

REACH OUT – Mbuya Parish HIV/AIDS Initiative REPORT ON ACTIVITIES MAY – DECEMBER 2001

Summary

REACH OUT was started in May 2001. Our main object is to provide the poor people in Mbuya Parish with HIV/AIDS with medical care and social and emotional support. During the last 8 months 136 people living with HIV/AIDS have been served, 79% of clients are women. 20 clients have died and 10 moved away leaving 106 active clients by the end of December 2001.Of these 106 clients 19 (18%) are in treatment for TB. Of 50 people offered testing 80% were HIVpos indicating that we have just started to deal with the top of the iceberg of HIV/AIDS in Mbuya Parish.

During many years the Mbuya Parish Fathers and Sisters have been working with local volunteers in the poor areas of the parish giving pastoral care for the dying and sick. This care was given to those in need with no difference of tribe and/or religion. In April 2001 a medical doctor joined the work adding medical support to the people visited. It quickly became clear, that the majority of the people living in these areas do not have access to medical care due to lack of funds to pay the fees required at local hospitals and the transport to these hospitals. It also became evident that the vast majority of the very sick and dying were suffering from HIV/AIDS.

It was in response to this need that REACH OUT – Mbuya Parish HIV/AIDS Initiative was started informally in May 2001 with two local volunteer women from three of the villages in Mbuya (Kinawataka, Giza-Giza and Kiswa) and a medical doctor in collaboration with the Parish Priest of Mbuya Parish.

Activities of REACH OUT

Medical programme

- The main focus is to provide care for people living with HIV/AIDS and TB in the poor communities of Mbuya Parish and thus strengthen the Ugandan response to the HIV/AIDS crisis
- When a sick person requests a visit we come to the home and give initial examination and treatment if necessary. Similarly, if a person is worried about having been infected with HIV/AIDS.

- Referrals and funds are provided for HIV and/or TB testing and transport to testing centre
- Referrals and funds for other relevant medical units (e.g. Mulago Hospital, TB unit, Nsambya Maternity Care Unit) are provided as necessary.
- Weekly follow-up-visits by volunteer and doctor in the homes after testing HIV pos, where continued counselling, prophylactic treatment and treatment of opportunistic diseases are provided. Other needs like support for food etc is also provided in cases where no other funds are available.
- Volunteers often visit during the week if needed due to limited other social support or as follow up from the medical visit.

The medical programme started in Kinawataka and Giza-Giza / Kiswa in May 2001 with 10 HIVpos clients and some general patients. By the end of September a total of 42 HIV pos clients had been served – 11 had died and 5 had moved away. The number of active clients in the areas was 26 by the end of September (Annex 1).

Knowing that Banda (another village of Mbuya Parish) has many poor people in need, a volunteer living in that area was identified. The need and interest in getting tested for HIV/AIDS was almost overwhelming. Within a few weeks we had more than 80 people wanting to be tested. In Kinawataka and Giza-Giza we had been assisting in paying for transport to and testing at AIDS Information Centre (AIC), but we did not have funds for supplying 80 additional people with testing. AIC was very helpful offering to do sensitisation campaign in Banda 1 (Acholi Quarters), and to do testing for free. This and the continuing increase of clients coming to us from the two original areas made the active client number reach 106 by the end of 2001 (Table 1).

The clients we serve

- 79 % are women (Table 2)
- The majority is between 26 and 40 years of age (Table 3)
- In Kinawataka 21out of 25 offered testing for HIV/AIDS = 84% was testing HIVpos. In Giza-Giza / Kiswa 19 out of 25 = 76% HIVpos on testing. Overall 80% tested HIVpos.(Annex 1)
- Of the 20 clients who have died 50% are women (Table 4)
- 11 of the 20 deaths happened within 2 weeks after first contact (Table 4)
- Overall death of male clients is 10 out of 32 = 31.3% (Table 4)
- Overall death of female clients is 10 out of 120 clients = 8.3% (Table 4)
- More than 60 people in Banda 1 are still awaiting AIC to come back for free testing at the beginning of the new year.
- At the end of December 19 out of 106 clients (18 %) were being treated for TB.(Annex 2)

In is noticeable that almost 80% of our clients are women. Many reasons could account for that – women may be more open to testing, also they may have observed their husbands die and knowing the symptoms and progress of disease, they will recognize the disease in themselves. In addition, concern for their children may give them more courage for testing. However, it is also noted, that for the majority of men testing positive, they are more prone to telling their wives about their test result, whereas the majority of women are reluctant to inform their husbands fearing that they will be rejected.

It is interesting for us, that we have had only one person coming to us, who have felt that she did not want testing. We have found that knowing that there will be follow up by REACH OUT have made a big difference for accepting to be tested. Also, it is clear from the beginning of the programme, and strongly expressed in the high interest for testing in Banda 1, that there is a financial barrier for being tested and when that is removed people want to be tested.

Men have in general contacted us at a very late state in the progress of disease -31% of them died within the first 2 weeks of first contact. We need to put much more effort into getting in contact with the men at an earlier stage – thus preventing further spread of disease particularly to the wives.

