

## **Report: follow-up visit RACOB AO November 2015**

### **Strengthening community structures for sustained ART provision in Sembabule district using the RACOB AO model**

#### **Introduction**

This project is based on previous experiences of the same approach to improving access to antiretroviral treatment (ART) in Lyantonde district, Uganda. This “best practice” will now be replicated in a nearby district as a phase out project of the Forum Syd funded partnership between FuG and RACOB AO that has been active since 2007.

The overall aim of the project is that marginalized men and women living with HIV and AIDS in Sembabule District are empowered in a gender equal way to claim and fulfill their equal right to health resulting in increased, equal and sustainable protection from HIV and its impact.

The project objective is to strengthen community structures for sustained ART provision in Sembabule District by 2015, to achieve the basic right to health for marginalized people living with HIV.

In order to achieve this, support structures of community volunteer counsellors, treatment helpers and health care staff was strengthened through trainings. Coordination between different existing service providers was facilitated through regular coordination meetings and the construction of a referral directory. In addition, the project created new networks to advocate for increased and gender equal ART service delivery, including lobbying for distribution of ART to lower level health facilities. Already existing lobbying structures was strengthened through training in advocacy work. Finally, the capacity of partner organization will be strengthened through publication of the methods and results of this “best practice” at the end of 2015, enforcing RACOB AOs position as a leading national NGO in the field of HIV and AIDS and the right to health.

#### **Follow-up visit**

FuG representatives Maria Swartling and Eva Solly visited RACOB AO during Nov 8-13 2015 with the purpose of monitoring the current Sembabule project activities and evaluating the results of the project. Further, the visit aimed at following up the long-term results of previous project activities in Lyantonde district. Lastly, the visit also aimed at finding a way to sustain the results and also explore new possibilities for collaboration between FuG and RACOB AO.

A terms of reference (see appendix I) for the follow-up visit was set up before the visit with specific requests for meetings with named key stakeholders and beneficiaries within different parts of the project. RACOB AO was able to arrange most of the requested meetings.

Stakeholders and beneficiaries who participated in the evaluation:

#### *Sembabule*

Yatowa Theopista – Sembabule district HIV focal person

Dr Matovu Charles – Sembabule district health officer  
Musoke Twaha – Sembabule district probation officer  
Rev orald Matovu – Chair person, Sembabule NGO forum  
Pascal – PLHIV-group coordinator, Sembabule  
Tusiime Harriet – Nusing officer, Sembabule health centre IV. Trained health worker.  
Nakato Mackline - Trained treatment helper, Mabindo, Sembabule  
Nakuya Berna – Trained treatment helper, Nabisuuli, Sembabule  
Birimuye Girivazio - Trained treatment helper, Mabindo, Sembabule  
PLHIV-support group, Mabindo, Sembabule  
Nakato Joyce – PLHIV supported by treatment helper  
Grace - PLHIV supported by treatment helper  
Edward - PLHIV supported by treatment helper  
Dina - PLHIV supported by treatment helper

#### *Lyantonde*

Margareth – Lyantonde district HIV focal person  
Staff at Lyantonde hospital, HIV clinic  
Yiga Milly – Trained treatment helper, Kinuuka, Lyantonde  
PLHIV support group, Kinuuka, Lyantonde

The monitoring of activities was performed by interviews with stakeholders and beneficiaries. An activity was considered to be verified when confirmed by two or more persons. If there was conflicting or insufficient information, the activities were verified by documentation such as field reports and participants lists.

The evaluation of results was performed by asking the stakeholders and beneficiaries about the “most significant change” due to the project. Triangulation of the answers was used as a method to give an overview of the effects. Further, the RACOBABO staff and FuG representatives participated in a workshop where the results from the triangulation were discussed and participants views were added to the evaluation.

The sustainability of effects from the previous project in Lyantonde was discussed in the workshop with RACOBABO staff and FuG representatives. The lessons learned from expanding to a new district and managing a project in a new district were discussed. The potential for sustainability of the Sembabule project was explored in order to find new ways forward.

#### **Monitoring of activities**

The main activities in the project; training of health care staff, training of caregivers and volunteers as treatment helpers, training/orientation of DAC in the rights of PLHIV, coordination of NGOs in the district (including the production of a referral directory) were confirmed through meeting with participants and beneficiaries during the visit in Sembabule. The mobilization of PLHIV to form groups was in some instances based on previous efforts done by other initiatives where some groups had been formed before but was not active. In these instances they were reactivated by the project, not formed.

There were some activities that could not be confirmed in the field and where documentation at the RACOBABO office was reviewed instead.

### *Health outreaches*

During the visit, none of the health care staff, RACOBABO staff or PLHIV who participated in the health outreach was there to confirm this activity. The outreach was performed in remote areas and the RACOBABO field officer in charge of the activities of 2014 has since left the project. So, in order to verify this activity documentation was reviewed. At the RACOBABO office, evidence of payment of allowances to the health workers was found, but no activity report. FuG has asked RACOBABO to provide this report, together with contact information to the field officer in charge, as soon as possible.

