse the answers to the questionnaire forms that have been filled out by visitors to the Information Centre. KIWAKKUKI hopes that the analysis will give clues on how to improve the Information Centre. A medical student from the United Kingdom helped out with this analysis. They have expressed their preliminary impression that people who have used the Information Centre evidently have acquired a high level of knowledge about HIV/AIDS. Answers on the questionnaire, and the oral, spontaneous feedback people have given so far, has rendered some preliminary clues. In spite of evaluations always being very positive, with remarks like: *"This was so good! Magnificent! Continue your good work! We want more of this!!"* etc. However, KIWAKKUKI realises that it is not able to reach out to as many as it would wish. Therefore, the Education Team Outreach now plans to organize big public meetings three times per year. They wish to cooperate with the traffic police, hand out pamphlets, and have a varied program of singing, reciting poems and performing drama pieces. There are plans of bringing in musicians and good singers who can sing about being HIV positive. The hope is to reach out to more people in this way.

Branch life

KIWAKKUKI has now got 32 branches in different parts of the Kilimanjaro region. A new group has to have a period of 5 months of training, under close observation of the Head Quarters, before it obtains the status of branch. All branches get support from the Women's Front of Norway, 100.000 TAS (approx. 1000 NOK) provided they deliver an account of last year's finances and a well developed budget proposal for the coming year. The branches mobilize their respective local communities in the name of KIWAKKUKI.

The local branches are active in awareness raising of HIV/AIDS related issues and problems in their communities. They provide health education, organize home visits to AIDS patients, engage in income generating activities and care for the AIDS orphans in their community. The branches have monthly meetings, keep their own budgets, economy and records. When they are in economical difficulties, however, the KIWAKKUKI head quarters will help (see Annex 4). The local branches give 50 % of their annual membership fees, which actually constitutes a major part of their income, to the KIWAKKUKI head office. The branches have active orphans' committees, and their own general meetings.

KIWAKKUKI's vision to create awareness of HIV and AIDS in the whole Kilimanjaro region requires emphasis on cooperation between branches and head quarters. The branches thus send representatives to the monthly meetings at Head Quarters and submit progress reports every quarter. In return, the branches receive capacity building resources and monitoring from the leaders of the organisation. Some times the local branches send representatives to the head quarters to introduce good ideas to be incorporated in the organisational program. Information is shared, and if the ideas from the branches are good, they will be incorporated in the activities. For example, at the last meeting in KIWAKKUKI, the candlelight procedures and how they are going to be executed were discussed (see Annex 4).

Some local branches with their respective grass roots groups are difficult to visit because of the geographical distance and problems of transportation. However, KIWAKKUKI has hopes that in the future the political structures like the wards can be used for contact with the rural areas. The ward as a key unit will be a great help for the organisation, and it will be easier to detect whether it has succeeded in covering ground in all corners of the districts with the HIV/AIDS information and sensitising.

The evaluation team was able to visit three different branches and in two of them was able to be present at the branch annual meeting. The evaluation team was impressed at the energy, level of knowledge, level of initiative and zeal that was present in these groups of hardworking and inspired women. It was, however, also evident that the newcomers to KIWAKKUKI, who had recently become members, were much more shy and introverted during the meetings. Some new members were elected for their branch's new executive committee, because the branch insisted on every village in their district to be represented in the executive committee, and these newcomers were the only ones present from their villages. The newly elected women were evidently quite shy, timid, and soft-spoken in that context. However, they did take on the responsibilities handed them so challengingly. The evaluators see this as a very important step in the process of empowering women in their own local communities, and commend KIWAKKUKI for insisting on this procedure.

FUND-RAISING AND INCOME GENERATING ACTIVITIES

Members of KIWAKUKKI at branch level seem to show great imagination and incentive when it comes to different ways of sustaining their own activities economically. At the Mamboleo branch the members wanted two sewing machines. With these they are planning to stitch school uniforms for the 60 AIDS orphans in their district. Furthermore they will take up tailoring as a means of income generating activity among the members. Two sewing machines were donated from private donors, and the tailoring activities could start immediately. At the Kolila Branch the women had planned on chicken and egg-production as their means of sustaining themselves. For that they needed TAS 80 000 (NOK 800). The year report, narrative and financial accounts were handed over to the KIWAKKUKI executive committee representatives, which was a prerequisite for being given the TAS 100 000 (NOK 1000) from The Women's Front of Norway. This sum covered the chicken purchase and other calculated expenses of the branch. Mwanga branch is also quite creative at fund-raising: A "blue card" was developed with space for up to 12 donors' signatures. Every individual donor put the donated sum and the signature on the card. Each branch member had one or more cards and was responsible for the accountability. This idea has proved to be quite successful. The Mwanga branch has also been able to get the German Embassy as a sponsor. This influential sponsor has built a house with office and several rooms where different types of activities can take place, regular office work, counselling for individuals and groups, tailoring and baking classes for bakery production for single mothers, etc.

KIWAKKUKI has worked on inspiring and training members, as well as youngsters in vulnerable groups, to be creative in thinking fundraising and income generating activities. People have been given "soft loans", have been trained in growing vegetables, doing petty business etc., and KIWAKKUKI has encouraged them to form small groups of 5 to work together.

CO-OPERATION WITH OTHER ORGANISATIONS

"I work with youth and see that they are very affected by the HIV/AIDS epidemic, and therefore I understood that I had to work quite closely with KIWAKKUKI in order to serve the youth."

Some families find themselves in a deep crisis when it appears that one or several members are HIV positive, finally developing AIDS and passing away. Many personal reactions have been seen, with physical abuse, sexual abuse, abuse of children etc. KIWAKKUKI has offered family counselling in some of these cases. However, in many cases of abuse, of human rights, child abuse, loss of job, loss of women's right to inheritance etc., KIWAKKUKI has referred cases to the KWIECO, a Human Rights NGO in the region (Kilimanjaro Women's Infor-

mation Exchange and Consultants Co.). KIWAKKUKI has also co-operated the last three years, since 1998, with QOHELETH Foundation, a small NGO that has taken up work among young people in the villages. *"We train youngsters, both sexes, in different skills in order to assist in enabling them to cope in life. The main aim is to occupy them in useful occupations in their own villages and in that way preventing the youngsters from moving into town,"* says the director general of the QOHELETH Foundation (see Annex 9). KIWAKKUKI runs peer education programmes with this organisation. KIWAKKUKI is a network member to AIDS NGOs networks at the regional, national and East Africa level.

Work with targeted risk groups

"We do not speak so much about 'risk groups' any longer, because we know that we are all at risk. So we just give each other support without talking too much about these details."

KIWAKKUKI realizes that HIV/AIDS affects a vast population all over, and that it is not a problem which can be solved only by reaching out to specific "risk targeted groups". However, the authorities, together with other organisations, have during the years taken initiatives to fight the epidemic focusing on targeted groups in society. So, even if KIWAKKUKI recognizes that HIV/AIDS definitely represents a risk for each and everyone, the organisation has also responded to initiatives taken concerning work with especially risk-exposed groups.

The Kilimanjaro Regional government and Health authorities wanted to map out certain trades or professions that were in particular risk for HIV infection on a district level, so as to concentrate the information work to certain trades, professions or risk groups. Women in prostitution and truck drivers were considered as risk groups in this respect. One NGO in the region opted to work on this if the Regional government District Office would finance the expenses. However, this was not possible. In stead, KIWAKKUKI started an information program in the wards, with support from Oxfam Ireland. In this program, KIWAKKUKI seeks to reach men, in particular truck drivers. However, it has been found to be quite difficult to gather the truck drivers for meetings. The organisation is therefore in the process of finding ways of at least distributing condoms and pamphlets to this target group. This is a minimum activity, in relation to the list of activities that is actually wished for as far as information and awareness raising work is concerned and considering the needs of this group for information. KIWAKKUKI would rather be able to work thoroughly with this group of men, toward awareness raising and behaviour change. But this is a challenge, which may prove to be difficult, as it requires a considerable amount of time and personal resources, and also personal

access to the group. KIWAKKUKI has, however, a hope to be able to work with the people in the wards and sensitise them to reach out to the truck drivers and the women in prostitution in their neighbourhood.

The Mwanga branch of KIWAKKUKI has taken up work with young single mothers in their area. The young single mothers have been recruited from local groups of women in prostitution. The Mwanga branch initiative started with two young single mothers in the district who were HIV positive. They both told KIWAKKUKI that their only means to sustain themselves and their children economically was through prostitution. One of them said: *"I became HIV positive only because I worked to sustain myself and my child."* The KIWAKKUKI branch realised that there is a need for a special programme for these girls and therefore recruited the young single mothers for a programme where they are being taught how to care for themselves and be self-reliant. The Mwanga branch has bought three sewing machines, and teaches the young girls to sustain themselves in the tailoring profession. There is also a bakery, and baking is taught, and small scale farming such as growing vegetables. This also works as an HIV/AIDS preventive action. There are now 25 young single mothers participating in this programme in the Mwanga branch. The branch does not know the sero status of these young women at the moment, because no testing is required for joining the programme. The two first women were not open about their HIV status. One has already passed away; the other is still active in the programme.

Youth Alive Kilimanjaro

"Youth Alive vision statement: To see young people fulfill their dreams and ambitions with respect to humanity".

ORGANISATIONAL SITUATION

The organisation was established in 1998. In 1999 there were already 5 district branches. Today there are branches in 6 different places both in rural areas and in Moshi Urban. The organisation rents an office in downtown Moshi. There are 45 members in the Moshi branch; out of those 15 are girls. Some AIDS orphans are also active in Youth Alive Kilimanjaro. The Youth Alive has its own budget, is independent from the KIWAKKUKI and is registered as an independent NGO. However, KIWAKKUKI supports the organisation by paying the office rent. Youth Alive feels that this funding is not sufficient.

KIWAKKUKI and Youth Alive Kilimanjaro co-operate in teaching missions and information meetings to the different places or institutions where information is needed among young people. Three persons from KIWAKKUKI

will normally participate in these missions, together with three or four from Youth Alive. The Youth Alive office only manages to have contact with one of the 5 rural branches, for lack of economical resources.

All seven youngsters from Youth Alive who met the evaluation team were boys, aged between 18 and 22. Asked why no girls are present, the boys answered that two *"were supposed to come, but they have not appeared."* One said: *"That is a matter of individual personalities. Some girls are shy, some are bolder."* There are four girls and five boys in the management committee.

RECRUITMENT

From being some three or four youngsters at the beginning, the Moshi branch of Youth Alive now has become a group of 45. They are a mixed group of youngsters, some are working, some are in school still, and others are unemployed. They are not attached to any particular church or congregation, but are trained for visiting mosques, churches and other places to talk about the HIV/AIDS epidemic. They go wherever people want them to come, independent of creed. Youth Alive members are both Moslems and Christians.

One boy says he was attracted to the organisation by a teaching session, where the persons who taught about the Behavioural Change Programme behaved so well. Another boy states that their parents like and approve very much of their young sons and daughters activity in this work, because they feel that it helps the youngsters to keep away from bad free time activities.

The extent of the youngsters' concern about HIV/AIDS varies. However, Youth Alive representatives say that some become concerned only after having seen that other people they know have fallen sick. Youth Alive has started to offer some counselling, up until now only on small scale where they *"do not go so deeply into the matter"*. The young boys have the impression that young girls are more interested in listening to them rather than to other girls. Concerning the young boys, the Youth Alive members have had the experience of speaking about condoms, and then getting the response from some boys: *"Let us try without condoms, and then let's see whether we get sick or not."*

Some young people who are not active in the anti HIV/AIDS work suspect the Youth Alive activists for being active in the organisation because of the big unemployment in Moshi and they think that the Youth Alive members are being sponsored.

GENDER RELATIONS AND GENDER ROLES

The Youth Alive members work toward changing the quite fixed and seemingly "unchangeable" gender roles in the region by "telling them the truth" – that both men and women are supposed to work together, cooperate, in daily life. Youth Alive means that if both husband and wife work outside the home, then both of them will come back home tired, and this indicates that they both will have to share the housework and the daily chores in the home. Youth Alive also intends to engage in providing access to good learning processes regarding sexual behaviour and safety. The organisation aims to address men's and boys' attitudes towards sexual behaviour.

REACHING THE OUT-OF-SCHOOL YOUNGSTERS

Some youngsters in the region have quit school and picked up the habit of drinking and smoking. Some have also stopped attending church or mosque, and have acquired behavioural problems. AIDS orphans have been seen to be more vulnerable to join groups of these youngsters. Youth Alive seeks to reach them, and invest in empowering other youngsters and members to reach these groups. They also feel it is important to reach the ones who are still in school. The Youth Alive volunteers are not paid; the organisation in fact does not have the possibility to pay even for their transportation. According to the informants, this is a problem, because consequently the youngsters get tired time and again.

BEHAVIOUR CHANGE PROGRAMME

The first Behaviour Change Programme, BCP, was started by one of the Youth Alive groups. Some Youth Alive-activists came from Uganda to teach about change of behaviour and how to go about advocating for it. Youth Alive speaks about Behaviour Change, and by that mean a change of attitude toward careless sex. *"When young people have sex just to spend time and have pleasure, they are misusing their body"*, as one Youth Alive activist put it. Youth Alive actually advocates abstinence before marriage as a safe and positive lifestyle for young people these days. Two boys from the organisation have been sent to a church to inform about the Youth Alive work and the Behaviour Change Programme. The boys talked with the congregation about how they themselves also had changed their behaviour. Youth Alive means it is possible to change negative thinking into a more life assuring way of thinking: of what the person really values in life, which might be sports, having a future, having a wife and children.

”SECONDARY VIRGINITY”

The organisation promotes virginity and abstinence before marriage. However, if the young people have already had sex, they are urged to become “virgins” from that very day onwards, putting their earlier life of promiscuous sexual behaviour behind them and stay “secondary virgins” until the day they actually get married. Videos, songs, drama, and a lot of time, hours on end, are used to talk and explain about abstinence as the best alternative before marriage. Youth Alive believes in engaging the youngsters in healthy activities, and therefore have started a volleyball-team. The time after the matches is used for talking and networking.

