

EVIDENCE AND ACTION

GOOD PRACTICES

on Ending
the Health
and Human
Rights Tragedy
of Obstetric
Fistula

Campaign
to End Fistula



UNFPA

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Obstetric fistula is a severe morbidity caused when a woman or girl suffers from prolonged obstructed labour without timely access to emergency obstetric care, notably a Caesarean section.

The sustained pressure of the baby's head on the mother's pelvic bone damages her soft tissues, creating a hole - or fistula - between the vagina and the bladder and/or rectum. In most cases, the baby is stillborn or dies soon after birth, and the woman suffers a devastating injury - a fistula - that renders her incontinent.

The consequences of fistula invariably leave the victim ashamed, ostracized and alone. Many women and girls who suffer from fistula are excluded from daily community life and abandoned by their husbands and families, isolating them socially and emotionally and making it difficult to maintain a source of income or support, thus deepening their poverty and magnifying their suffering.

Virtually eliminated in industrialized nations, in the developing world it is estimated that as many as 2 to 3 million women and girls live with obstetric fistula and more than 50,000 new cases develop each year. Yet, with skilled attendance at birth and timely access to emergency obstetric care, these devastating injuries can be prevented, and in most cases, treated.

Good practices highlight UNFPA country programme components and Campaign to End Fistula partner activities that exhibit innovation and relevance, generate positive results, and provide opportunities for learning and replication in other contexts.

The practices highlighted in this publication include:

UNFPA Country Office, Uganda

Supporting the establishment of a National Task Force for Fistula to enhance coordination and partner collaboration.

UNFPA Country Office, Tanzania

Harnessing the power of mobile phone technology to reach and assist women with fistula in impoverished and remote areas.

UNFPA Country Office, Sierra Leone

Toll-free hotline enables women and girls to access free obstetric fistula care.

The Campaign to End Fistula

- Recognizing obstetric fistula as a neglected health and human rights issue, in 2003, UNFPA and partners launched the Campaign to End Fistula, with the goal of making fistula as rare in developing countries as in the industrialized world.
- A global coordination mechanism and advocacy body that facilitates dialogue and collaboration, the Campaign is present in over 50 countries across the world, bringing together over 80 partner agencies at global level, plus many others at national and community levels.
- UNFPA leads and coordinates the global Campaign to End Fistula, as well as serving as the Secretariat for the International Obstetric Fistula Working Group – the decision-making body of the Campaign to End Fistula, addressing all aspects of fistula.

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Sierra Leone

Toll-Free Hotline Enables Women and Girls to Access Free Obstetric Fistula Care

Rebuilding after a protracted civil war that ended in 2002, Sierra Leone continues to face major challenges, including improving access to health care services for vulnerable and underserved populations, especially women and girls. Maternal mortality is extremely high – nearly one in twenty-one women die as a result of pregnancy or childbirth.

It is estimated that for every woman who dies of pregnancy-related causes, another 15-30 women face long-term health complications, such as obstetric fistula. Fistula is a severe morbidity caused when a woman or girl suffers from prolonged obstructed labor without timely access to emergency obstetric care, notably a Caesarean section. In 2003, UNFPA, in collaboration with partners, launched the global Campaign to End Fistula, focusing on three key strategies: prevention, treatment and social reintegration.

Women and girls with fistula are often impoverished, have little or no education, and live in remote locations. Many are not aware that treatment is available. Moreover, those who are aware may not have the resources to cover the high cost of transportation to health facilities, or they may not even know where to go to access life-changing fistula repair services.

To raise awareness about fistula and to address the problem of access to treatment, a special toll-free hotline was launched in 2011 to provide information and care options for women and girls with fistula. The hotline is run by the Aberdeen Women's Centre (AWC) in Freetown and is a result of a public-private partnership between the Glog Foundation, UNFPA, USAID and telecommunications company, AIRTEL.



Implementation Strategies

Since 2010, UNFPA has been giving financial support to the Aberdeen Women's Centre (AWC), which provides the only comprehensive fistula repair service in the country.

In October 2011, in collaboration with the largest mobile phone company in Sierra Leone, AIRTEL, and other partners, a national toll-free fistula hotline at AWC was established.

This 24-hour hotline has a short, easily remembered number, 555 and enables women with fistula symptoms across the country, especially those living in isolated and remote areas, to call the toll-free number and speak with trained nurses to determine whether they need fistula treatment. The nurses also provide information about the causes of fistula and how the condition can be prevented. Arrangements are made to provide transportation for likely fistula cases to be brought to AWC for assessment, fistula repair surgery, postoperative care and rehabilitation. AWC also sends screening teams to diagnose potential patients and bring those suffering with fistula to the Centre.

