

GUINEA



Beyond Repair: Involving Communities in Fistula Prevention and Reintegration—Experience from Kissidougou, Guinea

WHAT IS FISTULA?

Obstetric fistula is a childbirth injury, usually occurring when a woman is in labor too long or when delivery is obstructed, and she has no access to a cesarean section. She endures internal injuries that leave her incontinent, trickling urine and sometimes feces through her vagina.

Fistula Care works to prevent fistula from occurring, treats and cares for women with fistula, and assists in their rehabilitation and reintegration. For more information about fistula and the Fistula Care project, visit www.fistulacare.org.

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Background

The city of Kissidougou, located in the eastern forest region of central Guinea close to Sierra Leone and Liberia, has a population of approximately 137,000 people. Kissidougou District Hospital, the referral institution in the area, provides a variety of health services, including surgery, maternity care, and pediatrics. Since October 2005, EngenderHealth, with U.S. Agency for International Development (USAID) funding, has supported Kissidougou District Hospital to provide fistula care services. In addition to the USAID support, EngenderHealth has provided private funds to support several of the community activities described in this brief. (Fistula Care also supports fistula repair at three other sites in Guinea, and the United Nations Population Fund [UNFPA] supports repairs at one site.)

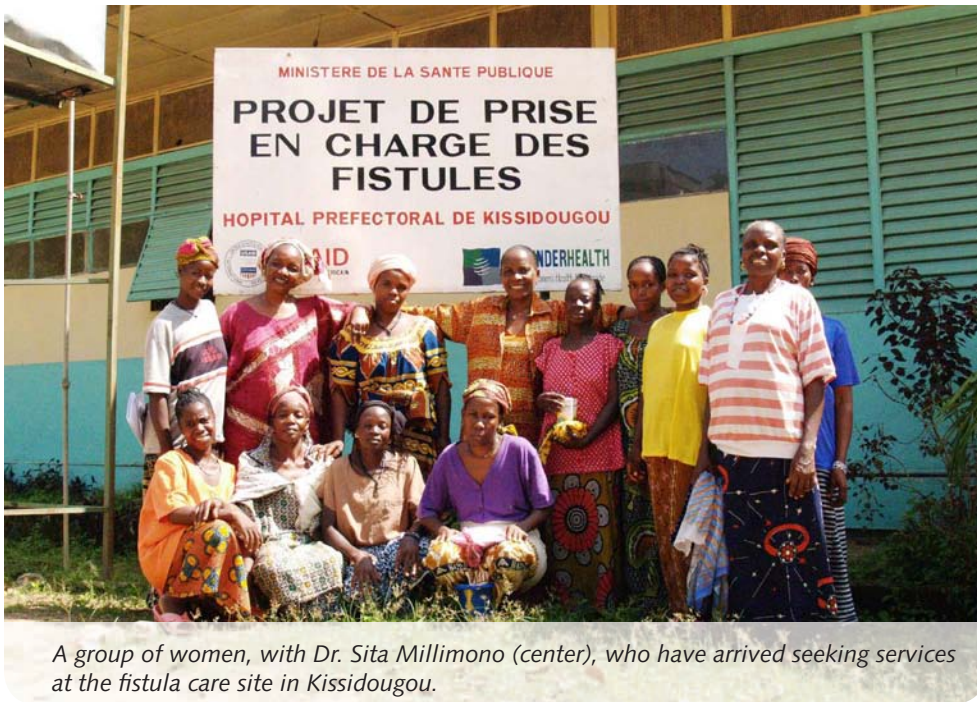
The program was funded initially by USAID through the ACQUIRE Project and most recently through Fistula Care. From the beginning, the Kissidougou project established three program services: surgical repair, fistula prevention, and reintegration of fistula patients into their communities.

USAID is working in Guinea to strengthen democratic processes and institutions and to help national and local governments become more efficient and accountable. That initiative has been an important building block for fistula repair efforts in Kissidougou, contributing substantially to the program, especially to prevention and reintegration.

Surgical Repair of Fistula

Women with simple fistula routinely receive treatment in the operating theater of Kissidougou District Hospital. Women who require more complicated procedures are operated on during periodic fistula repair workshops led by surgeons with advanced skills. During these workshops, surgeons receive training to perform complex fistula surgery. The workshops are held quarterly in collaboration with the senior urologist from Ignace Deen Hospital, the university teaching hospital in Guinea, and with expatriate surgeons from the Geneva Foundation for Medical Education and Research (GFMER). EngenderHealth has a memorandum of understanding with the foundation to manage these workshops. GFMER contributes the cost of the trainer salaries, travel, and some equipment and supplies for fistula repair surgery.