YOUTH ALIVE KILIMANJARO’S VISIONS FOR THE FUTURE

Youth Alive has several optimistic visions for the future: The members of the board want to increase the number of branches. They also wish to have an Information Centre with posters, video and other written material. They want to develop the volleyball idea further and form a sports team. A teaching team is also on the list of wishes, with equipment, a blackboard and chairs. They want to educate more youth health educators and have their own teachers, to be able to give health education in the rural areas. Therefore money for transportation is also needed. For four Youth Alive members, ideally two boys and two girls, to go to one of the local branches and hold seminars and information campaigns, they need 30.000 TSH (= 300 NOK), which is calculated to cover transportation and food for the four of them plus renting of a place to stay. This is a realistic budget, but a lot of money for Youth Alive. The organisation has applied to several sponsors, but has got no positive answer so far. The boys are thinking about the possibility of giving classes in health education for young people in their office. Representatives from the group have been to several secondary schools, and have now started talking about addressing the primary schools. The problem as they see it is their economic limitation. There are just not sufficient economic resources to be able to do all that the Youth Alive activists want to do.

The photographs on pages 47 and 61 are of children supported by KIWAKKUKI.

4

Key topics related to the Terms of Reference

"This is not the time for being shy!!"

"We cannot force men to change, it is difficult. However, if all the women can say NO, then all the men would run off to the forest and be ashamed, and hide their faces."

For women in the Kilimanjaro region, it is of utmost importance, and an urgent issue to be empowered so as to effectuate their informed decisions about HIV/AIDS prevention. Women are empowered and educated through various fora within the KIWAKKUKI: Monthly members meetings, capacity-building workshops, the Education Outreach team, the Information Centre and through networking with human rights NGOs.

The KIWAKKUKI policy is to give education on HIV prevention and condom use, so as to encourage informed decisions. This is being done in the Education Outreach program and also in the Information Centre. However, some people seem unable to apply the acquired knowledge and skills about condom use in their personal lives, due to the patriarchal society in which they find themselves, and the limited power women have to influence situations related to sex in their sexual and/or marital relationships. Therefore issues like condom-use have been picked up slowly by people at large.

Women's role as caregivers – how women meet the challenge of the changed care situation

"We actually realised from the very beginning of the epidemic that many people would get sick and need home care. And we were prepared that there would be orphans who would need help. These needs have been on the increase."

The women in the Kilimanjaro region lead the way in the fight against HIV and AIDS. They are also the ones to take responsibility for dealing with the impact of

the epidemic, which is the increased burden of care-giving in its different aspects – identifying AIDS orphans for support, visiting the patients at home and advocating for communities to own the care of their patients and AIDS orphans. This represents a heavy workload of women who have traditionally had the responsibility for care-giving tasks. The women have conscientiously gone about completing these tasks, to the best of their ability and beyond. As a result of the AIDS epidemic these tasks have been on the increase for the past 10-15 years and are continuously increasing. The burdens of care-giving that the women of the region carry are particularly heavy because most women are still not empowered to take a firm grip of their own lives, time, energy and sexuality.

KIWAKKUKI trains women to work in small teams, in order to share the increased care-giving burden by operating in small areas. KIWAKKUKI asks representatives from the branches to visit the churches and mosques every month, to sensitise the members of the congregations and encourage them to engage in anti AIDS work and care for the patients that belong to them. Schools are also encouraged to engage in this work.

KIWAKKUKI also trains women to partake and initiate a number of activities directed toward helping children who are going to be AIDS-orphans, preparing them for orphanhood:

- Women teach communities on the importance of writing wills and on how to write a will.

- Women support children of HIV positive parents, as potential orphans-to-be.

- Women perform family counselling on how the sick parents can plan for their children's lives after they themselves have passed away.

- Women advocate for communities to own and care for their orphans as a way of maintaining African traditions of neighbourhood support, and not leaving children unattended and uncared for.

- Women promote School Health Programmes which raise awareness of the needs of HIV infected children.

The Home Based Care implies that the community should be sensitised to apply the traditional African neighbourhood network resources. In the Bwambo area people have started to take up this traditional link again, by for instance donating small things from their homes in order to help the AIDS patients in their area. Nowadays people come from different tribes with different customs, which represents an additional challenge to this approach. Some have organised community house-to-

house prayer meetings in private homes in the neighbourhoods once a week. This functions as a security network, where it might be discussed, for instance, who can donate something to the person who is sick, or to the woman who has recently had a new baby, etc.

The role of HIV positive women within the KIWAKKUKI

As more and more people living with HIV/AIDS, and AIDS orphans, seek the services of the organisation, KIWAKKUKI has found itself expanding especially in care activities. The organisation has therefore found it necessary to initiate a process of changes in structures, modes of executing activities at all levels within the organisation and modes of cooperation with other organisations.

KIWAKKUKI has gained skills on how to meet people living with HIV/AIDS, particularly through the MUTAN project but also through a study tour to TASO in Uganda. Several of the early MUTAN project health educators and counsellors are today among the founders, staff members, and volunteers of KIWAKKUKI.

A group of openly HIV positive women was started within KIWAKKUKI through referrals from hospital counsellors and other NGOs like the Rainbow Centre. Today KIWAKKUKI's different working groups, members, home visitors and peer educators all invite and welcome HIV positive women into the organisation.

KIWAKKUKI speaks of the GIPA concept, Greater Involvement of People living with AIDS. The involvement aims to be at all levels, in education, in counselling and in home-visiting. In following this concept, the HIV positive women have themselves become HIV/AIDS activists. They perform an active work of advocating for behaviour change, testing, and openness regarding one's sero status. They do peer counselling to new clients, particularly those who have a difficult time accepting their diagnosis. They do an important work in the Education Outreach program, educating on HIV/AIDS prevention and care issues. They are also active in the Centre of Hope, where HIV positive women are in majority, although the Centre of Hope is also open for HIV positive men and for HIV positive male and female children.

PLHAS IN KIWAKKUKI ACTIVITIES

One openly HIV positive woman is central in the Home Visiting Team. Another is an active member of The Small Teaching Team committee. A Counselling Team of 6 persons has recently been elected, and among the members is also one who is an open PLHA.

The counselling team previously empowered and supervised the home visitors. The Home Based Care is now an independent unit with responsibility for that work, headed full time by an experienced HIV/AIDS counsellor. The Counselling team therefore has other tasks, and has access to different types of health and welfare service professionals who can step in and render their particular services. The Special Needs Team takes care of the problems that a home visitor is not able to take care of on her own. There is also a hospital-based counsellor, a medical assistant, a clinical officer and a doctor on this team. The team has access to a physiotherapist at the Mawenzi hospital, and a social worker is available for counselling on different types of social problems.

3 wards have recently united, and elected their own counselling leader, who reports back to the KIWAKKUKI Head Quarters counselling team. This structure is quite new, and therefore the organisation is not certain of how it is going to function yet. The leaders of wards that are located in the vicinity of hospitals will report their counselling cases back to their corresponding hospital. The various district hospitals that the counsellors report back to are:
Kibosho Hospital, Machame Hospital, Kilema Hospital, Marangu Hospital, Bombo Hospital, Bwambo Hospital, Kibongoto Hospital, Usangi Hospital and Huruma Hospital.

KIWAKKUKI has many active volunteer members who have regular employment in the different hospitals, medical centres and dispensaries in the Kilimanjaro region. These hospital professionals are nurses, clinical officers, doctors, 25 in total. A roaster list is made up for each month, where each of these professionals serves as counsellor one day per month in the KIWAKKUKI office. Some clients come with their "medical treatment cards", which entitle them to medicine. Many people who do not otherwise have access to medicines and treatment for opportunistic infections, or dietary and food supplements which can strengthen their immune system, now come to the KIWAKKUKI for this kind of help. Likewise, pre-test and post-test counselling is given. The tests can be taken at the Rainbow Centre, the Mawenzi hospital or at the KCMC hospital. KIWAKKUKI hopes to have its own testing facilities soon.

Donor agencies' influence on KIWAKKUKI policy

"KIWAKKUKI's Core Purpose: To unite women and help each other harness our skills/ talents, in order to face life's challenges and restore dignity, self respect, and purpose to the lives of individuals and our families".

KIWAKKUKI has maintained its identity as a women's organisation with empowerment of women as a key objective in the fight against AIDS. This identity has, over the years, not been affected by the diverse donors that eventually support KIWAKKUKI's HIV/AIDS related activities. KIWAKKUKI has, however, adopted a policy on condoms as one of the prevention approaches regarding HIV and AIDS. This has come about partly because of donors' active discussions and influence. The policy is to ensure people's possibility to make informed decisions to protect their health.

Regarding the support and care of the orphans, it has become clear that different donors calculate with different minimum expenditure per child. The KIWAKKUKI becomes obliged to use the minimum expenditure standard for all orphans, in order to avoid imbalances among the orphans.

Experiences with the reporting and auditing formats

The Women's Front of Norway supports most of the work related to reporting and auditing. KIWAKKUKI makes individualized reports for each different donor agency. In this respect, the FOKUS reporting system has shown to be quite useful when it comes to writing reports for other donors as well. After having written the reports to FOKUS, and answered the questions required by FOKUS, the KIWAKKUKI finds that they have thus actually done a good part of writing their own Annual Report as well. Thus, the approaches, requirements and points of reference that the organisation is required to make for the Women's Front of Norway turn out to be quite fruitful in many respects. Regarding writing of annual reports, KIWAKKUKI utilizes the format from the Women's Front of Norway as a pattern. This has been found to make the work with the annual reports a lot easier. *"We are constantly reminded of our main focus when we have to answer the questions put to us by the Women's Front of Norway",* as one central executive member put it.

The pressure of switching over to the Cash Principle came originally from FOKUS. In Tanzania this was not a utilized system before, so KIWAKKUKI found it difficult to change the system concerning the Audit Reports in the beginning. But

by now, the KIWAKKUKI auditors have adopted the Cash Principle system. The other foreign donors also appreciate this system, and actually give very positive feedback on it. There is therefore no problem about the finance format today. The KIWAKKUKI leadership and Head Office feel quite comfortable with it.

New organisational structures in the wake

Already at the end of 2001 the Management Committee suggested that all employees at the KIWAKKUKI headquarters have a 1-year contract, to be renewed or ended each consecutive year. Regarding the decision-making structures of the organisation, KIWAKKUKI has worked for a while on plans to change and reorganise these to facilitate shared leadership. The organisation was planning for an Extra Ordinary Meeting in September 2002 where these issues would be treated. Changes will be implemented according to the organisational decision-making bodies' decisions.

Today the 32 KIWAKKUKI branches each are invited to send 4 representatives to the Annual General Meeting of KIWAKKUKI. According to the discussions on the new organisational development plan, the branches will be included in the Management committee. Plans for the coming decentralisation include: having at least one representative from each branch present at the monthly meetings. For decision making KIWAKKUKI wishes to have one representative from each district. Today 10 members are elected from the Head Quarters. The new plan suggests 6 new representatives. This might mean that some of the previous representatives will be asked to render their seats. These issues were yet to be discussed as the evaluation mission came to an end.

Some groups within the organisation enjoy a good degree of cohesion, while others don't. In each branch the income generating activities are different, as is also the level of poverty in the districts. These factors may challenge the process of unity between the leadership of the organisation and the members at grassroots level. This is an ongoing process.

The new structure suggested for KIWAKKUKI will allow local level representation to a different degree than before. Individuals' chance to influence decision-making within the organisation can increase. Individuals should be able to channel their opinions through wards to district, and finally to the regional meeting. According to this planned new structure, KIWAKKUKI Head Quarters thinks that women from the grass roots branches will have more say in their organisation. (Households, ten-cells, villages, wards, districts and regions are structural entities within the nation of Tanzania).

Changes regarding KIWAKKUKI's gendered identity and the vision of empowering women have not been an issue in the organisational development process. The new structure is not meant to influence the organisation's identity as a women's organisation. Although the organisation empowers men, too, to a certain extent, it still enrolls women as ordinary members and men as non-voting, honorary members. There is a slow engendering process going on through the use of peer educators.

Solving internal conflicts within the organisation

USE OF KIWAKKUKI'S OWN CONFLICT RESOLUTION RESOURCES

Members of the Management Committee are used for solving internal conflicts whenever appropriate, either on an individual basis or as a group. The evaluators witnessed an excellent demonstration of this at a meeting with representatives of a local branch of KIWAKKUKI in a rural area. The Management Committee Chairperson and the executive co-ordinator of the organisation managed to point out the discrepancies between grass roots members and Head Quarters in a direct, friendly and diplomatic way, underlining the positive resources of the local group while at the same time indicating what was lacking in the cooperation with the head quarters. The meeting was matter-of-factly and to the point, and the two representatives of the Head Quarters managed to maintain a supportive and constructive atmosphere in spite of the discrepancies. The two parties agreed that the challenge was to find efficient ways of mutual information and reporting, and also to find ways of inspiring each other.

USE OF EXTERNAL CONFLICT RESOLUTION RESOURCES

KIWAKKUKI uses external consultancy whenever the internal conflict proves to be of a nature where the internal conflict solving resources do not suffice. One example:

At the end of 2001 the Management committee had a problem which it was not able to solve by itself, related to personal conflicts between persons who were crucial to the running of the organisation. A Tanzanian management consultant was summoned to KIWAKKUKI together with a woman lawyer from KWIECO. Together with these two external problem solvers, the 10 persons in the Management committee and the KIWAKKUKI executive coordinator sat together until the problem was solved.

The Centre of Hope

The Centre of Hope started as a small group of HIV positive persons, and was initiated through hospital and community based counselling work. Some of the PLHAs in the organisation went for a study trip to TASO, Uganda, and came back to the Kilimanjaro region with good ideas and zeal for initiating work among other PLHAs. The Centre of Hope is today growing fast. All members must be declared HIV positive. Most members are in difficult material and economical situations, and many come to Centre of Hope as a last resort, hoping to find support. Some have developed AIDS. Some have already passed away as the report is being written. Most members are women, although some men have also joined. The Centre of Hope has its own administration, chairperson, secretary and executive committee. The chairperson is currently a man. Meetings are held at the KIWAKKUKI head quarters every last Friday of every month. Some HIV positive children also attend (see Annex 10). The members look forward to the meetings as their *"best day"*, where they can relax together, make a simple meal and enjoy each other's company. They talk to each other, giving moral support and good advice on positive living in spite of the infection. A doctor from the KCMC hospital is always present, to meet the persons who have the need for consultancy.

