COMIC RELIEF 2010 APPLICATION (HIV+ SURVIVORS INTEGRATION PROJECT)

Glossary of Terms

ACR - AVEGA Central Region
AER – AVEGA Eastern Region
AWR - AVEGA Western Region
AERG – Survivor's Association of University Students and Secondary School Pupils
ARCT - Rwanda Association for Trauma Counsellors
ART – Antiretroviral treatment
ARVs – Antiretroviral drugs
AVEGA Agahozo – Association of Widows of the Genocide
CDWs – Community Development Workers
CR – Comic Relief
CTP – Care and Treatment Project
DFID – Department for International Development (UK)
FARG – Government of Rwanda Assistance Fund for Survivors
GF – Global Fund
GoR – Government of Rwanda
IGAs – Income-generating activities
MINISANTE – Rwandan Ministry of Health
Mutuelle – Mutuelle de Santé (Government health insurance)
NGOs – Non-governmental organisations
PLWHA – People Living With HIV and AIDS
SM – Solace Ministries
SURF – Survivors Fund

AVEGA / Solace Ministries

Please briefly describe how this organisation came to be formed and how this process has influenced its values and objectives. (100 words max)

AVEGA was established in the immediate aftermath of the genocide by a group of 50 widows who recognised that there was no one left to care for them or their children. Agahozo, meaning to "wipe away the tears" was added to the name when the organisation was formally constituted in 1995. Its motto is "united we stand". The organisation now incorporates 25,000 widows who continue to address their challenges together. Decisions are made democratically at an annual national assembly, and support is delivered locally through a network of five regional branches. This project includes three: Kigali, Rwamagana and Cyangugu.

SM was set up in 1995 by Jean Gakwandi, a survivor with a professional background in development. He began supporting survivors in the immediate aftermath of the genocide, and recognised that most were traumatised – and that trauma was an issue for him too. Though a Christian organisation, SM does not discriminate against any clients on the basis of religion. They strive to follow their Christian values in a humane way, bringing comfort to those in need.

Project Summary

Many women in membership of AVEGA and SM bear the multiple stigmas of being a survivor, of being raped during the genocide and of being HIV+. They will be provided with wraparound support including home-based care, counselling, nutritional supplements, legal aid, IGAs, and access to health clinics that offer a "safe, ideal space" to seek treatment.

Such holistic support has already been proven to be effective through the DFID-funded CTP. This project will herald a final phase of that project, building on the lessons learnt, to:

- empower economically active HIV+ women survivors to build livelihoods to better support themselves and their own dependents
- strengthen home-based care and enforce the legal rights of older HIV+ women survivors

- improve the life prospects of dependents of HIV+ women survivors, mainly orphans of the genocide and children born of rape, through improved access to education and HIV prevention.

In delivering these benefits, the project will strengthen the capacity of AVEGA and SM to manage integrated clinics established under CTP to continue beyond the project's duration. In opening the clinics to non-survivors, it will facilitate reconciliation through a sustainable model of shared service provision, and generate additional revenue through increased patient numbers.

Context

HIV+ women survivors have been resistant to accessing treatment in public health clinics. They lack confidence in the quality and confidentiality of the services (fearing being treated by those associated with the genocide), concerned about further psycho-social trauma and anxious of being stigmatised.

This final-phase project is rooted in substantive experience of working with such survivors:
- 2000 to 2005, a CR funded project building the capacity of AVEGA and SM to deliver support to 3,000 genocide widows and dependents, including ART for 45 HIV+ women.
- 2006 to 2010, a DFID funded project (CTP) to scale-up the capacity of AVEGA and SM to deliver wraparound support to 1,823 HIV+ women survivors, and their 3,826 dependents.

The 948 HIV+ women survivors that started early in CTP, have regained their shattered confidence, rebuilt their lives (through regular IGAs), and have joined the public health system. They are also now leading efforts to deliver support to those recently taken up by the project and to identify those still requiring support.