### *Community sensitization meetings*

Further, no one could verify the community sensitization meetings during the visit, but these were confirmed by activity reports and participants lists. In the communities, PLHIV and VHT members were targeted for this activity.

### *NGO forum meetings*

The NGO forum only had two confirmed meetings during 2014 as opposed to four meetings reported in the annual report of 2014.

### *PLHIV network meetings*

For the PLHIV network meetings, activity reports and participants lists were only located for two occasions instead of the four that were reported in the 2014 annual report. RACOBABO will investigate this and get back with information as soon as possible.

### *Lessons learned*

A lesson learned from this detailed monitoring was that there is a need to keep the documents in better order and to pay more attention to details when writing reports to make sure the accurate figures are being reported. Changes of plans might be very well motivated but should be transparent. Also, there has been a lack of transferring of information about activities between the previous and the current field officer. The field officer is the key person implementing the activities on site in the district. In this case, the information was only transferred through a written hand over report. The RACOBABO staff at the office in Lyantonde and the current field officer did not have the detailed insights in the 2014 project activities that was necessary for this monitoring session.

## **Evaluation of results – “most significant change”**

### *Treatment helpers*

During the visit in Sembabule, the training of treatment helpers and the initiation of their work in the district was mentioned most frequently as being the activity that has resulted in the most change for the beneficiaries. Officers at district level, as well as health care staff and the beneficiaries themselves mention this intervention as being most significant. The treatment helpers were selected among care givers and among people selected by the government as members of the district health team (DHT). By training volunteers within the government support system, the project was able to build on and enhance an existing system instead of creating a parallel function. Further, since the selection was made to include equal numbers of men and women, women have been empowered. The health care staff appreciates the new referral system that involves treatment helpers identifying people in need of treatment and referring them to the right level of care. They also appreciate that the treatment helpers give individual support to PLHIV, thereby providing a method for increasing adherence. Ideally, the health care workers should be able to provide home-based care but due to

shortages of staff and time, the support at household level was lacking before the project. However, all stakeholders agree that the number of treatment helpers trained by the project is far from enough. One suggestion was also to change the name to “treatment supporter” to shift focus from direct help to support.

### *Coordination*

The other result that was mentioned as most significant was the coordination of different structures working for PLHIV within the district. Through the project, the District AIDS Committee (DAC) was re-activated after a period of inactivity. An orientation/training concerning the rights of PLHIV was performed by the district probation officer and plans for advocacy work towards central government were put in place. Before the project, PLHIV were not mentioned in the district budget but now there is an agenda. Further, the District NGO Forum was mobilized to restart their work coordinating efforts to make the most use of the activities planned in the district. All new NGO initiatives have to be discussed and approved by the forum. The mobilization of groups of PLHIV and the formation of an organized network has also been an important factor when it comes to making PLHIV visible in the society. One representative from the PLHIV network is now a member of DAC. The District Health Officer was very happy with the way RACOBABO has planned and implemented this project in close collaboration with existing district structures. However, the project time has been short and the effects of the coordination efforts and advocacy might not yet be visible.

### *Access to ART, health outreaches*

One of the main objectives, the increase of health centers at level III accredited to distribute antiretroviral treatment (ART), was reached already before the start of the project by a separate government initiative. Therefore this was not mentioned as a result from this specific project. However, it was clear that there is still a need to keep lobbying for ART services even further out on the country side, at level II. In the meantime, health outreaches were mentioned as an important activity to continue. For this type of activity to be effective and valuable to the PLHIV, it should be done at regular intervals and targeting a specific site. A one-time outreach to a given site, as was done in this project, makes no sustainable difference.

### *PLHIV groups and network*

During the workshop with RACOBABO staff, they lifted the importance of the formed support groups and the PLHIV network. The impact of these groups was also confirmed by a visit in Kinuuka, Lyantonde, where a group formed by a treatment helper three years ago was very active and had moved from being a support group for PLHIV to being a group of people working together with income generating activities and their own savings/loan association to provide economic opportunities for all members. That showed a clear example of the sustainability of the interventions in the project model.

### *RACOBABO expansion*

The third objective of the project focuses on the development of RACOBABO. This project was an important first step for RACOBABO since they left Lyantonde district for the first time. During their work in Sembabule, they were recognized by other actors and donors and have since started projects in other districts as well. The documentary that was produced during the project has been aired nationally and even FuG has noticed that RACOBABO and the partnership with FuG is more well known, since FuG has been approached by other Ugandan NGOs asking for funding. By the end of

2015, a “best practice” document will be produced and distributed to districts and organizations wanting to launch an ART adherence intervention. Further, FuG and RACOB AO will continue the work of presenting the work at an international conference and/or an international journal.

### **Project management and sustainability**

With this project, RACOB AO moved its activities to a new district. However, Sembabule was not entirely new to some of the staff since they worked there with a project when RACOB AO was still a part of Lutheran world federation (LWF) about 10 years ago. The experience of having worked in Sembabule before made the start-up a little easier since they could use an old LWF office and they also recruited a field officer who used to work with LWF before. If this concept is to be set up in an entirely new district, more time and effort need to be spent in the startup phase.