Candlelight services

Every May for the past many years ceremonies, processions and public meetings, the so-called candle light services, have been arranged in villages, wards and cities, at innumerable places within the Kilimanjaro region. The purpose is to remember those who have already passed away due to AIDS and to inspire the public to produce new strength in the anti-AIDS work.

The evaluators were able to attend a Candlelight service for those who have died from AIDS in a ward on the outskirts of Moshi on May 31st. The whole ward was gathered, and procedures were followed as on every May for several years. The children paraded around in the neighbourhood with banners saying NO TO AIDS. A girls' choir sang a very touching song, with a chorus saying: *"Funeral is with us."* The chairperson of the ward held a speech, likewise the KIWAKKUKI executive coordinator. The ward chairperson underlined that *"God has kept us alive until today, so that we can light candles for all our friends, relatives and neighbours who have died in AIDS. Maybe you have a friend who is dead in AIDS, or you have a relative – nobody in this ward can say that they are not in some way or other touched by the epidemic. We therefore light the candles for all of them who are dead."* The children and the grown ups all shouted: *"Bury AIDS! NO to AIDS!"*

KIWAKKUKI is planning to help all 15 wards in the town of Moshi with the provision of chairs for their anti HIV/AIDS activities through the year. The organisation feels that it is important to support the wards in organising annual candlelight ceremonies each May, and also have meetings and seminars where people will be sensitised about the spreading of the disease.

Meeting dramatic challenges

During the evaluation mission, KIWAKKUKI also shared with the evaluators some dramatic stories of significance in the organisation's HIV/AIDS work.

The Rombo case:
This is the story of a 7-year-old girl whose mother had recently passed away in AIDS. She used to be a clever girl in school, but suddenly there came a change in her behaviour. She started falling asleep in class. The teacher was quite observant, and tried talking to the girl several times. In the beginning the girl did not say much, but one day she burst out crying and told the teacher that her father abused her sexually every night. The teacher took the girl to a doctor immediately. Fortunately she was still HIV negative, but her vagina was, according to the doctor, *"the vagina of a 60-year old woman"*. The teacher presented the case at a Human Rights Workshop. The press was invited. The little girl was also there. KIWAKKUKI, KWIECO and ENVIROCARE wanted to assist the girl and her little brother of 5. The father of the girl was jailed, and the girl and her little brother were brought home to the parents of a nun who had become quite engaged in the case.

The Mawenzi Secondary School teacher's child case:
One boy who was previously a student at the Mawenzi Secondary School used to be a very clever student. His father had passed away in AIDS several years ago. The boy's younger brothers were all HIV negative, which indicated that the eldest boy had not obtained his HIV positive status by way of maternal transmission. It appeared that his father had actually abused him sexually over time. The boy's mother passed away in early May 2002 from AIDS. The boy was by then very weak with AIDS himself, and was taken to his mother's funeral in a wheelchair. Because of his sores and Kaposis sarcoma all over his skin, he was covered with large pieces of cloth. He brought with him beautiful flowers for his mother. This boy died only two weeks later. His grandfather is a pastor, and works as a hospital chaplain. He is taking care of the younger siblings.

An individual child's story:
This is as the story was told by one of the experienced counsellors: *"I counselled the mother of an 8 year old boy. She was HIV positive and had developed AIDS. By the way, she was the sister of someone who is very active in our organisation. The 8-year-old son came together with the mother for counselling sometimes. I observed that his lymph glands were swollen and that he suffered from skin blisters and sores. So even if he said he did not feel sick, I wanted to test him. I asked to be allowed to take his blood test. He cried and said, it is my mother who is sick, not me. I told him that he might be right, but I would really like to test him, because if he actually happened to be sick, we could make his life a little better by knowing for sure at an early stage. He conceded to testing and was actually HIV positive."*

Greatest achievements of KIWAKKUKI's work

- The organisation has been able to activate a large number of women in the Kilimanjaro region in the fight against AIDS and its impact. Today KIWAKKUKI's objectives are extended through 32 branches within the region. The number of branches is constantly increasing, from 25 branches at the beginning of 2001. The branches and the active women represent both urban and remote rural areas.

- KIWAKKUKI attracts more than 10.000 persons annually at the AIDS Information Centre and the Voluntary Counselling and Testing program.

- Women living with HIV/AIDS are integrated at all levels of KIWAKKUKI's organisation and activities. They play an important role in prevention and care activities, and represent encouragement and inspiration to many women.

- One HIV positive woman was sponsored by FOKUS to attend an international conference in Botswana in 2001. She attended, and stood forth publicly at the conference, stating that she was HIV positive and urging others to do the same. This was an important act of fighting stigma and supporting others living with HIV/AIDS to live positively. This event became a major break-through for this particular woman from KIWAKKUKI, but also for the whole conference and for KIWAKKUKI's anti-stigma work and the care for people living with HIV/AIDS. Several other women have later on come forth as PLHAs in KIWAKKUKI and are now working voluntarily with an admirable strength to fight stigma and give hope to other PLHAs.

- KIWAKKUKI sent two representatives from the Centre of Hope to the important event of the first national network of active PLHAs in Tanzania. This new national network was established at a meeting of PLHAs in Dodoma in May 2002.

- The Centre of Hope, KIWAKKUKI's organisation for HIV positive individuals is today attracting approximately 60 women, some men and also children, for the motive of supporting each other for positive living. Although several active members of the Centre of Hope have already passed away, the number of members is constantly increasing. Meetings are held every last Friday of each month, and at each meeting there are new individuals who step forward and wish to belong. An increasing number of HIV positive persons have come out into the open publicly about their sero status locally, nationally and internationally.

- The organisation also brings more hope to the AIDS patients through supportive counselling at their homes and through the Home Based Care program.

- KIWAKKUKI has managed to fight stigma in local communities where HIV/AIDS patients have been ostracized, and linked persons victimized by stigma up to other Human Rights organisations. Through counselling people's quality of life has improved, and the silence at family level concerning HIV/AIDS and related issues is broken in many families and neighbourhoods.

- KIWAKKUKI's work with AIDS orphans brings hope and more positive living to more than 2000 AIDS orphans in the Kilimanjaro region who would otherwise have been in distress, left to themselves and/or in poor economical, social and/or health condition.

- KIWAKKUKI has made a book on AIDS, which is now being used from Standard 4 upwards.

- The formation of the organisation Youth Alive Kilimanjaro has been important for mobilising young people in the HIV/AIDS work in the region. This organisation collects youngsters for active work in behaviour change. It is important to have youth working with youth. Young people thus guide others to choose their values in life and how to hold on to them. KIWAKKUKI helped to initiate Youth Alive Kilimanjaro, which is now registered as an independent NGO. Youth Alive still receives support from KIWAKKUKI.

Climate for celebrating

- Members of KIWAKKUKI have an impressive and energetic way of singing, "Things are getting better", "We are one big family" and other inspirational songs every time they gather, or every time there are guests or donors arriving. They have a talent for making social gatherings totally successful, with singing, celebrating and socialising, thus promoting the feelings of fantastic group cohesion. The active PLHA lead on in singing and dancing, proving that they are tremendously multi-talented assets to the KIWAKKUKI.

- The annual Social Action Trust Fund cheque for primary school sponsorship for the AIDS orphans supported by KIWAKKUKI is always presented in the office of the Regional Commisioner, with a procession, cheering and singing.

- Each Annual general Meeting is like a festival for the KIWAKKUKI members. For the 10th anniversary of the organisation there were a series of celebrations.

Sources for inspiration and energy

The KIWAKKUKI core values, Voluntarism, Unity, Recognition of talents, Love and Respect, are a constant inspiration to the members of the organisation. The individual experiences that each member of the organisation has, of AIDS in their homes, in their families, in their neighbourhoods and among their friends, put the epidemic on the personal agenda of everyone, and urge them to go on. Several of the people that the evaluators have talked with over the evaluation period – people active in the Management committee, and/or among the founders of the organisation, and/or working in the Head Quarters, have been directly affected by the epidemic in their own immediate family. It also feels like an enormous inspiration that friends and family members, parents and husbands, support the work and share the visions of the active members.

Dreams of transcending the current situation

Reduced AIDS rate is the utmost dream for the future. It is also important to work and hope for grassroots self-sustaining in the KIWAKKUKI branches. A more responsible community is clearly a goal. To achieve this, KIWAKKUKI has a vision for the future, which is to supervise and monitor the AIDS Prevention and Care Programmes, Projects and Interventions in the Kilimanjaro region. Greater socio-economic empowerment of grassroots, for a greater improvement of community life and overall development compared to the underdevelopment caused by HIV/AIDS is also on the wishing-list. Likewise, the construction of an office block for the organisation, for sustainability, is also a wish. KIWAKKUKI wishes to partake actively in the creation of a gender-balanced society where rights and responsibilities are equally shared.

5

Conclusions and recommendations

Conclusions

The main objective of the planned assessment was to provide qualitative information about the reflections, lived experience and visions for the future, from actors, participants, members and recipients at different levels of KIWAKKUKI's many core activities. The evaluators managed to collect the data as intended. Based on the individual and group interviews, interactive discussions, the evaluators' participation in several of KIWAKKUKI's daily activities, field visits to local branches of the organisation, home visits to patients, and interviews with orphans, the evaluators conclude that KIWAKKUKI is a strong organisation with clear visions and objectives and with very dedicated members at all levels.

KIWAKKUKI has had an impressive development from the organisation's inception in 1990. KIWAKKUKI's many members are clearly conscious of KIWAKKUKI as a women's organisation and of its importance in empowering women in the fight against the AIDS epidemic and its impact. The core activities of KIWAKKUKI are headed by mature and open-minded women who reflect on their daily challenges, who are open to criticism and new ideas, who think of their organisation in terms of constant improvement and strengthening. The leaders are conscious of the importance of including and empowering women from all walks of life and all age groups in their region, and of the importance to collaborate with other like-minded organisations in the fight against the epidemic.

The organisation includes HIV positive women at all levels, and these women play an important part in HIV-prevention, home visits and care, as well as in the activities of The Centre of Hope (activities which only allow participation of People Living with HIV/AIDS). The HIV-positive KIWAKKUKI members play an important role in inspiring others both within the organisation and in the general public, and in creating hope for the future both at the individual level and in their community. They are important role models for others.

The AIDS epidemic has spread and reached different stages during the history of KIWAKKUKI. Many people in the Kilimanjaro region are now in the terminal phases of their lives and in need of care, people are dying every day

in large numbers, and the number of AIDS orphans is increasing dramatically. KIWAKKUKI had foreseen this development at an early stage, and has therefore constantly worked to improve its skills and its capacity to meet the increasing challenges and to mobilise the local communities to take responsibility.

The evaluation team represents 15 years of experience from HIV/AIDS related work in Eastern and Southern Africa, and can clearly say that KIWAKKUKI is a leading organisation against AIDS in the area. This does, however, not mean that KIWAKKUKI does not face difficulties and enormous challenges. As most African NGOs, KIWAKKUKI is constrained by limited resources and constantly face the risk of overburdening its devoted members. In this context it is admirable that KIWAKKUKI's members manage so well to celebrate small and big victories and that they continuously manage to give each other moral support and encouragement. This is, on the other hand, maybe one major reason why KIWAKKUKI manages to face up to the difficulties and challenges without facing symptoms of overburdening.

Recommendations

With these overall positive concluding remarks, the evaluators will, nevertheless, point to certain challenges that could deserve more attention from the KIWAKKUKI leadership, and make the following recommendations:

- **Admit and permit needs to rest.**

KIWAKKUKI members are good at encouraging each other, but seem to have no culture for employees and volunteers to tell each other when they are tired, drained, depressed, and need a rest or new stimulation. The evaluators realise that the daily challenges are of a character that does not invite KIWAKKUKI members to think much about themselves, but wish to encourage KIWAKKUKI to take care of each other also in terms of creating culture for breaks and new stimulation to minimise the risk of burn out.

- **Strengthen access to updated AIDS transmission and medication knowledge.**

KIWAKKUKI counsellors, staff and volunteers have acquired an impressive level of skills in HIV/AIDS health education and counselling, both on individual, couple, family and community level. However, they still feel the necessity of updated knowledge on AIDS (e.g. new knowledge based on medical research, new

knowledge on what to advice HIV-positive mothers concerning breast feeding, knowledge on side effects and risks connected to certain available medication, etc). AIDS is not only a medical and social challenge, but also involves sensitive political issues. KIWAKKUKI should be given opportunities to be updated and to take part and play a leading role in the public debate in a well-informed way. One example of current and future challenges is the offering of AIDS medication that has not been adequately tested before recommended for use. Linking KIWAKKUKI to international networks that might have updated knowledge on drugs and related issues is therefore recommended (see Annex 6 for one recent example).

- **Strengthen counselling capacity and relevant counselling skills in talking with women and men about their sexuality.**

KIWAKKUKI also wants and needs to strengthen its counselling capacity. Counselling the women who come in search of information and guidance is an important part of KIWAKKUKI's work. As one of the counsellors said: *"We certainly need more skills to all our people who do counselling, like we do. Women talk so much with each other, and therefore it is so important that we know how to meet them, and give the correct answers to all the questions and worries."* The counsellors feel that they see so much potential in a woman-to-woman conversation, and they often receive feedback stating that it is very reassuring to be able to talk as a woman to a woman who is skilled in the matters of sex education and HIV/AIDS related issues. But skills to talk about sex should also include skill to talk about sex to men. Interestingly, (indicating that women are leading the way!) in KIWAKKUKI today, there is actually a steady increase in the number of men who come in for counselling. This opportunity of influencing men's sexual risk behaviour and their attitudes to women should not be lost. The work with men's sexuality can be strengthened and the counselling requests can be used constructively if the counsellors receive more training on how to talk to men about their sexuality.