The Fistula Care project covers the costs of treatment, equipment, and supplies. It also supports training for providers in fistula repair, nursing, counseling, and quality improvement. The Ministry of Health provides salaries for all doctors and nurses who provide fistula care services and supports hospitalization costs for patients and all laboratory exams. From 2005 through June 2010, the Kissidougou program performed 678 fistula repair surgeries.



A group of women, with Dr. Sita Millimono (center), who have arrived seeking services at the fistula care site in Kissidougou.

Involving the Community and the Local Government

Since the program began in 2005, Kissidougou District Hospital has implemented a holistic approach that goes beyond fistula repair and that builds upon USAID's democracy and governance efforts. The District Hospital and EngenderHealth have worked closely with the Urban Development Commune (UDC) of Kissidougou, a district governmental body consisting of the mayor and his council, to improve community and local government involvement in fistula prevention, treatment, and reintegration and to increase support for fistula services.

In July 2007, EngenderHealth staff conducted semi-structured in-depth interviews with women who had received fistula repair services at Kissidougou District Hospital. The goal was to understand more about the women's social situations and needs. The staff found that many women had experienced profound emotional distress and a dramatic social decline from living with a fistula. Like women with fistula in other places, they continued to struggle with social challenges even after repair.

The interviews indicated that prevention and reintegration services were lagging. It was also clear that external funds would never be able to provide the support for these services that the local community could offer. Recognizing the importance of local governance and with the interview results in hand, Kissidougou District Hospital, with assistance from EngenderHealth, began to partner with the UDC to make improvements.

During 2007 and 2008, Fistula Care project staff provided technical assistance and training to the UDC to improve community and local government involvement in the fistula care program. The UDC, in collaboration with the Ministry of Health, the National Division of Decentralization (NDD), and the district health management team of Kissidougou, began implementing four interventions:

- The Market Town Approach, to increase the use of local government funds for fistula services
- Safe motherhood committees, to address fistula prevention and the referral of fistula patients for treatment
- A waiting home, to provide short-term convalescence for women after repair surgery and a place where women can begin to reintegrate into society
- Social immersion with host families to support reintegration of fistula patients

The Market Town Approach

The Market Town Approach has been a critical and highly successful component of the fistula care program in Kissidougou. It has increased local ownership of fistula



A fistula survivor holds her newborn baby alongside the surgeon who repaired her fistula.

care efforts and has provided crucial nonmedical support for fistula repair patients.

Beginning in 1990, USAID/Guinea began supporting efforts by the NDD to promote local revenue generation. The project, called “Market Towns and Local Resource Mobilization,” operated under the Human Resources Development Assistance program. Representatives of the district hospital serve on the mayor’s council.

The objectives were to increase the district’s revenue by improving management of the central market in Kissidougou and to allocate a portion of that revenue to support public services in the district.

The NDD conducted orientation sessions for the UDC and the broader community that addressed the rule of law, civic rights, citizen-based local program development, implementation and monitoring, financial management, advocacy, gender equity, and women’s empowerment. The NDD and the UDC worked together to create an enabling environment that fosters transparency, community participation, and community ownership.

As a result of this capacity building, the UDC developed market management committees to:

- Foster the participation of all parties involved in the system
- Restructure the market space
- Hold quarterly open meetings to discuss revenues collected, the use of funds, and any issues related to improvement of the market

Since the intervention began, the market has operated more efficiently, and the training and regular meetings increased trust and transparency, the vendors’ confidence in the district-level government, and their willingness to pay their taxes, as they are well-informed about and participate in determining how funds will be used. As a result, the district’s revenue from the market has



Residents of Gbangbadou community attending an awareness-raising session.

increased by over 400%. At least 5% of the funds generated are allocated to the fistula program. In addition to generating much-needed funds, the Market Town Approach has raised the visibility of the problem of fistula, the repair program, and safe motherhood among community members.

Moreover, the UDC has gone above and beyond its commitment to allocate 5% of market revenue for fistula care. For example, it received a grant through the United States Embassy to install solar panels in the maternity ward at Kissidougou District Hospital. Furthermore, the UDC provides funding for two other fistula care interventions: the village safe motherhood committees and the waiting home.