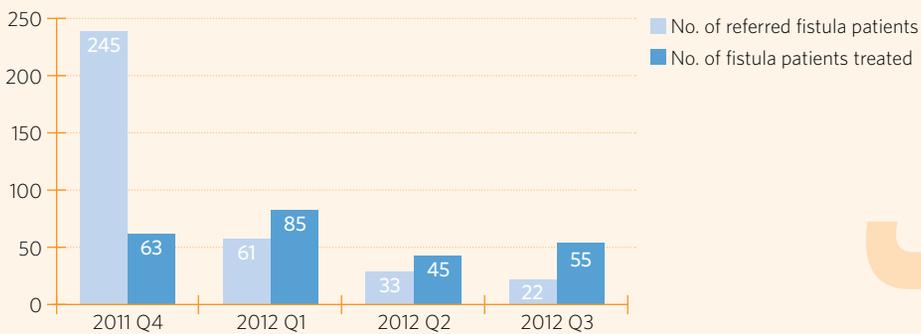
To ensure that the initiative receives national and widespread media coverage, radio messages are broadcast in the local Krio language and in English advertising the hotline, describing fistula, including prevention and symptoms, as well as encouraging affected women and girls to seek medical attention.



Progress and Results

In the first three months, when there was intensive media attention on the initiative, more than 200 fistula patients were referred to the Centre for treatment. The number of patients who have undergone fistula repair surgery varies from 85 in the first quarter of 2012 to 55 in the third quarter of the same year.

Number of fistula patients referred to and treated at Aberdeen Women's Center (2011-2012)



Source: Aberdeen Women's Center Database, 2012.

Since the hotline was launched, 31 radio stations across the country broadcast over 10,000 jingles about the new fistula hotline. Five television programmes and 10 newspapers also advertised the free hotline and the available treatment service at AWC, which has a resident expert surgeon offering fistula repair surgery routinely, as well as a 24-hour on-call obstetric team.

Repair
Fistula
Service

Lessons Learned

- Given the stigma and shame associated with fistula, the creation of an accessible toll-free phone hotline is a convenient and highly effective tool to identify and refer women and girls suffering from this devastating childbirth injury for treatment, especially poor women living in hard-to-reach remote areas, while contributing to respect their right to privacy. Furthermore, it is an opportunity to partner with modern communication technology companies that believe in giving back to communities where they operate as part of their corporate social responsibility.
- Launching the hotline initiative and harnessing the support of high-profile figures, such as the First Lady of Sierra Leone, who is a strong advocate for fistula elimination, as well as high-ranking government officials and respected civic, business and philanthropic leaders, helps promote the cause of ending fistula.
- Mounting extensive media campaigns through radio, newspapers and television to advertise the toll-free fistula hotline and treatment facilities amplifies public awareness of these services. Many women who have had their fistulas successfully repaired subsequently serve as advocates, raising awareness about the condition, including its prevention and also assisting other affected women to access care.

Partners

Sierra Leone Ministry of Health and Sanitation, Aberdeen Women's Centre, Airtel, the Gloag Foundation, USAID, Haikal Foundation, Health Poverty Action and the UNFPA Country Office in Sierra Leone.

Acknowledgments and Further Information

This case study was produced in collaboration with UNFPA's Programme Division, Technical Division, the Africa Regional Office and the Sierra Leone Country Office with inputs from the following experts and consultant: Gillian Slinger, Laura Laski, Ratidzai Ndlovu, Erin Anastasi, Jarrie Kabba-Kebbay, Etienne Franca and Rene Desiderio (Fordham University Institute of International Humanitarian Affairs).

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Tanzania

Harnessing the Power of Mobile Phone Technology to Reach and Assist Women and Girls with Fistula in Impoverished and Remote Areas

Every year, it is estimated that more than 50,000 girls and women worldwide develop obstetric fistula. Fistula is a childbirth injury caused by prolonged and obstructed labor without timely medical intervention, notably a Caesarean section. Fistula largely affects girls and women living in poverty and in remote rural areas where communication and infrastructure are often limited. Furthermore, in such contexts, they frequently lack access to adequate health services, education and information and cannot pay for medical treatment.

In 2003, UNFPA, together with partners, launched the global Campaign to End Fistula, which focuses on three key strategies: prevention, treatment and social reintegration.

In Tanzania, where about half of all births take place at home, often without any help from skilled birth attendants and far from health facilities, obstetric fistula is widespread with an estimated 3,700 new cases occurring each year and only about 1,000 receiving treatment. The rest are either unaware that treatment exists or cannot afford to access it.