- **HIV Test-kits should be available.**

The evaluators support the KIWAKKUKI's expressed wish to have HIV Test-kits on the KIWAKKUKI premises. The counsellors feel that they would be able to do a much better job if they would be able to do the HIV testing in the KIWAKKUKI's premises. Having the test-kits would also mean they would be able to test patients on their home-visiting missions as well.

- **Strengthen the knowledge on AIDS orphans' needs and the skills in counselling children.**

KIWAKKUKI meets a rapidly increasing group of AIDS orphans at different ages. Some of these children are themselves HIV-positive. The AIDS orphans have usually gone through long processes of witnessing their parents' illness, terminal phase and death. They have fears and fantasies of what the dangers entail. Usually the adults in their surroundings do not talk to them about what is going on and what will happen to them and why. The children have often been thrown into premature adult roles of caregivers. Often the siblings are separated after death in a family. Children's grief processes and reactions to traumatising conditions are often different from those of adults. KIWAKKUKI needs more knowledge on children's basic needs at different age levels and on children's reactions to death and traumatising conditions. The training should also include how to talk to and counsel children at different age-levels. This means that skills in counselling children should be strengthened.

- **Intensify the incorporation of PLHA in the organisation.**

Even if the evaluators praise the way KIWAKKUKI includes HIV positive women, the organisation might be even more active in involving HIV-positive women in the development and implementation of policies and programmes within the organisation. Their position in decision-making within the organisation can also be strengthened. If finances do allow, more HIV-positive women who are skilled in health education or in other relevant areas of work, could also be employed on the same terms and conditions as the current employed staff.

- **Strengthen the network for economic empowerment of financially disadvantaged women.**

KIWAKKUKI should also look into possibilities of targeting economic empowerment and strengthen income-generating activities for women. This can be done through linking up with other organisations and work places. Special efforts might be needed for HIV-positive women who are at an advanced level of disease development. The evaluators realise that economic empowerment and income-generating activities represent a general challenge in the geographical region, but still think that there might be some new avenues to be pursued in co-operation with others in the region.

• Community-based anti stigma work needs more efforts.

One of the important challenges KIWAKKUKI is faced with is the stigma in the region. Even if stigma has decreased since the early period of the epidemic, it is still substantive, particularly in the rural areas. KIWAKKUKI puts great emphasis on openness about one's sero-status and encourage people to share their diagnosis with others if they are HIV-positive. From a prevention point of view this is of course very important. However, the families and communities are not always supportive. There are still great individual loads of social and cultural, psychological, some times even legal and economical, burdens implied in coming out and being open about one's sero-status. The main burden for increasing openness is therefore often put on those who already are infected / affected by the epidemic and who already carry heavy burdens. We recommend that KIWAKKUKI intensify the anti-stigma work in the communities, so as to stimulate the development of more supportive and enabling communities. If people living with AIDS realise that they might receive sympathy and supportive reactions from their family and neighbours, it will be easier to come forward as PLHA. We therefore recommend that KIWAKKUKI intensify their community work on the challenges related to fighting the stigma connected to AIDS.

• Need for a mobile Information Centre.

The evaluators support KIWAKKUKI's idea about a mobile information centre for use in the rural areas.

• Question Youth Alive's major strategies for HIV prevention.

The Youth Alive has several optimistic visions for the future. They want to increase the number of branches, have an Information Centre with posters, video and other written material, have a sports team, and a teaching team. They wish equipment, a blackboard and chairs, in order to educate more youth counsellors. They want to have their own teachers. They also wish to give health education in the rural areas and therefore need money for transportation. The evaluators question Youth Alive's strategy of "Secondary Virginity" as a main approach to preventive work among youth. The questioning is based on research knowledge from the Kilimanjaro region which shows that young people in Kilimanjaro has a high level of sexual activity and has their sexual debut at an early age. "Secondary Virginity", however well intended, may not meet the sexual needs and desires of young people in an adequate way to minimise the risk of HIV-prevention. The role of the young girls in Youth Alive seem unclear and they might need more empowerment support and skills training in how to meet sexual approaches from elder men (confer the high

rate of HIV infection among the youngest groups of girls in the area). According to KIWAKKUKI informants, KIWAKKUKI feels that it has not been able to follow up Youth Alive well enough. The issue of condom promotion and condom use should be followed more closely (see also recommendation below).

• Strengthen the emphasis on condom use as a preventive strategy.

The evaluators realise that the promotion of condoms meets many obstacles at cultural and religious levels as well as from the public discourse on the quality of condoms and issues of promiscuity. The recurring stories on failing quality of condoms as assessed by the national institution for quality control of condoms, should be used as a way of ensuring people that quality control is taken seriously in Tanzania. Since people continue to have sexual intercourse it is certainly better and more protective to have intercourse with condoms than without.

• Challenge Political leaders and the Government.

The evaluators support the KIWAKKUKI members who state that "to influence men's sexuality one must start at the top". The evaluators encourage KIWAKKUKI to challenge the regional leaders and the Government to take a clear stand and show their attitudes towards sexual risk behaviour.

The evaluators realise that KIWAKKUKI is constrained by limited resources, few employed people and that the organisation works mainly in the spirit of voluntarism with its many members. The suggestions for improvements / changes / strengthening should be understood as a way of constructively encouraging the organisation, and hopefully inspire KIWAKKUKI members, in their many current and future challenges. The recommendations must also be interpreted in the context of the overall impression of KIWAKKUKI's work. KIWAKKUKI is an impressive NGO, which leads the way in the fight against AIDS.

Annex 1

Terms of Reference

1. INTRODUCTION, KIWAKKUKI AND THE 2002 EVALUATION

KIWAKKUKI (Women's Group Against AIDS in Kilimanjaro) is a grass roots initiated organisation in Tanzania. The organisation has received financial support from 1997 and to date from Kvinnefronten/Women's Front of Norway through FOKUS, Norway. The funding from the Women's Front of Norway has mainly subsidised the running of the Head Office, sponsored female secondary school AIDS orphans and activities of Education Team Outreach, as well as supported grass roots women's activities through soliciting support from the Tanzanian district councils. The Women's Front of Norway is but one of several donors who support KIWAKKUKI's diverse activities.

KIWAKKUKI sends annual reports and audited accounts to the Women's Front of Norway. Such reports contain statistics of activities with brief descriptions. The annual reports also describe planned activities and activities performed, and provide explanations for deviations from planned activities (whether positive or negative). KIWAKKUKI's financial report system / format for auditing has already been evaluated. The annual reports and annual audited financial reports which are quantitatively oriented in an input–output format, fulfil the requirements that most donor agencies expect from a donor recipient.

The main objective of the planned assessment is to provide qualitative information from the reflections, lived experience and visions for the future based on information from actors/participants/members/recipients at different levels of KIWAKKUKI's many core activities. Such qualitative information will be explored through interactive interviews/discussions with key informants. The hope is that the assessment process will provide useful insight and be a learning process for KIWAKKUKI as well as for Kvinnefronten/Women's Front of Norway and FOKUS, Norway.

Photograph left: KIWAKKUKI in the field.

2. PROJECT BACKGROUND

The need to organize women for HIV/AIDS fight and community advocacy in Kilimanjaro region began after a group of women from in and around Moshi ran educational activities for the 1990 WHO's World AIDS Day around the theme of "Women and AIDS". It was already evident that AIDS was a women's burden in many senses. It is against this background that KIWAKKUKI was formed as an opportunity for voluntary members to:

- Raise community awareness about HIV/AIDS, particularly targeting women and young people.

- Help restore dignity, self-respect and purpose to the lives of individuals and families affected by HIV.

- Help develop a sense of responsibility within communities for HIV prevention.

- Identify the physical and psychological needs of HIV infected people and their families and coordinate support for those in need.

- Raise the status of women in family and community life so as to reduce the threat of HIV infection.

- Cooperate with other groups and organisations dealing with HIV/AIDS, including the sharing of information and resources.

Date of Registration: 3rd July 1995. Registration No. SO.8488.
KIWAKKUKI celebrated its 10th Anniversary in the year 2000.

KIWAKKUKI's Vision

To see Kilimanjaro community taking responsibility for HIV prevention and Care for an AIDS free generation.

KIWAKKUKI's Mission

To provide HIV/AIDS education, offer support to those infected and affected and to stimulate a sense of responsibility to individuals, families and communities for HIV prevention.

KIWAKKUKI's Core values

Voluntarism, Unity, Recognition of talents, love and respect.

KIWAKKUKI's Core Purpose

To unite women and help each other harness our skills/ talents, in order to face life's challenges and restore dignity, self respect, and purpose to the lives of individuals and our families.

KIWAKKUKI's Stakeholders

(i) KIWAKKUKI beneficiaries:

- People Living with HIV/AIDS (PLHAs), i.e. the infected.

- Families of PLHAs like orphans and those caring for the AIDS patients i.e. the affected.

- Various community segments, e.g. women, men, youth and children in urban and rural areas.

(ii) KIWAKKUKI Service Providers:

Volunteer members who work in teams of mainly women, youth and a few men.

- Education Team members, inform the community at large about HIV/ AIDS Prevention and how to live with the disease by caring for the infected and the affected. They also provide information about other services offered by KIWAKKUKI.

- Home visiting Team members, visit the clients at their homes and provide home care and counselling to individuals couples and relatives.

- Orphans' Identification and Monitoring committee members, devote their time helping this very needy group throughout the year.

- Employed staff who act as a link between the volunteers and the community.

(iii) Like-minded organisations:

KWIECO, NAFGEM, Rainbow Centre, NGOTAC, ANNEA, NACP, TGNP etc.

(iv) Local / National / International authorities:

The Ministry of Health, The Regional Medical Officer, The District Medical Officer, UNAIDS and the donor community.

(v) KIWAKKUKI members:
who are mostly women from all walks of life and men who are accorded honorary membership.

KIWAKKUKI's Project site/area
The project area is Kilimanjaro Region which is one of the 20 regions of Tanzania located in the North East of Tanzania with an estimated area of 13,309 sq. km., and the estimated population is 1.509.750. KIWAKKUKI offices are situated in the Moshi AIDS Information Centre, Mankin'ga Street, Moshi.

KIWAKKUKI's Sources of Funding
KIWAKKUKI has received funding from the following sources:

- German Development Services – office running and internal evaluation.
- Child Foundation of Netherlands – construction of 1 house for orphans.
- Women's Front of Norway – office running, programme management, office equipment ,capacity building for grassroots women, publications etc.
- Terre Des Hommes Foundation (Switzerland) – AIDS Orphans' support, primary school, secondary school, vocational training and Youth Alive Kilimanjaro Club.
- Social Action Trust Fund – AIDS Orphans' primary school sponsorship.
- Netherlands Organisation for International Development Co-operation (NOVIB) – Home-based care project.
- Friedrich Ebert Stiftung – Capacity building and Annual General Meeting.
- Oxfam Ireland – for Community Empowerment / ownership of HIV/AIDS prevention and care.

3. PURPOSE AND OBJECTIVES OF THE EVALUATION

The main objective of the planned assessment is to provide qualitative information from the reflections, lived experience and visions for the future based on information from actors/participants/members/recipients at different levels of KIWAKKUKI's many core activities.

The assessment participants will be asked to think back (for those who have participated for a long time) and reflect upon the visions they had for KIWAKKUKI and their own roles when the organisation started, how such visions have been influenced by experiences over time and how. For those who are relatively new in KIWAKKUKI, they should be asked why and how they joined KIWAKKUKI and what their impressions of KIWAKKUKI's activities and visions are.

Specific key topics to be covered at the evaluation will be:
a) Local HIV/AIDS situation of women in the region – implications for prevention and care.

- The local situation of women (including themselves) regarding HIV-prevention initially and today: The perceived risk for HIV-transmission, women's potential for taking preventive action, women's power and negotiating capabilities and how KIWAKKUKI did/can strengthen such power and negotiating capabilities. The issue of condoms and women's role in negotiating condom use. How have these issues changed over time?

- Women (including themselves) as care-givers in the era of the evolving epidemic, the changed care-situation and how women themselves individually and through KIWAKKUKI have met the changing care challenges.

- Women and the AIDS-orphan-generation. Women as caregivers and their role in preparing the children for becoming orphans, planning for alternative care- and support systems. KIWAKKUKI's role in orphan advocacy in the local communities.

- Women living with HIV/AIDS, how were they met/included initially in KIWAKKUKI and how are they met/included today. What is their role in KIWAKKUKI? Has there been a we/they orientation? Are women living with HIV/AIDS considered full-fledged members/activists? What about their roles in empowering others and in HIV/AIDS advocacy work?

- What is your personal history of why you as a woman joined KIWAKKUKI and why you are a member/activist of KIWAKKUKI?

- How do you feel that working with KIWAKKUKI has strengthened your own role as a woman and as an HIV/AIDS activist?

b) Organisational issues – size, decision-making structures, donor influence, feminist perspectives, inclusion, urban/rural variations.

- KIWAKKUKI has grown within a 12 year period from being a small grass roots initiated movement to a relatively big organisation with funding from several agencies. How has the change in KIWAKKUKI's organisation in terms of size, structure, modes of co-operation and visions/objectives influenced the kinds of activities that KIWAKKUKI is involved in? Do the donor-agencies' terms and conditions put restriction on some of the ways KIWAKKUKI wants to function? If yes, in which ways?

- Does the reporting format and auditing format required from the different donors influence the way KIWAKKUKI works and how KIWAKKUKI makes its own priorities?

- What about the reporting format required by FOKUS?

- KIWAKKUKI sees itself as an organisation that needs to network with other local, national and international organisations. How has this co-operation/ networking changed over time, why and what are the current visions of KIWAKKUKI in this regard?

- Has the internal decision making structure within KIWAKKUKI itself changed as the organisation has grown? In what way and why?

- How does the changes in decision making structure influence individual women's suggestions and possibilities of influencing KIWAKKUKI's priorities and activities?

- Has the change influenced KIWAKKUKI's identity as a women's organisation and the vision of empowering women? In what way?

- What do you consider the biggest achievements / victories of KIWAKKUKI's work?

- How does the organisation solve internal conflicts or discrepancies? How are new suggestions being met?

- The Centre of Hope, how was it initiated, by whom and why? What was it like when it started and how does it function today?

