

## **TERREWODE Fistula Treatment and Re-Integration Center Project Proposal Brief**

### **Background**

TERREWODE, a Ugandan based NGO, was founded in 2001 to improve the livelihoods and status of women, children, and youth. TERREWODE's mission is to empower women, children and youth to actively participate in development activities to improve their livelihoods, and that of their families and communities. Critical to TERREWODE is the deteriorating reproductive and maternal health situations among Ugandan women. TERREWODE seeks to effectively address the broader issue of reproductive health of women and girls by addressing the root causes, such as lack of human rights and lack of rights to economic resources; and to find treatment, prevention, and rehabilitation services for victims of obstetric fistula.

In 2001, TERREWODE began a pilot program in the Teso Region designed to identify and treat women who suffered from obstetric fistula. Inclusive in this pilot program were prevention and social re-integration components. After twelve years, this pilot program has been thoroughly tested, improved upon and proven both effective and sustainable. There are three key components of TERREWODE's obstetric fistula program.

First, the Obstetric Fistula Awareness and Advocacy Network (OFAAN) is a grassroots network of trained outreach volunteers working in community settings to identify fistula survivors and help them connect with TERREWODE, and spread awareness about the cause and risk factors of obstetric fistula. OFAAN involves training three distinct groups of volunteers: leaders of local women's groups and community groups, retired community leaders- known as the Dignity Watch Leaders, and finally, fistula survivors who have received treatment, counseling, and re-integration assistance. The training consists of obstetric fistula awareness and advocacy education, along with safe motherhood preparation and legal rights advocacy. The model is sustainable due to the fact that the work is carried on by a diverse group of volunteers. This not only preserves valuable resources for treatment and counseling for the fistula survivor, it also continues to work to end fistula long after the initial resource input.

Second, TERREWODE ensures that women who are identified as suffering from an obstetric fistula are able to access treatment. TERREWODE has built partnerships with the Ministry of Health, hospitals and health centers, local and international doctors, and nurses to provide quality treatment. TERREWODE has sought grant funding to cover the cost of treatment and when needed, provide additional training to surgical and nursing staff. In addition to providing continuous treatment at Soroti Regional Referral Hospital, TERREWODE has also organized several fistula camps in neighboring regions to treat additional fistula survivors.

Finally, realizing that surgery alone is not enough to heal from the trauma of an obstetric fistula, TERREWODE is committed to improving post-surgical care and social rehabilitation. In June 2013, TERREWODE launched a new Social Re-Integration Centre, thanks to our partnership with the Worldwide Fistula Fund. The center provides vastly improved post-surgical care for women, along with nutritional support, counseling, income generating skills training, and social re-integration services.

TERREWODE's program has proven itself to be both effective and sustainable. To date, TERREWODE has helped more than 600 women suffering from obstetric fistula in eastern Uganda receive treatment, counseling, and social reintegration services. In addition, TERREWODE's program has been instrumental in highlighting the urgent need for health professionals to work closely with women and human rights activists to address the not only the primary causes of obstetric fistula, but also root causes, such as widespread poverty and the lack of land rights of women.

### **Need**

Approximately 340,000 women in Uganda live with obstetric fistula.<sup>1</sup> However, only a very small proportion of them have sought treatment for their condition and, on average, women with obstetric fistula live with their condition for 10 years. An estimated 4,300 fistula cases have been reported to health facilities countrywide and are awaiting repair. Fistula repair is constrained by workforce limitations in health care facilities, insufficient medical supplies, transportation costs and stigmatization that comes from the continuous leakage of urine and/or fecal matter. These limitations are exacerbated by the population of which fistula affects poor, uneducated women living in rural areas.

In Uganda, the majority of patients are treated in obstetric fistula surgical camps by local and visiting fistula surgeons, with success rates of above 80% being reported. Despite these efforts, the capacity to repair and reintegrate obstetric fistula survivors in the country remains low, with an accumulated 4,300 fistula cases reported to health facilities still awaiting repair countrywide, according to the national obstetric fistula strategy (2011/2012-2015/2016) by Ministry of Health. This backlog of cases causes women to wait months to years to receive treatment. There is an urgent need to have dedicated regional treatment centers that can offer either free or subsidized fistula repair surgeries to patients on an on-going basis. In addition, rehabilitation and re-integration services in Uganda lack basic standards. The majority of organizations providing services operate on a small scale and can only assist with transportation refunds and basic counseling. Yet obstetric fistula has social, economic and psychological consequences for affected women, these sequels include; stigmatization, isolation and loss of social support for both treated and untreated women with fistula.