At CCBRT (Comprehensive Community Based Rehabilitation in Tanzania) hospital in Dar es Salaam, fistula surgery is provided free of charge, but the high cost of transportation and accommodation still prevents fistula patients in remote villages from seeking treatment.

In 2009, with support from UNFPA, CCBRT started an innovative project using a mobile phone money-transfer service, M-PESA (M for "mobile" and PESA for "money" in Swahili), to enable women to undergo fistula repair surgery in the hospital.



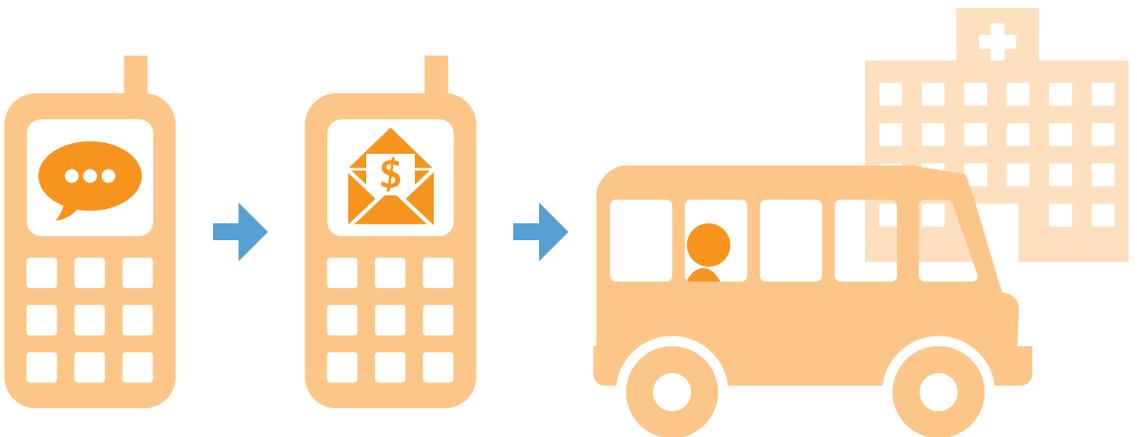
Implementation Strategies

UNFPA has been giving support to CCBRT, which is the largest provider of fistula repair surgery in Tanzania.

In collaboration with partners, CCBRT has been assisting women with fistula from poor and isolated communities, through a network of community-based volunteers consisting of doctors, nurses, health care workers and traditional midwives from various regions who serve as “fistula ambassadors.” These ambassadors identify and refer potential fistula patients for treatment to CCBRT through a mobile phone text message.

Upon confirming the likely diagnosis, CCBRT, with support from Vodafone, sends money through SMS using the M-PESA mobile banking system to cover the transportation costs of the fistula patient and the caregiver, if needed. The fistula ambassador retrieves the money from a local M-PESA agent and pays for the bus fare of the patient, who travels to Dar es Salaam where she is met at the bus terminal by a CCBRT driver.

When the patient arrives at the hospital, the referring ambassador receives a small incentive via the same M-PESA system. The patient receives the necessary surgery and then remains for a period of rehabilitation in fully catered, safe and free accommodation.

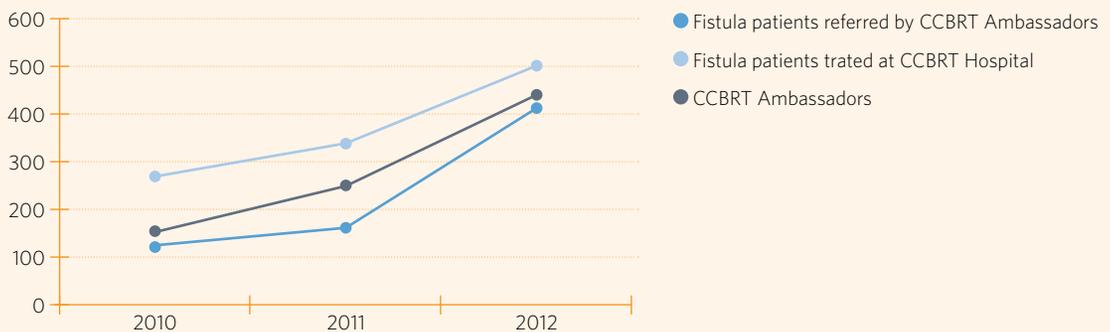


Progress and Results

The number of women and girls receiving fistula treatment nearly doubled from 268 in 2010 to 500 in 2012.

Likewise, the number of ambassadors and potential fistula patients they referred to CCBRT has significantly increased in a span of just three years.