- The urban / rural variations. What was the vision behind creating smaller centres in the districts? What kind of co-operation is there between the Head Office and the smaller centres?

- Are there special challenges in the local smaller centres in the districts? In what way and how do/can women empower each other in the rural areas / the smaller centres?

c) Stigma / antistigma and other obstacles.

- The issue of AIDS-related stigma, how did it affect women initially and how does it affect women today. Have there been any changes/improvements? What has been and is the role of KIWAKKUKI to fight stigma? What are the current challenges?

- Fighting the culture of silence, empowering women and others to be open about their sero-status in different forums (family/including children, extended family, neighbourhood, local community, publicly). Obstacles experienced and overcome from within (among the women themselves), from partners, from family-members, extended family-members, community at large, etc. Experiences from within KIWAKKUKI and KIWAKKUKI's experience from raising these issues with others (male partners, family, neighbours, community key leaders etc.).

- Overcoming obstacles at a personal level, at family-level, within the community, within KIWAKKUKI. Taking responsibilities at different levels, women's experienced obstacles, challenges and victories.

d) Inspiration, hopes and visions for the future.

- Is there a climate/tradition in KIWAKKUKI for celebrating small and big victories? If yes, how?

- Where does the energy and inspiration to continue working come from, and how to create and nurture such energy and inspiration when the impact of the epidemic is increasing?

- What are your dreams for the future?

- What are your visions of future gendered relations?

- What are your personal visions for the future of KIWAKKUKI?

- Do you have suggestions/dreams for transcending the current situation? Where should we jointly put our hopes and efforts in the future, in your opinion?

4. APPROACH AND METHODS

The qualitative information will be explored through interactive interviews / discussions with key informants (Denzin, N. K. Interpretive interactionism. Sage,1989, Newbury Park). The interviews will cover key topics listed in the terms of reference, but will also invite the evaluation participants to express their own concerns, reflections, good experiences, ideas and visions for the future, their perspectives on feminism and the empowerment of women, their hopes and aspirations for the coming generations regarding gendered relations, and their views on how KIWAKKUKI can contribute to a better future.

Key informants in this context refer to women who are involved in / central to KIWAKKUKI's 8 core programme components and the 2 specific projects (AIDS Orphans School Sponsorship and KIWAKKUKI Home Based-Care). Women at all levels of the organisational structure should be selected for interviews / interactive discussions. The selection of persons to participate in the assessment should therefore include representatives of all stakeholders whether they are defined as 'beneficiaries' (PLHA, and families of PLHA), 'Service Providers' (activist, volunteers, paid staff) in the Education Team, Home Visiting Team, the users of the Centre of Hope, the Committee for Orphans' Identification and Monitoring. Members from the local rural branches should also be involved in the assessment process. The selection of participants should thus reflect both the range of KIWAKKUKI's activities, the range of levels of active/passive membership, the range of roles in the decision-making structure (e.g. women in the Management Committee, the Board of Trustees, employed personnel, volunteers, members) the range of rural/urban diversity, different age-groups of KIWAKKUKI members/ beneficiaries. KIWAKKUKI stakeholders will be called upon to assist in selecting individual representative assessment participants from the different core program components and specific projects. Group discussions and focus groups can also be performed in order to obtain insight regarding the visions, impressions and experiences.

5. OUTPUTS

The main output of the assessment will be a report of not more than 30 pages (excluding annexes) containing:

- Executive summary (introduction; background; main conclusions and recommendations).

- Presentation of the visions, the experiences, the lessons learned, obstacles overcome, inspirations and energy for KIWAKKUKI as expressed by the diverse participants of the organisation.

• Conclusions and recommendations.

• Annexes including the evaluation terms of reference, methodology, timetable, findings, and background documents reviewed.

6. TEAM MEMBERS, SCOPE OF WORK AND TIME SCHEDULE

The evaluation will be carried out by a team of two independent consultants: Gro Th. Lie, professor and Director of the Research Centre for Health Promotion (HEMIL), University of Bergen, and Ellen Alexandra Lothe, lecturer at the Lovisenberg Diaconal College. The team will work together in the Kilimanjaro province for six days on the evaluation objectives, Lothe will continue this work alone for another four days. Professor Lie will be contracted for 12 days (4 days for desk review, preparatory work and meetings; 8 days for travel and field work). Lothe will be contracted for 25 days (3 days for desk review, preparatory work and meetings, 12 days for travel and field work, 10 days for report writing).

The terms of reference will be reviewed by KIWAKKUKI and will be approved by FOKUS, the Women's Front of Norway and Norad.

The evaluation will take place in the Kilimanjaro region in Tanzania from 21st May to 1st June 2002. Prior to this, Professor Lie and Lothe will meet in Bergen with Agnete Strøm from the Women's Front, and Mette Moberg from FOKUS, to plan the evaluation, prepare data collection tools, and review background material.

The proposed timetable for the field work is as follows:

Wednesday, 22nd May:	Visit to KIWAKKUKI head quarters. Introductions, planning and initial discussions with project staff, review of monitoring records and project reports, finalisation of qualitative data collection tools.
Thursday, 23rd May:	Visit to local rural branch of KIWAKKUKI (I).
Friday, 24th May:	Visits and meetings with the Information Centre and with Orphans' Identification and Monitoring committee.
Saturday, 25th May:	Visits to Centre of Hope and interactive discussions with members/users of Centre of Hope.
Sunday, 26th May:	Visits with Home Based Care Group.

Monday, 27th May:	Meetings with Education Team members.
Tuesday, 28th May:	Visit to local rural branch of KIWAKKUKI (II).
Wednesday, 29th May:	Meeting to discuss tentative summary of findings with KIWAKKUKI staff and leaders.
Thursday, 30th May:	Compile findings, prepare report outline and presentation.
Friday, 31st May:	Oral feedback to KIWAKKUKI staff

Note: Visits to KIWAKKUKI activities are just tentatively scheduled above. Finalizing of programme will have to be done on location, in co-operation with KIWAKKUKI leaders / stakeholders.

Lothe will present her preliminary findings and recommendations to KIWAKKUKI staff and activists at KIWAKKUKI headquarters prior to leaving Tanzania. Lothe will produce a draft report by 28 June 2002. The draft report will be reviewed by KIWAKKUKI representatives and Professor Lie. The final report will be produced with feedback from the review process incorporated, and will be submitted to the Womens' Front and FOKUS by 26th August 2002.

References

Denzin, N. K. (1989):
Interpretive interactionism. Newbury Park: Sage Publishing House.

Annex 2

Timetable for fieldwork

DATE	ACTIVITY	RESPONSIBILITY
Tuesday 21st May	Receive guest at KIA	D.K.Itemba,A.Mlay, R.Olomi, L.Kissija
Wednesday 22nd May	Visit to KIWAKKUKI headquater. Introductions, plannings and initial discussions with project staff, review of monitoring recordings and project reports, finalising of qualitative Executive.	- Projcet officer - Other employees - Chairperson - Evaluators
Thursday 23rd May	Visit KIWAKKUKI Information Centre. Meet Education Team members and Youth Alive	- Prigramme officer - Health Education - Evaluators
Friday 24th May	Visit to KIWAKKUKI grassroots branch Kolila. Visit to some orphans	- KIWAKKUIKI Chairperson - Executive Coordinator - Evaluators
Saturday 25th May	Visits with home based care	Fuasia Kishe Dora Elia
Sunday 26th May	Community visit to grassroots Branch Mamboleo	- Going to church with Eunice. - PLHA - Dr. M. Temba
Monday 27th May	Meet Counselling and Home Visiting Team. Meet Youth Alive Kilimanjaro. 2 visits School of Nursing.	- Home visiting team - Chairperson/Secretary of Youth Alive Kilimanjaro
Thuesday 28th May	Visit orphans identification and monitoring committee. Visit Mwanga branch.	- Orphans project Officer - Prof. Gro Lie leaves - Kiwakkuki Management
Wednesday 29th May	Meeting to discuss tentative summery of findings with Kiwakkuki staff and leaders.	- Project Officer - Management Committee - Ellen A. Lothe
Thursday 30th May	Compile findings, prepare report outline and presentation.	- Ellen A. Lothe
Friday 31st May	Visit Centre of Hope and interactive discussions with members/users .	- Chairperson Centre of Hope - Kiwakkuki management - Ellen A. Lothe leaves

Annex 3

People met and places visited

AIDS orphans supported by the KIWAKKUKI:

- "Ellinor", 17-year-old girl, supported by Women's Front of Norway
- Anonymous girl, who came to the KIWAKKUKI office to collect her yearly support (supported by Women's Front of Norway)
- 5 secondary school students (3 boys and 2 girls) at the Julius K. Nyerere Secondary School
- "Ruth", 18-year-old girl

Home visits to AIDS orphans:

- "Wilfred", 10-year-old boy, AIDS orphan and HIV positive
- "Elisa", 15-year-old girl, AIDS orphan and HIV positive
- Two AIDS-orphaned brothers and their aunt
- "Betty", 18-year-old girl, one of the students/orphans met at the Julius K. Nyerere Secondary School

Some of the founder members of KIWAKKUKI:

- Dr. Sabina Mtwewe, M. D., M.P.H.
- Alewio Macha, teacher

Visits to KIWAKKUKI local branches:

- Kolila, participated in branch's General Annual Meeting. Approx. 40 members and several male honorary members from the village were present, among them the village Chief. Also present were approx 30 women from a neighbouring village, as invited guests.
- Mamboleo, participated in branch's General Annual Meeting. Approx. 30 members and one male honorary member, the village Chief, were present.
- Mwanga, meeting with two key persons: the Chairperson and Co-ordinator of the local Education Outreach Team.

Visits with Home Based Care Group to HIV positive patients:

- Woman in her late 40's, who was among the first to be tested positive in 1991 (in the MUTAN project) after her husband died. At this stage feeling weak, with head aches, blurred vision and trembling.

- Elderly woman, widow, whose grown-up children have all married and moved away. Weak, lonely, bedridden, dependent on young housemaid.
- Young woman in her early 20's, single mother of a four-year old child who lives elsewhere with relatives, and a newborn baby who died four months ago. The young woman lives with her mother, who herself is a widow who already has lost two of her children in AIDS. The young woman is extremely thin, has suffered an extreme weight loss, has severe difficulties moving around and suffers from sores on scull and extremities.

KIWAKKUKI executive committee members, office staff employees and KIWAKKUKI branch members:

- Mary Mallya, assistant accountant
- Eunice Maringo, accountant
- Dafrosa Itemba, executive co-ordinator the last 4 years
- Lui Mfangavo, Orphans' Project Officer
- Piala Arcadi, volunteer in the Orphans' dept., and assistant office attendant
- Agness Urassa, volunteer in the Orphans' Project, employed by the government in the Regional Social Welfare office, and Vice Chairperson of the KIWAKKUKI management committee
- Rayline Ndanshau, office attendant
- Romana Mallya, secretary
- Valentina Swai, member of Centre of Hope
- Anna Mgonja, Programme Officer for Teaching Team and Counselling Team
- Valeria Shayo, management committee member
- Shirikiande Moshi, member from Kolila Branch
- Farida Mkwizu, chairperson Mwanga branch
- Ester Bura Nahato, co-ordinator of the Outreach Team, Mwanga branch
- Scolastica Mbuya, treasurer, member of the Kolila branch working group
- Amina Mlay, Chairperson of the KIWAKKUKI management committee, nurse and midwife at KCMC Hospital

Youth Alive members:

- Joseph E. Kimaro, member
- Anaeli Mosha, vice chairperson in the Youth Alive executive committee
- Mussa Ally, member
- Ludovic Samora, B- chairperson in the Youth Alive executive committee
- Laurence Joseph, S- chairperson in the Youth Alive executive committee
- Kirama Urio, treasurer
- Daniel Elias, member

People living with HIV/AIDS (PLHA):
• Dora
• Valentina
• Esta

The Centre of Hope:
Approximately 60 HIV positive participants, among them approximately 40 women, 10 men and 8 children aged from 2 to 14.

Members of the Education Team:
• Catherine A. Puka, nurse
• Dr. Martha F. Temba, AMO at Mawenzi Hospital Eye Department
• Alewio Macha, teacher
• Dora Elia, member of KIWAKKUKI, member of Centre of Hope
• Very Nice Monyo, teacher, Chair Person of Education team
• Romana Olomi, nurse/social worker, counsellor and health educator

Co-operating organisations/networking participants:
Mr. Ezekiel E. Muhubiri, director general of the QOHELETH Foundation, Tanzania – a rural youth development organisation with head quarters in Moshi.

Members of the Counselling Team:
• Valeria Shayo, nurse
• Dora Elia, PLHA
• Caroline Sululu, nurse at the MCH clinic
• Valentina Swai, PLHA
• Fudasia Kishe, nurse
• Catherine Puka, nurse

Leader of the Home Based Care Unit:
• Lightness Kaale, Clinical Officer

Annex 4

Excerpts from interviews with founders of KIWAKKUKI

Dr. Sabina Mtwewe, M. D., M.P.H.:

– If you reflect back on your visions at the time of the birth of the KIWAKKUKI, how has the organisation developed?

"We gave priority to giving out information in the beginning. We saw that people came to our functions, raising questions and showing interest. We thought then that what is needed here is information, in order to change behaviour and stop the AIDS epidemic. Now we have seen that people are being infected at a horrendous rate, in constantly bigger numbers, even if we have given out such a lot of information for years. So we actually feel a bit disappointed, asking ourselves if maybe we have not had as much impact on the development of the epidemic as we had thought we would in the first place.

We actually realised from the very beginning of the epidemic that many people would get sick and need home care. And we were prepared that there would be orphans who would need help. These needs – information, home care and help to orphans – have been on the increase.

However, what we needed to have considered much more was the economical situation. We must have income generating activities. But this is difficult. We are trying, but are not successful as of yet. We do work on it, and try to connect with people who have knowledge on income generating. The general income here in Tanzania has decreased during the last 10 years. The people we are working with are poor, and their salaries do not have the same buying power as before. Life is getting harder. Demand on the services that KIWAKKUKI can render has increased – both demand on material and economical aid and also demand on the time we are expected to give as volunteers in the organisation.