Fistula centers, or wards dedicated specifically to fistula treatment, offer many advantages—from clinical expertise to the sisterhood that forms among fistula patients. These facilities serve as a center for surgical training programs and help foster innovation in techniques and methods for physical and psychosocial rehabilitation of fistula survivors. Dedicated centers also help raise awareness and understanding about fistula. The very presence of a fistula center helps bring the condition to wider attention. Doctors and staff at the centers develop a deep understanding of fistula, and often become powerful advocates for its prevention and treatment.

A rapid needs assessment was conducted late in 2011 by TERREWODE and the assessment affirmed the need of a rehabilitation, and re-integration support program for fistula survivors as well as long-term living accommodations (rehabilitation center) for women suffering from incurable fistulas. During Dr. Lewis Wall's visit to TERREWODE in May 2012, he was able to visit the TESO region and he proposed a similar facility. District managers and politicians of the

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<sup>1</sup> Uganda Bureau of Statistics (UBOS) and ICF International Inc. 2012. *Uganda Demographic and Health Survey 2011*. Kampala, Uganda: UBOS and Calverton, Maryland: ICF International Inc.

region offered him their overwhelming support for the project, making it well-known that the TESO region is ready to take on a project of this sort.

The creation of a fistula treatment and re-integration center will effectively address several critical issues, including the shortage of well staffed and equipped operating theatres, the tremendous reliance on the work of visiting, foreign doctors from other countries and the shortage of physicians and allied health professionals with the fistula treatment skills.

### **Proposed Treatment Center**

TERREWODE aims to increase access to quality treatment services and care in the region and to set up a demonstration facility, to serve as a model for the government and other regions in Uganda and eastern Africa.

### **Objectives**

The objectives of the Fistula Treatment Center are:

- To increase the number of fistula surgeries and women cured from fistula per year.
- To tailor services specifically to the needs of fistula survivors and by providing adequate nutrition, pre-post surgical support, and counseling and psychological support services.
- To provide survivors of obstetric fistula with services they need for re-integration into society, including trainings in fistula awareness and prevention.
- To provide women with incurable cases of fistula a place to live a dignified life and an opportunity to become active members of their community.
- To mobilize fistula survivors into solidarity groups, and enhance their capacities to act as change agents for altering of social norms away from stigma and discrimination of fistula patients and towards the promotion of treatment and re-integration of fistula survivors.
- To build the capacity of **TERREWODE**, improve internal structures and mechanisms of service delivery.

### **Staff**

TERREWODE continues to grow as an organization with six full time members of staff who include an Executive Director, Manager of Programs, Manager Advocacy and Training, two field officers in- charge of counseling and mobilisation; and Accountant/Administrative Manager and other support staff. TERREWODE has enthusiastic, experienced, and committed staff and associate trainers who feel passionate about the vision of the organization.

While the rest of the staff are university graduates (hold first Degrees), the three support staff are college graduates. Three of the program managers are social workers with post graduate certificates in various fields including Gender, Human rights, sexual reproductive health, psychosocial counseling. The Executive Director who is the strategic “driver” of this organization recently obtained a master’s degree in social work, majoring in maternal health and administration. In addition, she brings into TERREWODE a wealth of experience as a journalist and graduate of mass communication. She is also biased for gender and women’s health; and

conducted a multi-country academic study on fistula and other operational and action-oriented researches on fistula, particularly in Africa.

**Budget and Project Specifics**

To date, TERREWODE has located an ideal parcel of land for the treatment center.

TERREWODE has also identified potential grant funds for construction through the Embassy of Japan. In order to qualify for the grant funds, which have a January 2014 deadline, the land must be owned by the applicant organization. Thus, this grant is seeking funds to purchase the land for the treatment center.

**Total land cost: \$64,000**