Village Safe Motherhood Committees

With supplies, training, and organizational support from Fistula Care, the UDC has created volunteer safe motherhood committees in villages surrounding Kissidougou. The committees work in 12 districts and cover villages 8–25 km from Kissidougou. About 40,000

people live in the areas served by the committees.

The committees play a primary role in preventing fistula. Six to seven male and female volunteers serve on each committee; they work to sensitize their communities about how to protect maternal and child health and reduce morbidity and mortality. Members receive no financial incentive except reimbursement for transportation when committee members are required to travel to Kissidougou. A volunteer coordinator manages the committees, provides technical support, and schedules activities and training.

Chosen by their communities, committee members are often already serving as community-based matrons or health workers. To qualify for committee service, members must be long-term village residents and opinion leaders.

As of May 2009, Kissidougou had 12 safe motherhood committees. In June 2009, eight additional committees were created, for a total of 20 committees with 127 members (64 women and 63 men).

Committee members receive initial basic training, followed by refresher

training to update their knowledge and then a final training to affirm each volunteer's knowledge. Training topics include the importance of antenatal care, danger signs during pregnancy and childbirth, obstetric fistula, birth spacing and family planning, the health risks of early marriage, and data collection techniques for births and maternal deaths. The program gives volunteers flipcharts, data collection tools, sacks, t-shirts, hats, raincoats (for visits made during the rainy season), megaphones, and flashlights. (During harvesting periods, when people are busy during the day, volunteers must do their work at night, using flashlights to help them find their way.)

To engage with the community, committee members visit family compounds, checking in with pregnant women, and participate in social events such as weddings and baptisms to deliver health talks. During these activities, volunteers discuss fistula and its causes. They encourage women to receive antenatal care and to deliver at a health facility. In addition, committee members have the following responsibilities:



A woman in Kissidougou whose fistula was repaired at the facility.

- Identifying all pregnant women in the villages, and educating and encouraging these women to attend antenatal care and to get necessary vaccines
- Referring women with danger signs during pregnancy and childbirth to a health facility
- Identifying and referring fistula cases to health facilities
- Promoting family planning and birth spacing
- Advocating against marriage before the legal age (17 years)
- Collecting information on new births and maternal deaths

Committee members meet quarterly in Kissidougou to report on their activities and referrals and to provide data about pregnant women, new births, and maternal deaths. The group discusses accomplishments and challenges and creates workplans. The mayor or his representative and a member of the district's health management team attend these quarterly meetings. Local government participation is essential to ensure the sustainability and accountability of the committees.

Between January 2007 and March 2010, the committees recorded 1,993 births and 13 maternal deaths; they referred 41 fistula patients and 66 women for pregnancy or labor issues.

Committee members have faced many challenges, including transportation issues and the limited number of opportunities to make visits during rainy season and harvest time. Despite such difficulties, committee members are strongly dedicated



The launch of community activities to raise awareness of fistula in the village of Limanya, Kissidougou.

to their communities. Proud of their work, they enthusiastically speak about their activities and the knowledge they have gained.

The Waiting Home: Where Reintegration Begins

In the early days of the Kissidougou fistula care program, women lacked a place where they could wait for treatment and convalesce after surgery. The UDC has provided funds generated through the Market Town project to rent a “waiting home” for fistula patients near the hospital.

Patients come to the home approximately two weeks before their planned surgery, for preparatory testing and other intake processes at the hospital that must happen before surgery takes place. After two weeks in the hospital’s postoperative ward, they return to the waiting home for the remainder of their recovery period.

The home has 21 beds and can accommodate up to 28 fistula patients if some use floor mats. The UDC provides electricity, running water, and a cook, who prepares meals for the women. The mayor’s office provides a guard. When other government sectors donate food to the commune, the mayor sets aside a portion for the waiting home.

Fistula Care supports a consultant coordinator, who has several responsibilities:

- Managing the waiting home
- Ensuring that the facility is functioning well and meeting the patients’ needs
- Arranging placement of patients with host families when space is not available at the waiting home
- Serving as a liaison between the hospital and the waiting home
- Supporting patient morale
- Helping to create a sense of community in the home

By September 2012, the mayor’s office will support this position.