We have achieved a lot, though: Women who have been active with us in the organisation have been empowered – they are now being able to talk, to lead groups and discussions, to bring up topics for discussion. From my own experience I can say that we who have worked here in the KIWAKKUKI all these years, now have so much more of courage, and empowerment. Now we are able to stand up and say what we mean.

We do not discuss so much about our own visions, neither about the support we give each other. All of us have been affected by the epidemic in some way or the other. Myself I have lost a brother and his wife, and my husband and I take care

of two orphans from two different families within our family network. Our own children are 23 and 19. We do not speak so much about 'risk groups' any longer, because we know that we are all at risk. So we just give each other support without talking too much about these details."

– *Your visions for your children?*

"My wishes for the youngsters in the family are that they be able to be open to their partners, be able and willing to discuss everything with them, admit faults to each other, and understand each other. It is so important to be open to each other about having been infected. This is such a sensitive issue, and very dramatic to the children, but I believe we must work hard to be open about our own sero status as well."

– *How do you foresee that KIWAKKUKI can be of help?*

"We will be able to work more with the school health programs, and teach people not to be too harsh on their children. We will teach people to be more patient and understanding towards their children. You know we are quite strict with our children here in Tanzania some times. We ought to be more understanding, also because that is a way of encouraging honesty in the children. Even outside school we should work with this, in small groups. But in our culture it is common that men hide what they are doing, and women also hide what they are doing."

– *What are your visions for KIWAKKUKI today?*

"I want us to network more with other organisations, find out what the others are doing, influence them and find out what we can do together. One of the core problems is family life and sexuality, and people ought to be able to discuss it. There is a need for openness on these issues. I also want to expand our co-operation with the schools, in order to be able to socialize and sensitise the children at an early age.

Our Regional Commissioner here in the Kilimanjaro Region, who is a woman at the moment, wants us to start a new KIWAKKUKI group in Mbeya, in the Rungwe district. I think this is a sign that we are doing a good job and that people, even politicians, are aware of it."

Mama Alewio Macha, teacher:
Mama Macha is a member of the Education Team and also one of the very first members of the KIWAKKUKI. She says:

"The founders of the KIWAKKUKI were a small group of nurses at the KCMC hospital. We started with a small and informal group in 1989. I was in a group in the Lutheran Church, and a sister included us in the KIWAKKUKI group and we became incorporated. We worked as a fund-raising group, went to people and asked for donations, and had an expert from Uganda come here and help us. Diesel run grinding machines and oil pressing machines for the sunflower seeds were given to us by a German group. From what we earned we had to give 20 % to the KIWAKKUKI, for the running of the office and for the AIDS orphans. We also arranged fund-raising dinners. When KIWAKKUKI was recognised as an NGO, the support became more structured. Then we got a chairperson and a co-ordinator, later on we formed committees according to functions. We also got, for free, a hall in which to have our monthly meetings, which we have up till today. In these meetings everyone reports on what they have been doing during the last month.

The various district branches have their own budgets and economy, but when they are in economical difficulties, the KIWAKKUKI head quarters will help. The district branches give 50 % of their income, which is their annual membership fees, to the head office. The branches have their general meetings before they come here to head quarters to introduce good ideas to be incorporated. Information is shared, and if the ideas from the branches are good we incorporate them in our activities. For example, at our last meeting we discussed the candle-light procedure and how we are going to do it."

– *In your experience, what about your visions you had for the organisation in the beginning?*

"The problem of this epidemic is now growing bigger, and many more people have AIDS. Therefore more people see the necessity for action, and it is now easier for each district to have active groups and be self-contained. The amount of AIDS orphans is growing. In the Kilimanjaro region we count on a minimum of 50.000 AIDS orphans today. The actual number is probably bigger, but because of stigma many of the orphans are not openly AIDS orphans. Out of these 50.000, KIWAKKUKI supports 1570. The Norwegian Women's Front supported 17 of these in 2001. The government leaves the problem for the community to solve, giving only minimal help. In a certain Standard 7 in a particular school, 3 out of 5 children were AIDS orphans. The KIWAKKUKI reported it to the District Commisioner, who replied that, *'the basket is empty'*.

The AIDS orphans who finish form 6 and want to join the university, have a serious problem of financing their studies. They are entitled to have 40 % of their costs covered by the ward they belong to, but 60 % of the cost has to be covered by government grants, and this has to be applied for. Normally, youngsters from poor families are not able to get these funds because they do not have anyone to lobby for them. This is very particularly true also for the AIDS orphans. They need a letter of support from a local leader. The relatives of the AIDS orphans have to walk from house to house with such a letter from the District Commisioner, the letter asking for donations for the 40 % of the expenses that should be covered by the ward. These are often low-income districts, and to collect money is hard. People are poor, and cannot contribute.

In KIWAKKUKI we often find that after we have prepared our budget and distributed the resources we have, then new AIDS orphans appear, with many needs, some even without shoes. It is hard for us in those cases to tell them that they will have to wait for next year's budget. We have also found certain orphans who have been stripped of their rights to inheritance after their parents died in AIDS. KIWAKKUKI found a lawyer to fight their case, and was able to build a small house for these siblings.

Our cultural rites concerning burying and mourning are changing these days. The priests are saying that we should cut the mourning process down to one day only, otherwise too many days go away for mourning.

I work in the municipality of Msaranga. I can share with you a recent case from my practice: A child of approximately 10-12 years of age, in Standard 2, whose mother died in AIDS. The boy was born healthy, but became sick last year. The father is married again, to a young girl recently out of 7th Standard. If he had told anyone that he is HIV positive, he would not have got a new wife. So the father keeps up an image of being healthy. He tells his son: *'Don't play with other children.'* He is afraid the others will tease his son about the death of his mother. Last week the boy was so sick, and the teacher told the father. The father denied that the boy was sick, he said: *'Just beat him!'* He told the boy: *'If you take these medicines, I will beat you to death!'* The boy is so sick right now, with diarrhoea, but keeps coming to school. The teacher has had to tell the father that the boy should not come back to school until he is better from his diarrhoea.

We try to get the couples to come in for counselling before they get married, but they most often don't want to, they come when the wife has become pregnant, and by then there is nothing that can be done except marry them or bless them.

There is a rich family here in town who used to have seven sons and a good living standard. All the seven sons and their respective daughters-in-law are now dead. The grandparents are left with all the grandchildren. There was no-one to take care of the thriving business any more, so the grandparents decided to move

to the village. This has been quite dramatic for the children who were born and raised in the city."

– As you see how the epidemic is growing, which are your reflections as a woman, on the challenges that women have to face today?

"There is a challenge for our government to recognise this, i.e. how deep a problem this epidemic is, and that it is a problem for everyone in our nation, not only the infected ones, and then that everyone has got to fight against it. Give support; help with our own hands – we as women have to set an example so that the men can learn from us.

I, and we, have been committed to this work for years now, and it has become a part of us. We are touched by all the people we work with and the problems they have, and we feel attached to them. That gives us motivation to continue. Besides, we know it is our duty to do this."

– What do you do when you get tired of working in this field?

"The KIWAKKUKI does its very best for us, provides a drink of water when we are tired, and provides transport money. You can always come to the others in your group or in your committee, and refresh your mind. We might watch TV, or we might talk together, and the burden comes out. The others always welcome you if you are tired, they won't let you go until the problem is settled or you have been able to lay down your burden. The Information Centre is very useful. It is really a problem solver – when you walk in with a heavy heart, you walk out with a lighter one. I have experienced this myself. "

Annex 5

Excerpts from interview with KIWAKKUKI Orphans' Project Officer, Lui Mfangavo.

Lui Mfangavo is by profession a nurse with specialisation in Paediatrics. She joined KIWAKKUKI in 1996, wishing to participate in AIDS prevention by using her skills and experience to educate people and work with AIDS orphans. The KIWAKKUKI Orphans' Project started in 1998. Lui applied for the position as Orphans' Project Officer, and has been active in that position since 1999. Lui is responsible for KIWAKKUKI's work with orphans all over the Kilimanjaro region. She is heading a committee that plans all activities dealing with the problems of the AIDS orphans in the region.

– *Lui, tell us about the procedures for identifying and selecting AIDS orphans for support.*

"Each of the current 32 KIWAKKUKI grass roots groups has got an orphans' committee. The members of these committees are trained to identify the AIDS orphans in their neighbourhoods. The women in these local grass roots groups know each other well, and have a good knowledge of the different families in their districts. Therefore they have a fair knowledge of who is in need. Due to our economical limitations regarding the possibilities of sponsorship, these committees must try to seek out which of the orphans are in greatest need. They discuss their priorities at their meetings, and normally come to an agreement, although some times by voting. It is very difficult to have to judge the degree of other people's needs. However, I trust the voluntary work and assessment of these local grass roots women. Some times, though, I do pay unexpected, not notified visits to the local orphans' committees, and talk to the family members of certain orphaned children, in order to acquire an overview of the different levels of needs of the individual orphans, in relation to the priorities of the orphans' committees.

Whenever an AIDS orphan is identified in his or her local community, the Orphans' committee will find out whom, if anyone, takes care of the child. The committee will subsequently look into the financial situation of the possible caretaker. The ten-cells leader is approached and asked whether anyone in the child's family is able to take care of the child, or support the child and its caregiver financially. If nobody is capable of this support, for economical or other reasons, the Orphans' committee will consider the child as a 'needy orphan' Each local Orphans' committee within the KIWAKKUKI follows this procedure. Finally, representatives of all the local Orphans' committees will come together to discuss who of the needy orphans will be most in need, in order to qualify for the scarce amount of sponsorships available. When that decision is made, the AIDS orphan

will from then on be registered in the files at the KIWAKKUKI Head Quarters, and the child starts to receive help from KIWAKKUKI. Most of the recipients are children from 4 to 18 years of age, the majority between 4 and 13. There are also orphans younger than 4, but the majority of the ones that approach KIWAKKUKI are school age children, since word has got around that KIWAKKUKI sponsors education and gives scholarships. The Women's Front of Norway supports some of the eldest AIDS orphaned girls in the schools.

Whenever a new AIDS orphan approaches me in my office, I check the child's story with the school and neighbours. I collect data on the situation around the death of the parents, when the deaths occurred, the cause of death, who has taken care of the child and provided school fees up until then. After assessing these different aspects of the child's situation, a decision is made on the extent of sponsorship from KIWAKKUKI."

– Lui, which are your experiences with relatives supporting the orphans?

"The relatives often feel that they do not have the sufficient economic resources to support the orphaned children. Some relatives are also ignorant as to the real need of the orphans. I think that the local communities should be more sensitised regarding this issue, because some times the families actually do have enough resources to support an extra child. KIWAKKUKI is thinking of building up a fund in support of schooling for children who cannot be supported, neither by their relatives nor by other key persons in their social network.

Our AIDS orphans often need a total help, that is, very extensive help. Some of them are orphans from parents who came to Moshi from different parts of the country, and therefore do not have relatives in this district. An example: A set of siblings lost their home when their parents died, because the home was only rented. The parents had moved to Moshi from outside the Kilimanjaro region. The children did not know of any family members anywhere. Through the good work of a doctor, and lots of "detective work", the relatives were traced and resources were obtained. The KIWAKKUKI was finally able to build a home for these orphans. The siblings have lived together in that house for 5 years by now, and are self-dependent, even having a garden where they grow different vegetables and fruits. The eldest, a boy, who is physically disabled, has now finished his training as a shoemaker, and is able to support his younger siblings."

– How does the stigma related to HIV/AIDS affect the orphans?

"Stigmatisation is actually reduced nowadays, if we compare to how it used to be before. But it is still there. Skin sores and rashes, Kaposis sarcoma, can be important signs of the disease, and this raises stigma. When the other children know that an

orphan's parents died of AIDS, they immediately think that sores or rashes on the child's skin are a sign of the child being HIV positive. Some HIV positive children are subsequently teased and harassed in school because of their skin defects, and every once in a while some of them will refuse to go back to school because of this. One teacher came to my office and complained that a child had smeared fluids from his sarcomas purposefully on to the other children who teased him.

I can tell you about one experience we had here at the office some two-three weeks back: One 12 year old boy whose mother had died from AIDS fell sick himself from time to time. He came to my office with a relative, and asked to know what he suffered from. He had learned in school about minor and major signs of AIDS, like fever, skin rashes etc, and insisted on knowing his status. He was tested HIV positive, but was not told about the result, only asked to come back after 3 months for a second test. In the meantime the boy became quite rude, aggressive, stubborn and badly behaved, throwing stones around. His aunt came to the office and said the boy insists on knowing the result of his test. Subsequently the boy was invited to come to the KIWAKKUKI office, and a counsellor talked with him. The boy said he was aware of the reason for his mother's death, and asked why he was not told his own sero status. The counsellor asked him: *'what would you do if your blood test is negative?' – 'I will go to church every day.' – 'But if your blood test is positive, what would you do then?' – 'Then I would not beat the other children, I will be very obedient to my grandparents, so I will die peacefully.'* After this, he was finally told about his HIV positive test results, and took the news with calm serenity. This incident happened only three weeks back, but so far, the reports from school and his relatives are that he behaves well, is calm and poised.

There are so many cases. Some of the orphans who receive sponsorship are themselves HIV positive. Many youngsters come here to inquire about their sero status. Today one 11-year-old came. Many are HIV negative, but worry that they might be positive. However, most of the ones who are worrying actually also prove to be HIV positive, so obviously they are worried because they recognise signs and symptoms. The children do realize a lot.

Some of the elder orphans, especially the ones who attend secondary school, aged from 14 to 18, are well aware of which disease their parents died from. They reflect a lot about their own lives, and of how they can cope in life. Their performance in school tends to drop, they become depressed, anxious and mentally imbalanced. They approach the KIWAKKUKI office to talk about their depressive thoughts, and ask advice on how they can manage their lives in the future."

– How do you counsel teachers who refuse to have HIV positive children in school?

The teachers are invited to come here to our KIWAKKUKI office to talk about their problem. Every Tuesday the children themselves can also come here and talk

with us. After having talked with the child who is HIV positive, I go to her or his teacher and have a talk with him, and after that, things are normally quite OK, the problems work out well in most cases.