There remain however, 875 women that started ART in the past 18 months, and a further estimated 500 in Rwanda's Western Region that have yet to start treatment at all. They continue to need urgent support to sustain their treatment regime.

DFID's priority is to ensure "all existing services provided to survivors by the CTP will continue after March 2010" when their funding ends. Still in negotiation is a final bridging grant to sustain IGAs. Partners are still awaiting confirmation of funding from GF, but have been forewarned that it will not cover full wraparound support (IGAs, counselling, home-based care) which is of grave concern to the target group.

MINISANTE has challenged partners to raise 50% of the funding to sustain this wraparound support. This proposal is their response to that challenge.

Consultation, Research, Evaluation

This application for a final phase of the work builds on the success of CTP which established the capacity of the partner clinics to deliver wraparound support to the target group.

It was developed by AVEGA and SM in partnership with SURF and is based on extensive consultations culminating in two weeks intense preparation in early 2010. The process also included discussions with CR, as well as with DFID to understand the lessons learned from the work to date.

The primary lesson is that wraparound support is critical to rebuild the lives of HIV+ women survivors. It is the comprehensiveness of the package, each component working synergistically to enhance women's lives, which is so effective. Before the project commenced, over 30 deaths a year were recorded by AER alone from AIDS-related illnesses. Since 2006, that has fallen to an average of 2 a year, despite a growing membership.

The trauma of the genocide remains strongly-felt for many women, and for services to be effective they must be delivered by those sensitive to the experience of the women. The minimum package of care available through public health clinics does not include the essential psychosocial support, home-based care and IGAs.

However, CTP has also demonstrated that for clinics to be licensed they must open their doors to non-survivors. This model is proving to be sustainable through a new clinic opened by AER in October 2009.

The first baseline survey of the prevalence of HIV amongst women survivors was undertaken by AVEGA in 1999. Of the 1,125 sampled, 951 (85%) women were raped and 327 (29%) were HIV+. The national HIV prevalence rate of 3.1%. A DFID study in 2005 demonstrated the need for a special programme to secure the rights of HIV+ women survivors to ART. SURF and the First Lady of Rwanda (Mrs Kagame) were key advocates for this.

An independent study commissioned by DFID in 2008 found that 92 (37%) of 250 HIV+ women survivors interviewed refused to access treatment in public clinics. As a result, the study recommended that a special approach is required, as pioneered by SURF through funding from CR and scaled up through CTP.

DFID has offered to commission and fund further research for data that at present is known only anecdotally - that survivors continue to require wraparound support.

Representation of HIV+ survivors in the application

In developing this application, SURF has endeavoured to ensure that the priorities and ideas of partner organisations remain at its core. SURF has consulted and worked with a Forum of Partners, made up of survivors' organisations in Rwanda with which SURF has previously or is currently working. The partners are led by survivors, representing the views of their members. In the case of AVEGA and SM, nearly 30% are HIV+ women survivors. The importance of sustaining the support delivered through CTP is the current primary priority for these organisations, and access to secure healthcare and IGAs is the priority of their members.

HIV+ survivors are represented on the staff of each partner organisation, and work as volunteers to lead the outreach delivering the services (in particular counselling and home-based care) and assessing the needs of the target group.

Though HIV prevention is not the primary aim of the project, it is considered an essential component so that volunteers and CDWs can convey pertinent information to the target group. Although the effectiveness of HIV prevention messages has not been studied systematically, a proxy indicator is the low prevalence of new HIV infections revealed by the testing of dependents.

How have you sought to identify more vulnerable/marginalised groups within your target groups and what do you understand of their needs? (150 words max)

CDWs undertake critical outreach to the target group, even in the most rural communities. The most isolated potential beneficiaries are referred to CDWs, mainly through existing beneficiaries. Their status is recorded and verified, they are then counselled before testing and treatment.

Awareness that support is available is a trigger for even the most vulnerable survivors to come forward. Even though sixteen years have passed since the genocide, some women are only now disclosing their status as survivors, and victims of sexual violence, because they trust the process involved and they trust the CDWs. Many CDWs have been in post since the role was first created through funding from CR and thus have unparalleled accumulated knowledge of their constituencies.