Health education is an important part of each patient’s experience at the waiting home. She learns about the causes of fistula, how long she must abstain from sexual activity after surgery, family planning, how to prevent reinjury,

fistula, and the availability of treatment. In this way, they have become empowered agents of change. From July 2008 through March 2010, 72 of the 137 women who had stayed at the waiting home (53%) conducted at least one awareness session

In the waiting home, women say they are able to participate—without judgment—in routine tasks, such as washing their clothes with other women. For many patients, this is the first time in years (and sometimes even in decades) that they have been able to take part in such commonplace activities.

and the need for cesarean section in subsequent pregnancies. The Fistula Care team based in Kissidougou provides patient education.

During women’s stay at the waiting home, the Fistula Care program officer provides an orientation to public speaking and interpersonal communication. Women who are skilled communicators receive additional guidance on how to speak in public. After returning to their communities, many of these women use social events, such as weddings and baptisms, to raise community awareness about the causes of fistula, how to prevent

in their communities; most had conducted more than one.

Unfortunately, funding is not currently available to support other types of skills-building or income-generation activities in the waiting home; such activities would further facilitate patients’ reintegration. The Fistula Care project plans to partner with community organizations and other elements of civil society to develop skills-building activities for patients.

For many patients, reintegration begins in the waiting home. In this caring environment, women receive both physical and social support. They are welcomed



Prof. Mamadou Bobo Diallo and Dr. T. H. Barry operate on a woman suffering from obstetric fistula in Kissidougou.

into a nonjudgmental community of women with whom they can identify.

Social Immersion with Host Families

Although the waiting home provides excellent care and lodging for many women before and after repair, some patients face long recovery periods, while others are financially unable to go home and then return for their three-month postoperative check-up. To complement the waiting home, host families provide residences and support for many patients after surgery or between procedures.

Using local radio announcements supported by community networks, the UDC has raised community awareness about the patients' needs and has mobilized families to host women during their convalescence. Host families provide a supportive, caring environment as fistula repair patients recuperate. Because the families make it possible for women to extend their stays in Kissidougou, patients benefit from continued postoperative care. To assist the host families initiative, the waiting home coordinator identifies the families and arranges for patient placements.

For many women, the host families facilitate the transition between the waiting home and their return to their village. After being socially isolated, sometimes for years, patients can once again participate in family life.

While in the care of their host families, fistula repair patients join in

“I have joy with my [host family]. They accept me as if I do not have a fistula and provide me with food and housing.”

— Recovering fistula client living with a host family

normal family activities but are not pressured to do so. Some help with daily chores, such as cooking and washing, and attend baptisms, weddings, and other events. Others prefer less activity. Each woman participates in family life to the extent to which she is comfortable.

Host families receive no remuneration or other incentive beyond the satisfaction of engaging in a humanitarian act. When a fistula patient is placed with a family, representatives of the UDC and the local radio station visit the family. The station often interviews families about their experiences hosting women.

Such attention may be a source of pride and motivation for families. For most families, however, the main reason for volunteering is the emotional and spiritual satisfaction they receive when helping a woman recover and reintegrate into society. Because the UDC has used local radio communication, the community

has become more aware of the needs of women with fistula.

Families often began hosting fistula patients on their own. They later linked to the Kissidougou program to help women gain access to treatment and reintegration services.

Host families have expressed sincere satisfaction with their experiences. Often they are interested in hosting women again in the future. Some families, interested in helping women to avoid the pain and suffering of fistula, want to learn more about fistula, its causes, and how it can be prevented.

The host family initiative began in March 2008. From that time through March 2010, 137 of 639 fistula care patients stayed with a host family.

Challenges

Although Kissidougou has made significant advances, it faces two particular challenges:

1. Sustaining the Market Town Approach
2. Ensuring continued capacity building

Women in Guinea and in neighboring countries are beginning to learn about the fistula care treatment provided at Kissidougou; consequently, demand for services exceeds the program's capacity. For instance, space at the waiting home is limited and needs to be expanded.

In addition, the program needs to do more work to address the psychosocial



Women attending an outreach session at the Kissidougou maternity ward.

needs of patients and to improve the knowledge of host families and committee volunteers. Host families need more information about fistula, what causes it, and its consequences for women. They may not be well equipped to deal with some psychosocial challenges; the hospital and the district health team are working to identify specialists who can provide assistance in such cases. Volunteers need additional training about fistula, family planning, safe motherhood, and interpersonal communication.