One important lesson from this project was that a 2-year project period is too short to launch the project, implement the activities and make sure that the activities are maintained long enough to ensure that they produce sustainable results. Many of the staff at the workshop expressed frustration that the project did not have enough time. In the “best practice” manual it will be clarified that a project time of at least three years is necessary when starting these activities in a new district.

Another lesson learned is that of the challenges of working in such a large and remote district as Sembabule. Interventions tend to be concentrated to one sub-county, leaving other parts of the district without improvement. In this project, with its limited time, the activities were focused on the central parts of the district since the remote areas were too hard to access with the given resources. However, the project has now strengthened structure within the district, such as the NGO forum and DAC that can direct future initiatives to the areas in most need.

### **Risk analysis**

During the workshop, the participants also discussed the risk analysis that was made prior to the project start. The issue of potential corruption when entering a new district was discussed. The monitoring and evaluation officer confirms reported activities through telephone contact with participants as a part of the routine work surrounding all projects. A risk that was not explored prior to the project was that Sembabule is a very political district compared to Lyantonde - “a political hotspot”. There might be strong opinions on for example in what parts of the district the interventions should be directed. In order to prevent this from affecting the project, RACOB AO involved the government officials in the planning of the project and in what sub counties the activities should be held. However, there is a risk that there are people with political power in the district that do not agree with this.

### **Way forward**

When looking at the whole time period that FuG and RACOB AO have collaborated, there have been some substantial changes. The ART-projects were very important and necessary at the time when our work started. The government was not able to take responsibility for distribution and adherence. When the treatment was new to Uganda, safe structures to ensure optimal use was lacking. But now, 10 years later, the government is catching up and taking more responsibility for the health services. What is still lacking is the service and support at village level and the focus on adherence. Therefore, these aspects were identified as being most important to focus on in the future.

During the workshop with RACOBABO staff, the different parts of this project were discussed in relation to the vision and mission of RACOBABO. The conclusions were that activities such as training of health care staff and health outreaches might be better performed by other organizations that work more directly with health care. In the strategic plan, the organization has taken a step away from health rights and the HIV-focus. Instead they move towards a broader approach on human rights and focus on education, environment and advocacy work. Further, RACOBABO now has a mandate to work country-wide and aspires to expand activities, and might also move into the humanitarian sector.

In future, RACOBABO want to have more of a facilitating role, not an implementing role. It will mean more projects involving coordination and training. Making others work.

Based on the results from the workshop, these are ideas for future projects and possible collaboration with FuG:

- Further work with the PLHIV networks/exchange of experiences between groups
- Income generating activities for PLHIV
- Creating safe spaces for men to be involved in HIV care.
- Treatment helpers/supporters - continued capacity building
- Collaboration/exchange with other organizations for capacity building within RACOBABO
- Crowd funding as a new way of fund raising

The FuG representatives will bring these ideas for discussion with the FuG board and explore if there is a way the partnership can continue. Both FuG and RACOBABO agree that our partnership has been very beneficial for both organizations and that we enjoy working together. All workshop participants hope to work towards a way for future collaboration if possible, even if it has to be on a smaller scale without the financial support from Forum Syd.

## ToR for follow-up visit RACOB AO November 2015

### Requested activities/meetings and related preparations

- Audit of activities
  - o Meet with field officers, stakeholders in charge of activities, trained volunteers, trained health workers.
    - We want to meet and discuss with **project field officers** active during 2014 and 2015 respectively. Individual meetings during the time in Sembebe is fine, it does not have to be one gathering of all field officers at once.
    - Stakeholders we specifically want to meet are: **Yatuwa Theopista (essential to meet), Rev Borald Matobu, Dr Matovu Charles. Also someone involved in the DAC/SAC trainings** (if none above).
    - Meet representatives of the **trained volunteers**, for example the three treatment helpers you suggested
    - Meet representatives of the trained **health care staff** and Tusiime Harriet who trained them
  - o Single out 1-2 specific activities to monitor in detail, including documentation.
    - We want all documentation from the project made available upon request, such as attendance lists, field reports, etc.
- Evaluation of achieved results
  - o Meet with beneficiaries and talk to them in groups or individually
    - We want to meet representatives from the **PLHIV networks**, for example Girivazio Birimuye as you suggested, and **PLHIV supported** by treatment helpers
  - o Discuss results based on MoE activities performed by RACOB AO in a workshop looking at each objective using evaluated and documented indicators.
    - We want to meet with the project team and review the MoE activities performed so far. We want documentation such as questionnaires, HMIS reports, project reports and other documents supporting the results made available upon request for this session.
- Project management
  - o Discussions with RACOB AO during a meeting/workshop, management issues in a new district, lessons learned, financial management, management of project budget cuts, etc
- The way forward for continued work focusing on ART and health rights
  - o Discussions with RACOB AO during a meeting/workshop
- Follow up on sustainability of outcomes from the previous Lyantonde based projects
  - o Field trip in Lyantonde to meet beneficiaries and health care staff etc . Focus on what activities/results have been long-lasting, lessons learned.
- Information gathering for feedback to FuG-members, video, photos, human interest stories
  - o This will be done by FuG representatives during the field visits