Survivors, particularly in the Western Region, are under-served because CTP did not include them. This project has an outreach component led by AWR to identify new beneficiaries in this more remote area.

Target groups (and descriptions)

Economically active HIV+ women survivors
The primary target group - the majority of which are already supported through CTP. Almost all were infected with HIV by rape during the genocide, and as such are also affected by trauma. They care for 3 dependents on average, including orphans adopted after the genocide and children born of rape.

Older HIV+ women survivors
Many HIV+ women survivors are now housebound and economically inactive. They are dependent on home-based care, delivered through CDWs. Due to the loss of their families during the genocide, they have no support network except through their membership of the partner organisations.

HIV+ children born of rape
An estimated 5,000 children were born to women survivors following rape during or after the genocide. SURF is scaling up education support to reach 500 of these children, half of which are HIV+, by the end of 2010. This prevalence rate is an estimate based on those children already supported.

HIV+ genocide orphans
A small number of orphans being cared for by HIV+ women survivors are themselves HIV+. They range in age from 5 to 25, some being orphaned after the genocide after their mothers died from AIDS-related illnesses (and before ARVs became widely available through CTP in 2006).

Non-infected dependents
The majority of dependents are not infected, but are affected, by HIV. They require educational support in particular, due to the inability of their carers (HIV+ women survivors) to fund their schooling, or maintain a nutritious diet. Also, HIV prevention will reduce risk of infection in the future.

Aims of the application

1. To ensure the successful integration into the public health system of 875 HIV+ women survivors on CTP that have been identified as needing additional support, as well as a further 500 HIV+ survivors in the western region of Rwanda that CTP did not reach. This will be achieved by ensuring they are secure in receiving confidential and comprehensive care.

2. To ensure that the associations in which the economically active HIV+ women survivors are formed can be viable over the medium to long term, and that economically inactive HIV+ women survivors, who are dependent on the farming of their land, can legally enforce land rights. This will enable them to afford Mutuelle.

3. To ensure that the clinics owned and managed by AVEGA and SM are sustainable, by maximising revenue from the MINISANTE for treating Mutuelle holders (survivors and non-survivors alike) and ensuring standards of care remain at the consistently high level established through CTP. Access to training for clinic staff, as well as business support for clinic administration, will be delivered through the project.

4. To improve the life prospects of dependents of HIV+ women survivors, in particular children born of rape and orphans. The project will support dependents to access and remain in education (at least through secondary school), by ensuring that they have the food security and psychosocial support to do so. The project will also include HIV prevention measures and access to counselling to those infected, as well as to all affected, by HIV.

5. To strengthen the capacity of AVEGA and SM to advocate for their members to ensure that the GoR and other primary stakeholders involved in healthcare delivery in Rwanda are informed and persuaded of the case for special treatment required by the target group.

Please explain how you believe this application will bring about the expected changes, referring to the chains of actions, relationships and external factors which are needed for change to occur, and how these link together (400 words max)

For example which organisations or individuals do you need to work with or influence; what do you need these individuals or organisations to do; what do you, your partners and your target groups need to do; and what changes do you need to influence in the external environment e.g. changes in policy.

For both beneficiaries and local partners, a high-engagement approach has proven to be necessary to empower them to transition from dependence to self-sufficiency.

Wraparound support will be delivered by the local partners. Their CDWs create the vital grassroots network necessary to ensure that all potential beneficiaries are reached and that home-based care is effectively delivered. CR funding will strengthen the capacity of the local partners to deliver the intensive support necessary to sustain, accelerate and monitor integration of the target group into the public health system.

SURF will support the local partners to manage the IGA programme, as well as their health clinics. Training and mentoring of the IGA associations will be vital, to ensure that the beneficiaries are able to break their cycle of poverty through a secure income generated by the associations. IGAs will include arable farming, textile projects, handicrafts and animal husbandry with a focus on modern and efficient production techniques. Sales and marketing support will also be provided. Beneficiaries will be able to better economically, psychologically and socially support themselves as well as their dependents

The project is aligned with the national development agenda. The local partners will be able to advocate for additional resources, in particular funding, to scale up the support offered to survivors, if it can be proven that the project is delivering sustainable benefits.