Number of fistula patients referred to and treated at CCBRT and number of fistula ambassadors (2010-2012)



Source: CCBRT Hospital Database, 2012

Many women have nowhere to stay before and after they are treated. Their stigmatizing condition means that even family members may not host them. With support from UNFPA, CCBRT has refurbished a 20-bed hostel near the hospital, where women and a caregiver can stay on-site before surgery. The hostel provides three free meals daily, a cleaner service and health education.

In collaboration and with support from Vodafone Foundation, new fistula wards were opened in November 2012 that have enabled CCBRT to treat more patients. In the same year, 12 health personnel were trained in the general care of fistula cases.

Fistula patients have access to the CCBRT Mabinti Center that trains women to sew, bead and manage a business. The aim is to equip recovering fistula patients with income generating skills to gain socio-economic security and empowerment.

Social reintegration is a key element of the healing process. In 2012, CCBRT followed up on the reintegration of 127 former fistula victims and found that 96 per cent were able to participate more in community activities than before they had the operation and 97 per cent felt more accepted and supported by the community compared with before their operation.

Lessons Learned

- Mobile phone technology has the power and capacity to greatly improve access to maternal health facilities, including disseminating information about fistula services and follow-up of former patients who have been reintegrated in their communities.
- The CCBRT fistula and mobile phone technology initiative has generated great interest not only in the broader fistula community but has proven a successful public-private partnership, resulting in Vodafone Foundation pledging to help eradicate fistula in Tanzania and explore how this good practice might be replicated to help fistula cases elsewhere.
- Apart from covering the transportation costs of fistula patients, providing free accommodation and meals before and after surgery is important, especially since this is the second biggest barrier to accessing fistula treatment. It enables women who do not have the resources or are too embarrassed to lodge elsewhere to seek fistula treatment.

Partners

Ministry of Health and Social Welfare, Comprehensive Community Based Rehabilitation (CCBRT) in Tanzania, Vodafone Foundation and the UNFPA Country Office in Tanzania.

Acknowledgments and Further Information

This case study was produced in collaboration with UNFPA's Programme Division, Technical Division, the Africa Regional Office and the Tanzania Country Office with inputs from the following experts and consultant: Gillian Slinger, Laura Laski, Mariam Khan, Clement Ndahani, Vindhya Pathirana, Kaspar Mmuya, Erin Anastasi, Etienne Franca and Rene Desiderio (Fordham University Institute of International Humanitarian Affairs).

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Uganda

Supporting the Establishment of a National Task Force for Fistula to Enhance Coordination and Partner Collaboration

Obstetric fistula is a devastating childbirth injury, which can affect any woman or girl who suffers from prolonged or obstructed labor without timely access to an emergency Caesarean section. It is a global health problem that afflicts an estimated 2 to 3 million women and girls in the developing world, mainly those most impoverished and living in rural and remote areas.

UNFPA, together with partners, launched the global Campaign to End Fistula in 2003 focusing on three key strategies: prevention, treatment and social reintegration.

Progress has been made on integrating obstetric fistula into countries' national health policies and plans. In addition, the importance of establishing a national coordination mechanism to facilitate planning and interaction between partners working on all aspects of obstetric fistula has been recognized.

In Uganda, the Ministry of Health has identified fistula as a silent morbidity among women and has been collaborating with various partners, primarily with UNFPA, to ensure harmonized acceleration of prevention, treatment and social reintegration services. The number of Ugandan women suffering from fistula is estimated at between 140,000 to 200,000, with about 1,900 new cases occurring every year.



Implementation Strategies

UNFPA has been providing technical and financial support to the Ministry of Health, which is the lead and pivotal agency on issues relating to fistula.

UNFPA's strategic interventions have focused on supporting three critical areas:

- The establishment of a National Fistula Technical Working Group (FTWG)
- The formulation of a National Obstetric Fistula Strategy
- Seconding a fistula focal point to the Ministry of Health to work closely with both the Clinical Services and the Reproductive Health Departments in coordinating fistula activities.

Initiated by UNFPA, the formation of the FTWG comprised of key stakeholders – government, donors, civil society and UN agencies – was vital in coordinating and harmonizing disparate efforts in fistula prevention and management. UNFPA provided technical support and guidance in formulating the terms of reference of the FTWG and in enlisting membership. It also provided financial support to ensure that meetings and dialogues are regularly conducted.

The FTWG plays a pivotal role in the development and review of policies, guidelines, protocols and standards relevant to fistula; in defining priorities for effective national response based on needs, gaps and available resources; in the technical review of new fistula programmes and projects; in developing a common advocacy agenda; and, in joint mobilization of resources for fistula interventions.