No matter what complaint you may have or for what reason you contact us, we have suggested people to do testing and have offered to pay for it. It is therefore very concerning that 80% of people tested have tested HIV pos.

By the end of December 18 % of our clients were being treated for TB. Considering the expected high prevalence of TB in the slum areas we work in, we would expect to have a higher number of clients with both HIV/AIDS and TB. We have a number of clients clinically suspected of TB, but we have not been able to diagnose them for enrolment in TB programmes.

The rapidly increasing number of clients has made it a high priority to start an out patient clinic. A clinic is planned to be opened at Mbuya Parish Church, Our Lady of Africa, in January 2002 serving the clients in Kinawataka, Giza-Giza, Kiswa and Nakawa. Preparations are in progress for opening another clinic in Banda for the clients there (Banda is geographically big and far away from Mbuya Church).

Throughout the work of REACH OUT it has been a high priority to utilize already existing services available in Kampala.

Hospice Uganda, who provides palliative home care for people in severe pain, has been giving joint care with us to 7 of the 20 clients who have died since the programme started. They are continuing involved with several of our clients, and their services are immensely appreciated by the clients as well as by the volunteers working with REACH OUT.

Child Advocacy International based at Mulago Paediatric Department has tested and followed up on all the children, who have been taken to us. The HIVpos kids are followed by them at their clinic and with regular home visits. Some food assistance is also given to the families of the HIV pos children. The collaboration with CAI has been very gratifying for the clients as well as for us, since we do not have resources to include children in our programme.

AIDS INFORMATION CENTER has given tremendous support by providing free testing for the Banda 1 (Acholi Quarters) community. Moreover, their testing clients for Tuberculosis and follow up though Mulago TB Department facilitated identification and enrolment into TB programmes.

We have also collaborated with other programmes and we are continuing trying to identify partners for collaboration and thus better facilitate access for the poor people in Mbuya to services available in Kampala.

Social Support Programme

• <u>Operation School Fees</u> was started in October 2001 in response to the fact that many of the children in HIV/AIDS affected families are not attending school due to lack of funds.

A child-to-child programme was started with Lincoln International School of Uganda raising money for school fees. Other private people have joined with funds. It is expected that 25-30 children will be able to go to school when the school starts in February 2002.

The interest in the school fee programme from HIV affected parents and families or grandmothers taking care of orphans has been overwhelming, and we will seek to expand this programme in the new year.

Operation School Fees has collaborated with Folkolare (a missioner school providing high quality education for children from low-income families), as well as government schools in Mbuya and Banda. With the two latter agreements have been made that we do development of the school – to the benefit of all the children – in exchange for school enrolment for children referred through REACH OUT.

- REACH OUT was included among seven organizations for food support from *World Food Programme*. Preparations for this programme started in December 2001, and food will be provided beginning April 2002. The food will be a much needed support for the HIV affected families. Again the need is enormous and only active clients can be enrolled, there will unfortunately be no support for families or grandmother taking care of HIVneg orphans.
- Other social support activities have taken place during the report period. These include clothes distribution, informal library with book exchange for kids, and some used clothes for selling.

These services have only been on small scale and we plan to expand during the coming year, particularly we need to focus on income generating activities.

Volunteers working with REACH OUT.

The present REACH OUT team consists of the Director, Father Joseph Archetti, two medical doctors, and three focal point volunteers in three of the communities of Mbuya Parish. In addition there are several volunteers, most of them being HIVpos themselves, in neighbourhoods within the villages. Moreover, we have two volunteers working with Operation School Fees together with a social worker from Folkolare.

Following a brief presentation on REACH OUT at a mass end of December, 10 additional parish members joined our team of volunteers. We are very happy for this

support from the members of the parish and their assistance is much needed to further develop our activities.

Funding

Up until November the activities of REACH OUT were funded privately. Funding from bigger donors is limited for small programs like REACH OUT; however, during December we received some much-needed funds from external private groups and individuals; with these we are able to carry our activities into the new year. However, we need to keep on working on providing enough resources to serve the people in need in Mbuya.

Post Scriptum

When you prepare a report like this and compile the necessary data – you sit and look through the files of each client. In the report they end up as a number in a data sheet – as having TB, died, be of a certain age group, etc, but behind each number there is a name, a face, a smile, a history, a hope that can never be expressed when collecting data for an annual report.

We in REACH OUT – Mbuya Parish HIV/AIDS Initiative have had the chance to get to know these people – we have laughed together, wiped tears, heard about the kids, and tried to give a little help where we can. However, every time we meet with them we go away richer than when we came – their strength to cope with disease, poverty, no food, no education for the children, etc is incredible.

When we leave after a visit and they thank us for the very little we can do to help them in their difficult situation – you feel embarrassed, and want to answer, "Now, who is thanking who here?' The words of St. Francis Prayer comes to mind "it is in giving that we receive".

So, Thank you to all our clients for what you have given us, and thanks to you, who make it possible for us to have the privilege of working with these extraordinary, giving people.

For further information contact:

Father Joseph Archetti, Our Lady of Africa, Mbuya, Phone: +256 - 41 - 221 777

OR

Dr. Margrethe Juncker, Phone: +256 - 41-259 899, e-mail: usdanes@utlonline.co.ug