– *What does your work with the AIDS orphans signify for you as a woman?*

"As a woman I feel that I have a responsibility of caring, not only for my own children and immediate family, but also for my in-laws and my extended family as well. Here in our region many of the husbands are long distance commuters, which puts an even greater responsibility on the women in so many households. Whenever the long distance commuting husband comes home to visit, which might be once a month, or very often only once a year, then the wife is in no position to say *'NO'* to having sexual relations with him. So women are like a dustbin to carry on this burden of HIV/AIDS. Therefore it is high time we empower these women to be strong enough to say *'NO'* to their husbands. There is a need now, these days, to say *'NO'* to the men.

The experience of working here in KIWAKKUKI has made me strong. I am empowered now, so I can ask my husband: 'Where were you? Why did you come home so late last night? Give me an explanation!' And if I am not satisfied with the answer, I can say *'NO'* to have sex with him, or I can say, 'use a condom!'

We have meetings every month with the KIWAKKUKI members, and discuss specific topics. For instance: What are the responsibilities of the women? What can we women do to help the HIV/AIDS situation, and what is good to do? After having participated for years in these constant discussions and meetings, the grass roots women are now empowered. At our meetings everybody wants to talk! The women are not any more the same women they were some 4-5 years ago. Now they say: 'KIWAKKUKI has made me the woman I am today! It is KIWAKKUKI which made me strong and made me able to get up on my feet and talk.' So I can see a vast difference in the women from 1996 up till today."

Annex 6

Excerpts from interviews

PEOPLE LIVING WITH HIV/AIDS (PLHA) LIVING OPENLY AND POSITIVELY WITH AIDS AND ACTIVELY SERVING ON SEVERAL COMMITTEES IN THE KIWAKKUKI

Valentina Swai:

"My husband and I used to work together at the YMCA in Dar es Salaam a long time ago. But as the salary was small, my husband left to work for Links International Company and got a job there. He also found a girlfriend there, and built a relationship with her. When he fell sick and was admitted to a hospital in Dar es Salaam, I went there in order to stay close to him. My husband and I were both tested for HIV-virus, but without any offer of pre-test counselling. Both of us were tested positive. I despaired, and took an overdose of Chloroquinine tablets with purpose of suicide. However, I was found in time and taken to hospital for treatment. It was also found that I was pregnant at that time. However, I was not told about the pregnancy, and only found out for myself after some months. I gave birth to my baby girl in due time. When my husband gradually became seriously ill, the two of us plus our two small girls left Dar es Salaam and settled in Lindi with my husband's parents. My husband died in 1999. By then, my husband's girlfriend in Dar es Salaam had already passed away. Until my husband's death, the two girls and I had lived with him at his parents' place in Lindi. When he died, however, my in-laws blamed me for their son's death. My husband's parents never accepted the fact that their son suffered from AIDS. They believed me to have bewitched him, and asked me to leave. I had to return to my own parents' home. My father cried when he saw me, because I had lost so much weight. My mother is very strong, so she didn't say anything, but she has prayed very much for me. But whenever I fall sick, then she cries, because I am her only child and she is dependent on me.

I live in Moshi during weekdays, because of my voluntary work with the KIWAKKUKI. During the weekends I go to my village and stay with my mother and my two daughters who are now 12 and 14 years of age. Both of them are HIV negative. My father died last year. My mother is 58 and suffering from severe asthma."

An empowered woman

"Valentina, this thin, pale, infected woman and the mother of two, is strong at will and warm at heart. She has recently attended a conference on HIV/AIDS in Botswana, where she stood up in front of several hundred women from many countries and talked to them about the disease, how it feels to be living with it, and

the importance of empowering women. She says: 'when I speak up about this, then many people cry. I tell them that it is not for me they should cry, but for themselves'. Mama Kishe says that when people are sad, they lose weight. Therefore I try to tell myself, don't be sad, or angry, it is better to read the Bible. A human being always becomes sad from time to time, I do too, but then I cry and afterwards I become better. The people here know it when I'm sad, and then they say, Oh don't cry. I don't cry for myself, but for them. When you point at someone, then one finger is always pointing at that other person, while three fingers are pointing at yourself."

Expensive medicines

"It is expensive for ordinary people to suffer from HIV/AIDS. The price for the complete cure of these medicines is normally 50 000 TSH (= 500 NOK). I have been offered free medicine from South Africa, Xhumatek, through Lugalo Hospital in Dar es Salaam. The District Commisioner has given this offer to a group of openly HIV positive persons in the Kilimanjaro region, 15 women and one man, all from the Centre of Hope. It is said that this medicine helps increase the number of white bloodcells. The District Commisioner came one Friday for a meeting with the Centre of Hope members. After the information was given, 15 of the persons who had been members of the KIWAKKUKI Centre of Hope for a long time were picked out to receive this free medicine offer. But I am reluctant to take this medicine, because I feel that I get a headache, diarrhoea and stomach ache, and become worse whenever I take the tablets. This has happened to the others who have taken these medicines as well. We are supposed to take two tablets twice per day for one month, but I feel that this medicine might be good for the persons who have the disease in stage 3, but for me who am in a dormant stage right now, I don't think that it is good. 7 out of the 15 women from the Centre of Hope who got this free medicine offer have already passed away, and the one man likewise.

These days I feel relatively well, I am mostly only bothered about the Kaposis sarcomas on my skin. Some places the sarcomas have developed into open sores. But I don't have a headache, neither stomach-pain nor diarrhoea, neither malaria nor tuberculosis. I have, however, lost weight, and my Hemoglobin values are low. The medicines I need are expensive, and I am dependent on doctors' prescriptions in order to get them. This makes the expense even higher."

– *How does the stigmatisation affect you?*

"Not any longer it doesn't. A long time ago, yes, but not now. I even tell men who want to have sex with me that NO, I am infected.

I was interviewed on the radio in June of last year, about living positively with HIV and AIDS. My daughters told me that it was not good of me to do that.

They said that many people are HIV positive without going around telling people about it. They are afraid to be stigmatized. And they say that when everyone knows about my condition, I will die faster. They feel that everyone will look at me when I walk on the road. They also urge me to take the test again, just in case it will prove me to be HIV negative after all! They seem to have this hope that I might not be sick, because I have already lived for a long time after I was given the diagnosis. They are very loving and caring towards me, and whenever I get sick, my daughters always think about how they can help me."

Small loans for income generating activities

"Everyone who is HIV positive wants money, particularly because the medicines are expensive and the nutritious food also. KIWAKKUKI has provided a possibility for us who are openly HIV positive to get help to start an income generating activity. If you have a small business you will want to start up, you will be provided with a loan. KIWAKKUKI gave me a small loan of 20 000 TSH (200 NOK) in order for me to set up a small shop. But in the Centre of Hope we are 60 active members, and many of them use this money for food instead of starting the income generating activity. They say that KIWAKKUKI gives us money to start income generating activities, but where is the money for food? When we get good food and good medicine, we can increase our resistance."

Centre of Hope

"I was employed in a shop before, but as I started to attend the Centre of Hope meetings at the KIWAKKUKI, I just had to tell my boss about it and ask for his permission to attend their meetings on every last Friday of the month. I lost my work then, when I told the boss that I was HIV- positive. The boss, by the way, is my uncle. I am the only HIV positive person in my family.

18 of the members of the Centre of Hope are already dead. We tell all the HIV positive people that they should come to us if they feel sick. They should come here and meet the doctor! If they only stay at home, things will only develop in a worse direction. I teach the others at the Centre of Hope that they cannot infect others. And if you are open about your own sero status, then many more will be able to open up. People are often asking me: 'What is the point in being open?' Well, for one thing, it is tiresome to have to hide the symptoms all the time. If you come here to the KIWAKKUKI and the Centre of Hope when you are sick, you will get medicine, vitamins and good food, then you can live longer. They treat us real well here. If you take part in seminars they give you approximately 2000 TSH pr day (= 20 NOK). Many people don't want to come here, though, because they are afraid of the stigma they'll get if they come here. People say that everyone who works here is infected. We know, however, that most people who work here are HIV negative.

In church they say that you should not say you are infected. You should say that your health is good, that you don't have HIV, and that I am saved by the blood of Jesus.

Many women do not want to change their behaviour. But the Centre of Hope teaches people to change. Many women come here and in the beginning they are thin, feeling weak and sick, then they feel after a while that they are getting their appetite for life back. They feel that they are not alone any longer. So, the next time they come they have put on weight. They get some kind of small hope here."

– *If you should have some dreams and visions for the Centre of Hope, which should they be?*

"Well, KIWAKKUKI has grown big by now. I want them to have more money, and that they can create a centre for work possibilities for infected people so they could have their own small shops and other income generating activities."

– *What do you hope for the future of your daughters?*

"I am telling them to stay away from boys! You know, when you are together with them, you tell them everything about living a good life. I have already told them about their father, and about me, and about KIWAKKUKI. I also teach them properly about going to church, praying, having a good behaviour, and to study hard and be a good employee. For if they fail to do this, where can they go, without parents?

My children ask me so many things. They do not want to sleep with me, as they are scared of becoming infected themselves, because I have all these sores, the Kaposis sarcoma, all over my body. This is why I always wear long sleeves, so it won't show so much. I have asked my children to pray for me, that I should keep well for their sake. I have 4 acres of land where I have planted maize and have been able to build them a new house. I have warned my girls about boys, and urge them to take an education before they think of forming a family. I have also shown them the KIWAKKUKI office, and told them that when I am no more, they can come to this organisation for help. I came to KIWAKKUKI myself some years ago because I had been admitted to the Mawenzi hospital for my condition, and counsellors there suggested I go here. They said that if I became a member of the KIWAKKUKI, I would get help with acquiring medicines, small loans, and help for my children. So my 'young mother' (my mother's younger sister) took me here."

– You are strong, and you continue to teach people. From where do you get your strength?

"I was scared the first time I spoke in public, and started crying. But then, now I have acquired a lot of practice, and I get energy from practice. When you manage, you know you can do it again."

Dora Elia:
"I was born in 1954, here in the Moshi district, as number six in a family of 8 children. I have four children, born in 1969, 1972, 1976 and 1978. I was married in 1972. My husband was the father of all four children. He was a Moslem, and had work in Mombasa, so we all lived there. I was separated in 1980 and had to leave Mombasa, because my husband took a second wife. I had to leave all the four children with my husband and his new wife. My firstborn is a girl, my only daughter. She found out where I was living, and managed to come back here to me in 1987 with her own daughter. I have supported myself by selling charcoal. I still do, although I also work here in the KIWAKKUKI. My daughter has now four children. She was married in 2000. Myself, I met a man in 1998, and we now live together as husband and wife. He knows that I am HIV positive. He is 52 years old. In the beginning he was feeling weak, so there was no problem about the sex part of our relationship. Nowadays he feels better and we have sex approximately twice a month, without a condom. Some times he gets work at the railway station, when he feels healthy enough. He is normally healthy these days, because I know everything about nutrition and always give him nutritious food and a proper diet."

– How did you react when you found out that you were HIV positive?

"I suffered from recurrent attacks of malaria. I went for pre-test counselling and was tested twice in 1993, in June and then in December, at the MUTAN project. I was found to be HIV positive. I was shocked at first, but accepted the reality quickly. The counsellors at the MUTAN told me about KIWAKKUKI, and said that I would be counselled there regarding medicines, how to lead my life with hope, living a regular and positive life etc. So, in 1996 I joined the KIWAKKUKI as a PLHA, People Living with HIV/AIDS."

– What has KIWAKKUKI signified for your life?

"First of all, I was counselled on how to go on positively with my life. Secondly, whenever I fall sick, the KIWAKKUKI pays for my medicines. Thirdly, I now work with peer education, and as a volunteer at the Information Centre here at the KIWAKKUKI Head Quarters, and also in my neighbourhood at home.

Whenever I feel tired, it is accepted that I just come here to the office and say Hi, and then leave for home. I try always to come for the monthly meetings at the Centre of Hope here, in order to get new ideas, and share with all the others. We get treatment here, and at the monthly meetings we get a hot meal and money to cover the bus-fare back home. As a volunteer I get 2000 TSH (= 20 NOK) per day, independently of whether I am in the Information Centre, in peer education or participate in the home visits. My biggest worry is my house rent, which is 7000 TSH (= 70 NOK) per month, and I do not have a steady job, just my work here, and the charcoal I sell.

When the offer of medicines free of charge came to the 15 persons at the Centre of Hope, I declined the offer. I feel that I have not been sick, and am afraid that those pills will destroy my antibodies and the natural resistance of my body."

– *Are you open about your HIV status in your own neighbourhood?*

"Yes, I am, but people in my neighbourhood do not believe that I am HIV positive. They suspect that I have been given money to say that I am positive. They are never afraid of being close to me, because I am so healthy-looking. I think that people should continue being informed about HIV/AIDS, so that they will not be so scared about being infected all the time."

– *How do you feel when you visit patients who are very sick with AIDS?*

"I do not become depressed! On the contrary, I feel quite energetic, and become very encouraged when I visit someone who is bedridden. Then I feel that I can really use all my energy to encourage them – I sit down and talk with them, and try my very best to encourage them. I definitely do not want them to be sad about my being sad for them!"

Annex 7

Counselling situations

EXAMPLES AT THE KIWAKKUKI DURING A NORMAL ROASTER DAY

Excerpts from a meeting with health care professionals who serve as voluntary counsellors at the KIWAKKUKI office.

Sister Catherine Puka, nurse:
"Last time I had my roaster duty day at the KIWAKKUKI office, I had two couples coming in for pre-marriage counselling. One couple agreed to be tested, and agreed to receive the test results together. During the pre-test counselling I asked them whether they had ever had sex before. The young man said yes; the young woman, however, said that she was a virgin. When the test-results came, it appeared that the young man was HIV negative, whereas the girl was HIV positive. The girl was so puzzled. We had a long talk about the different ways of becoming HIV positive, and the girl answered in the negative to all the possibilities. She had neither undergone an operation, received blood transfusion, had injections of any sort, nor had her ears pierced, or any other thinkable act which could have infected her with the HIV virus. They are coming back for a second test in August. I'll have to wait and see what happens."