Also, turnover in staff, volunteers, and council members means that continued training is needed to maintain the quality of the program. Kissidougou District Hospital is working with Fistula Care and GFMER to increase the number of health care professionals providing treatment. Fistula Care is continuing to build the capacity of village safe motherhood committees and host families.

Replication

Because the Kissidougou experience has been positive, Fistula Care has replicated the approach in the Labe Region. Members of Kissidougou's UDC have served as peer mentors for that



The surgical team of Ignace Deen Teaching Hospital at the end of a fistula repair session.

effort, an experience that will reinforce their skills and knowledge.

Lessons Learned

Among the greatest assets of the Kissidougou program are:

- The profound sense of commitment and altruism provided by all levels of the society
- The mayor's strong, passionate, and honest leadership

- The active engagement of stakeholders
All levels of society, from the safe motherhood committees to the UDC, are strongly committed to capacity building, self-sufficiency, and ownership.

Democratic local governance: The Market Town Approach has facilitated a level of trust and transparency among stakeholders and has promoted local ownership of the program. As a result, the mayor and the UDC have been able to mobilize and capitalize on local resources to support patients.

Prevention: The safe motherhood committees are the critical link between the community, local health centers, and Kissidougou District Hospital and are a major contributor to prevention efforts. According to hospital reports, patients referred by committee volunteers have fewer complications, spend less time at the facility, and have higher recovery rates because they seek treatment sooner and are more likely to adhere to treatment regimens.

Reintegration: The waiting home and host families facilitate reintegration of patients into society. They provide transitional experiences that support women before they return home.



A member of the village committee in action, utilizing a picture box to discuss maternal health and fistula.

GUINEA



ABOUT GUINEA

Maternal health indicators in Guinea are alarming. Among pregnant women, 62% deliver without a skilled attendant.¹ The maternal death rate is 980 deaths per 100,000 live births, one of the highest in Africa.¹ Although unmet need for contraception is 21%,² only 6% of married women use a modern contraceptive method.¹ Fertility remains high, at more than five lifetime births per woman of reproductive age.³ Cultural norms encourage early marriage for girls; this in turn leads to early pregnancy, high fertility, and prolonged maternal health risks. Because of insufficient access to quality emergency obstetric care, these challenges lead many expectant mothers to face life-threatening complications during pregnancy and childbirth.

Fistula Care at EngenderHealth
440 Ninth Avenue, 13th Floor
New York, NY 10001
Tel: 212-561-8000

www.fistulacare.org



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Conclusions

To summarize, three promising approaches have contributed to the success of the Kissidougou program and can be applied to other settings. Strategies include:

1. Promotion of community awareness and participation to foster buy-in for good maternal health practices and to encourage families to host fistula patients
 - Appealing to people's religious obligations and concerns for human rights
 - Using mass media, particularly local radio, often highly valued by rural residents
 - Attaching prestige and public praise to participation
 - Promoting interdependence within the community
 - Delegating responsibility at all levels of the program
2. Development of a plan to garner resources
 - Reinforcing decentralization
 - Reminding the community that help will not come from somewhere else
 - Tapping into local resources
 - Promoting ownership and transparency
3. Demonstration of responsible use of resources
 - Investing in visible activities that benefit the community at large
 - Holding open meetings to discuss revenue
 - Planning how to use money and disseminating financial decisions widely, through local radio and posted information in public places
 - Paying salaries for critical positions

In summary, this programmatic example, with its emphasis on community engagement and organizational partnerships, is a promising model for sustainable fistula treatment and prevention programs.

Fistula Care will share this approach with other country programs and will aim to replicate it where feasible.

References

1. Direction Nationale de la Statistique (DNS) and ORC Macro. 2006. Guinea Demographic and Health Survey 2005: Key findings. Calverton, MD. Retrieved from www.measuredhs.com/pubs/pdf/SR116/SR116.pdf, Feb. 8, 2011.
2. United Nations (UN). 2005. Millennium Development Goals indicators: Guinea. New York. Retrieved from: <http://unstats.un.org/unsd/mdg/Data.aspx>, Feb. 8, 2011.
3. UN. 2005. World population prospects: The 2008 Revision. Retrieved from: <http://data.un.org/Data.aspx?q=Fertility+rate&d=PopDiv&f=variableID%3a54>, Feb. 8, 2008.

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