Training and technical support will be delivered to beneficiaries through the associations and separately to local partners to ensure the successful transition of their clinics into the public health system. An advocacy programme is being developed by SURF with the UK Conservative Party, to be delivered this summer. This will enable the local partners to lobby more effectively, and in so doing ensure that the GF and MINISANTE recognise the special treatment required by survivors and therefore provide the funding required to partner health clinics.

An evaluation will be led by the local partners under the coordination of SURF. It will feed into the ongoing development of the project, linking together the chains of action: identifying and sensitising the beneficiaries, forming and training the associations, building and strengthening the capacity of local partners, lobbying for and maintaining high-quality clinical services, delivering wraparound support to survivors and their dependents, and once self-sufficient identifying and sensitising new beneficiaries.

Activities

IGAs will form the foundation through which the project outcomes will be delivered. The IGA officers affiliated to each clinic will provide technical support to the 78 associations to which 575 HIV+ women survivors currently belong. 100 additional associations of economically active HIV+ survivors will be formed, replicating the integrated model of the most successful associations which include

sympathetic non-survivors to prevent boycotting of goods produced (as evidenced by survivor only associations).

Critical to the success of the IGAs will be the marketing of the goods produced, and facilitating greater profits margins and more profitable activities.

For economically inactive HIV+ women survivors, support delivered will be more intensive, led by the CDWs – a position developed by the local partners, and first supported through CR funding. Legal officers will prioritise support to this group to enforce legal rights to land and property still in dispute, and where successful, this will provide some income.

CDWs will coordinate the network of volunteers to deliver counselling and nutrition support to HIV+ women survivors and their dependents, as well assessing and reporting on the immediate needs of the group which will be delivered through the partner organisations. Additional training, as well as transport, will be provided to enable them to reach even the most isolated.

SURF will work with partners to ensure the efficient and cost-effective running of clinics and to deliver sustainable services. Training of clinic staff will ensure that the target groups will continue to receive the high quality care currently delivered.

With IBUKA, the partners will advocate for the additional resources required to sustain the services beyond the project's duration, in order to sustain the support required by the target group.

SMART Outcomes and partners to achieve them

100% of the 1,375 HIV+ women survivors who are not yet integrated into the public health system will receive the required support to be integrated by the project's end

- MINISANTE will be a critical partner as it will fund the core staff and medicines at the partner clinics. HDI Rwanda will provide training for the clinic staff. IBUKA is leading outreach to identify HIV+ women survivors still requiring support, to be transitioned into membership of AVEGA.

100% of the 948 HIV+ women survivors currently integrated into the public health system will remain integrated by the project's end

- GF will be a critical partner in complementing funding from CR for home-based care to this target group. MINISANTE will also be critical to ensure that they strengthen the minimum package of care currently provided through public health clinics.

70% of the 2,323 HIV+ women survivors will be actively participating in sustainable IGAs by the project's end

- DFID have committed to provide additional support for the IGA programme until March 2011, though funding the salaries of the three current IGA Officers at SM, AER and ACR.

80% of the 3,826 dependents of the HIV+ survivors who have graduated from primary school will be enrolled in secondary school by the project's end

- Foundation Rwanda will provide educational support to children born of rape, and their siblings (as they are ineligible for support from FARG). FARG will continue to provide educational support to survivors until 2012. GF is committed to provide home-based care to children infected and affected by HIV.

All 4 partner clinics to be sustainable by the project's end, delivering at a minimum 50% of their own running costs

- Technical support will be provided to the clinic administration by TRAC PLUS. SURF will play a high-engagement role in coordinating business support to the clinics. GF will also provide technical support to the partners. HDI Rwanda will provide training to clinic staff to ensure high quality standard of care.