Mama Valeria Shayo, nurse:
"One lady came with her 2 1/2 year-old granddaughter whom she had taken care of since the mother of the child died when the girl was only 4 weeks old. 6 months ago the child had started to become sick, and the grandmother took her to the Marangu hospital. A blood-test was taken, and the doctor said the results were ok. However, he advised the grandmother to give the child cod-liver-oil, milk, and eggs, and never let it go hungry. Two months later the child was again very sick, and the grandmother this time took it to the KCMC hospital. She stayed at the hospital for quite a while with the little girl. Blood-tests were again taken, and the grandmother was told that the child was HIV positive. At this stage the grandmother approached the KIWAKKUKI, and refused to accept that her grandchild was HIV positive. She said: 'she is just sick, so please give me some medicines for her'. I told the grandmother that if the little girl is going to get any medicines from KIWAKKUKI, the grandchild must be tested first. The grandmother almost cried, 'why are you always going to take blood from my granddaughter?' This really shows that you need so much time for each patient. To be a counsellor is a heavy

job, particularly if you are going to tell someone that he or she is HIV positive. In this particular case the grandmother does not know whether her daughter-in-law died from AIDS or whether her son has AIDS. The typhoid symptoms, malaria, TBC and AIDS symptoms can be quite difficult to differentiate.

Another challenge when one gives counselling to a couple is when the husband says that, 'I have been unfaithful, but my wife is so good and kind and faithful.' Then they both come for testing, and the results show that the husband is HIV negative, while the wife is HIV positive. If the couple comes in one by one, the wife might say: 'I have actually been unfaithful, but cannot tell him.' Then it is a great challenge to counsel the couple in such a way that the husband does not abandon his wife for her being HIV positive.

Actually we see that many women are also unfaithful. People drink a lot of the locally brewed beer, pombe, here. If the husband is away at work for months at a time, there are sometimes other men who give the wife pombe, in order to seduce her.

On one occasion I was given a hint that a neighbour might be sick with AIDS, and went to visit her. I asked her to come for testing. She did not want to. I went there again, and this time the lady said: 'Let the doctor come here and take the test'. I told her that unfortunately the tests can only be taken in the hospitals. Then the woman told me, 'ok, it's all right, let me die, it doesn't matter'. I asked her to come to the KIWAKKUKI, and we would be able to give her some medicines. Her children actually told me that the woman is capable of walking, it is just that she does not want to come. Her husband died from AIDS. They used to be well off, economically, when he was still alive and healthy. The woman had a child with another man after her husband died. How can we help this woman?"

Mama Fudasia Kishe, Nursing Officer:

"I could go to her house and take the test there; there would be no problem if we only had the test equipment here.

We have the problem that the churches often send couples who are going to get married to our office for pre-marriage counselling only three-four weeks before the wedding! This is much too late! We want the couples to come here before the weddings are announced publicly and before the wedding plans are already made.

Many young men who work in far away regions bring lots of money back to this region whenever they come home for a visit. They are able to pay a big dowry for the girl they want. The wedding is then often settled in a hurry, before the young man has to go away again for his work. Ten months later the couple comes to our office with a baby, and the young mother is tested HIV positive. This is a problem we face often."

Mama Caroline Sululu, nurse:

”A 70 year old woman came to me on my roaster day. Her husband died 5 years ago. He had been working for some years in Mombasa. She had started to feel sick for some time, and came for pre-test counselling. She already had Herpes Zoster. After a long discussion she finally agreed to take the test. The test results showed that she was HIV positive. She was very worried, and quite shy, because she is an old widow and felt that this was quite embarrassing. After having received the test results she exclaimed: “Don’t tell my children!” Her children, however, told me that if their mother was HIV positive, I was not to tell the result to their mother, because they felt that she might probably die from the shock. The old lady’s children knew that their father had died from AIDS, but did not want their mother to know about it. So as of today, there is only one of the old lady’s children, a daughter, who knows that her mother is HIV positive.”

Annex 8

Excerpts from interviews and meetings with AIDS orphans

"Ruth", 18 years old:

– *Can you tell us about your life and present situation?*

"This past week I finished Form 6 at the "K" Secondary School, which is an all girl boarding school. Now I am joining KIWAKKUKI for voluntary work. I have applied for entrance in an institute for social welfare, and hope to be able to use the practice I get here in KIWAKKUKI as credit-giving practice for my studies toward a diploma in Social Work. I want to help women with AIDS and AIDS orphans. I have come to the KIWAKKUKI Information Centre some times, but have not yet participated in other activities, because I have had to take care of my studies. It is only now that I have finished school that I can come here more often."

– *How did you get in contact with KIWAKKUKI?*

"I have a relative who is a nun, and she put me in contact with KIWAKKUKI in 2000. I was helped economically from then onwards, so I was able to finish form 5 and 6. The donations were only for the school fees, so my uncle has supported me in meeting the different other expenses I had."

– *Can you tell us about your family situation?*

"My mother is alive, but has suffered from a psychiatric disease for many years. She has been hospitalised and treated for her mental disorder, but to no avail, the treatment was never successful. I used to go and visit her from time to time. My father died in 1995, but I never had a particularly close contact with him. I did not know until lately that my father was dead and that he died from AIDS.I have 2 elder brothers and 2 younger ones, but hardly know them, as I never get to meet them. They live somewhere else, I am not sure where. I have never lived in a home I can call my own. I was brought up by a god-mother during the first few years of my life, and afterwards I was moved to an uncle's house, later on to an aunt's house. I am presently living with an uncle, and some times go to visit some of my other relatives.

In my spare time I do gardening, grow vegetables, and do house work. My best friends are some of my relatives. I feel close to my relatives. My brothers have

gone to look for jobs, maybe they will come back after two years' time. The relatives I am living with belong to my mother's side, and my brothers have been living with different people."

"Ellinor", 17 years old:

– *Can you tell us about your present situation?*

"I attend Form 3 at the "W" public secondary school, which is an all girl boarding school. I hope to join high school after form 4. After that I hope to join the university and study wildlife, which is a three-year course. I wish to get a job within the field of tourism. In school I prefer Chemistry, Biology, Geography and Nutrition."

– *How did you get in contact with KIWAKKUKI?*

"I had contact with KIWAKKUKI from Standard 7 onwards, through a teacher in Kiboriloni primary school. That teacher is a member of KIWAKKUKI. Myself and my 19-year-old sister are both supported by The Women's Front of Norway. Our school fees are paid by that organisation. I normally go to the KIWAKKUKI office to collect the money for one school year in January. This year there were some delays caused by the financial records of KIWAKKUKI etc, and I was not able to collect this year's fees until today (late May). I receive 100 005 TSH (= 1000 NOK) per year. This covers board, lodging and text books for one school year. Writing material is provided by the KIWAKKUKI Orphans' Officer. Pocket money for shampoo, soap, and other toilet articles are not provided for, and I will normally ask my elder sister for help concerning these necessities."

– *Will you tell us about your family situation?*

"My father died in 1990, my mother in 1998. I was not aware that my mother was terminally ill. My mother was hospitalised because she was quite sick, and I went to visit her on a Sunday morning in the hospital. After having spent some time with her, I went back home, and later on, that very afternoon somebody told me that my mother had passed away. I was then in 6th Standard, and reckoned that my relatives would take care of me and my sisters, but they did not do that. My mother had worked at a hospital, and we had lived in a house for hospital employees. After my mother's death all of us four sisters had to move out. I am the youngest of four sisters, the others are age 24, 21 and 19. My two eldest sisters are working, one as

a nurse and one as a medical secretary. My 19-year-old sister attends Form 4 (for the second time) at "K" secondary school. The three eldest are presently renting a small house, while I stay at my boarding school."

– *Tell us about your life at the boarding school.*

"There is a total of 800 girls in my boarding school. In my dormitory there are 70, four girls in each room, or "cubicle". We have to abide by strict timings for meals, classes, homework, prayers and sleep. The four girls in each room belong to four different classes. During holidays I go to my sisters' house. I have many friends, and like to spend time with them, talking about the future and exchanging ideas. Boys from an all-male boarding school in the vicinity are some times invited to our school for dances, but I don't go there because it costs 1500 TSH (= 15 NOK). It is OK, I do not like to go there anyway. For Easter we arrange a dance only for us girls here at school, and then I attend."

HOME VISITS TO AIDS ORPHANS

We visited 10-year-old "Wilfred", HIV positive, with growth retardation and multiple sores and Kaposis sarcomas on his legs. His skin is pale, but he has a very vivid facial expression, bright and intelligent-looking eyes. He shows an eagerness to communicate with us.

His 15-year-old sister "Elisa" is also HIV positive, suffers from the same kind of growth retardation, multiple sores and Kaposis sarcomas, pale skin. In addition to that, "Elisa" suffers from de-colouring of her hair, loss of hair, sores and blisters in her face, particularly around the eyes. She is evidently very weak, with a heavy cough that seems to strain her very much due to an apparent lack of lung capacity. The two siblings became orphans several years ago, and KIWAKKUKI representatives gather that they were probably born with the HIV virus. They are living with their maternal grandmother and one 14-year old girl, "Cathy", also a relative. "Cathy" is healthy-looking and helps her grandmother with the household chores. KIWAKKUKI has managed to find a school for "Elisa" quite close to her grandmother's house, because she is too weak to walk to her original school. The two sick children are given clothes, some food elements and medicines from the KIWAKKUKI representatives, and "Cathy" is also provided with some clothes.

We visited a small house where there are two AIDS orphans living with an aunt and uncle. We met the aunt, who gave the impression of being mentally slightly off balance. The uncle suffers from TB and is said to be an alcoholic. The uncle's mother is also living with them. KIWAKKUKI has built a door in the small house,

to provide a separate bedroom for the children who up till then were sharing bed with the uncle and aunt. The organisation is now going to build a small house on the premises, for the two AIDS orphans and another orphan.

We visited a secondary school, where we met 5 AIDS orphans, 3 boys and two girls, out of whom 3 wanted to become medical doctors (the both girls and one boy) and two boys wanted to become engineers. All five were promising students. We met the head master, who confirmed that the school has a good reputation and is quite sensitised on AIDS-orphans.

We made a home visit to "Betty", 18, one of the AIDS orphans we met at the secondary school. "Betty" is sponsored by the Women's Front of Norway. We met "Betty"'s mother and a 3 year-old nephew. "Betty"'s father was a teacher, and died from AIDS in 1999. He had provided for a new house which was finished exactly at the time of his death, and the family regrets that he was never able to share the family's satisfaction of moving into that house. "Betty"'s mother is quite worried as to the financing of her daughter's further education. She grows vegetables in order to sustain herself and "Betty". "Betty" is the youngest child, the other children in the family are already married and have moved away from home with their new families.

Annex 9

Excerpts from interview

MR. EZEKIEL E. MUHUBIRI, EXECUTIVE DIRECTOR OF THE QOHELETH FOUNDATION, KIWAKKUKI COOPERATING PARTNER

QOHELETH FOUNDATION, Tanzania, is a rural youth development organisation. Mr. Ezekiel E. Muhubiri is the director of the organisation and visits the KIWAKKUKI head office for collaboration and meetings. Mr. Muhubiri's organisation is working especially with the Rombo district, Mawala, and Kahe in the Moshi Rural district. He tells us:

"We train youngsters, both sexes, in different skills in order to assist in enabling them to cope in life. The main aim is to occupy them in useful occupations in their own villages and in that way preventing the youngsters from moving into town. We have seen that there is no sand in the Rombo district for the young adults to build their houses, and therefore help them by teaching them other methods of building. In one of the districts we also activate the youngsters in the villages to construct houses for AIDS orphans, at low-cost and without profit-making. We work together with the KIWAKKUKI in peer education programmes, teaching the youngsters. We also assist KIWAKKUKI during elections when there is a lot of organisational work to be done. We have co-operated the last three years, since 1998, because I work with youth and I see that they are very affected by the HIV/AIDS epidemic, and therefore I understood that I had to work quite closely with KIWAKKUKI in order to serve the youth. I now very much wish to acquire some support in order to start a production of avocado oil extraction for use in cosmetics production, particularly for the girls.

The idea for my organisation came from the women. We were 10 women and 7 men as founding members, and we first came together to work for the street children. In addition to these 17 we have today 47 members. All of us work voluntarily. We wanted to find a way to support and encourage young people to stay in their own villages. That is why we started trying to make life in the villages more endurable to them, by creating employment possibilities, possibilities for entertainment in the village in the late afternoons and evenings, football and other sports activities etc. Some youngsters already have decided to stay on in their villages, and with the support from NGOs, alliances, and from KIWAKKUKI, I am sure we will succeed."

Annex 10

Visiting the Centre of Hope

The Centre of Hope meets every last Friday of each month. The evaluation team was able to attend one gathering during the evaluation mission. Approx 60 persons arrived at the day-long meeting, out of whom were 9 HIV positive children between 2 and 14 years of age, approx 7-8 men and 40 women. The Chairperson of the Centre of Hope spoke at length about his experience at the recent meeting at Dodoma, where he had attended as a representative of Centre of Hope. At this meeting the first national network of active People Living with HIV/AIDS in Tanzania was established.

New members of the Centre of Hope were welcomed during the gathering, and were encouraged to give s small greeting to the meeting. All members of the Centre of Hope have to be HIV positive. Otherwise one is in fact not allowed to attend the meeting. One healthy grandmother, who came with her HIV positive 4-year-old granddaughter, was asked to leave the meeting and go and see the doctor instead, in order not to disturb the meeting rules.

Interactive discussions with members and users of the Centre of Hope were initiated by the Chairperson, and the members gradually gathered courage to speak up in the meeting. They gave testimony to the others about how they managed to live positivly with the virus. The KIWAKKUKI PLHA activists played an active part in the meeting that went on for hours. Some Centre of Hope members were responsible for cooking a nourishing meal for the participants for lunch.

The children present were silent on-lookers until some crayons, colouring books and sheets of paper were provided and they were able to have a very interesting drawing session at the big meeting room table. At the beginning the children were at a loss about what to do with the crayons, not being used to that kind of activity. But as the minutes went by they quickly got a hang of it and finally entertained themselves enthusiastically for several hours.

Annex 11

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