With the support of UNFPA and partners in the FTWG, a national strategy for fistula elimination was developed and launched in September 2012. An important step in streamlining fistula prevention and treatment interventions, the Ugandan National Obstetric Fistula Strategy represents the concerted efforts of all stakeholders, led by the Ministry of Health, to accelerate the reduction of maternal mortality and morbidity.

To assist in the coordination of various fistula activities in the country, UNFPA has been supporting a fistula focal point based in the Ministry of Health, which chairs and convenes the FTWG meetings. A key person committed and knowledgeable about fistula can assist in the planning and implementation of the National Fistula Programme and in the role of the FTWG in ensuring synergy in all fistula activities.



Progress and Results

UNFPA has successfully placed fistula on the national health agenda, thereby increasing its visibility as a public health concern. It has also made fistula part of the national reproductive health policy enabling fistula patients to have their right to treatment duly recognized.

With its critical leadership role and success in bringing key stakeholders around the table to harmonize their efforts, the Ministry of Health led FTWG is seen as the most effective component of the National Fistula Programme.

The development of a national fistula map, which identifies fistula treatment and care facilities, the number and locations of fistula surgeons and areas that are over or underserved, has greatly helped in strategic planning and programme interventions.

The FTWG has identified capacity development needs and supported capacity building for teaching and regional referral hospitals providing fistula interventions. Fistula repair equipment and supplies have also been provided to health facilities in various parts of the country.

Tapping into the reservoir of expertise in the region to advance the skills of Ugandan fistula surgeons and surgical technicians in the context of South-South Cooperation has been recognized as the best approach to improve the skills required to effectively perform fistula repair surgery.



Lessons Learned

- The challenge of putting an end to obstetric fistula in Uganda requires intensified and united efforts of stakeholders at all levels, including national, regional and local. Strong government leadership, commitment and ownership are essential ingredients for success and long-term sustainability of the National Fistula Programme covering all aspects of prevention, treatment and management. Such efforts must be part of a strengthening of the national health-care system aimed at achieving Millennium Development Goal 5 as well as future goals under the Sustainable Development Goals Agenda, including addressing issues of gender equality and empowerment.
- Under the leadership of the Ministry of Health, it is important that all key players in the fistula programme take advantage of the momentum around the issue and the increasing demand for fistula services to promote and pursue their common goal towards an operational and sustainable fistula service infrastructure both at the national and local level, moving towards ending obstetric fistula in the future.
- Obstetric fistula is a recognized public health and human rights problem that will continue to need major funding. With no resources earmarked specifically for fistula management, there is an urgent need to mobilize resources from various sources, including foundations and the private sector.

Partners

African Medical and Research Foundation (AMREF); EngenderHealth; local civil society groups, including Hope after Fistula, TERREWODE, Women at Work International; medical establishments including regional referral hospitals, medical training institutions, departments of OBGYN and fistula surgeons; Uganda Ministry of Health, UNFPA Uganda and WHO.

Acknowledgments and Further Information

This case study was produced in collaboration with UNFPA's Programme Division, Technical Division, the Africa Regional Office and the Uganda Country Office with inputs from the following experts and consultant: Gillian Slinger, Laura Laski, Janet Jackson, Erin Anastasi, Peter Mukasa, Primo Madra, Roselyne Achola and Rene Desiderio (Fordham University Institute of International Humanitarian Affairs).

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Invitation to Contribute to this Set of Good Practices for Fistula

This *Good Practices* set highlights innovative and transformative practices and the power of partnerships to achieve life-changing impact. Improving the lives of the poorest, most vulnerable and often hardest-to-reach populations is a key strategy for eliminating maternal mortality and fistula. Ground-breaking initiatives across the globe, including in the most remote and challenging contexts, are changing the landscape and futures of women and girls suffering from fistula.



Campaign to End Fistula Partners

For further information or to contribute to and expand this set of fistula good practices, please contact Gillian Slinger, Coordinator, Campaign to End Fistula, UNFPA: slinger@unfpa.org

Acknowledgments and Further Information

This set of good practice documents is the outcome of collaboration between the Sexual and Reproductive Health Branch in the Technical Division (SRHB/TD) and the Strategic Information and Knowledge Management Branch of Programme Division (SIKMB/PD), UNFPA. This knowledge sharing initiative was led by Gillian Slinger and Bobby Olarte, with support from Erin Anastasi, Laura Laski, Chief, SRHB/TD; and Charles Katende, Chief a.i., SIKMB/PD. Each brochure was written with inputs from UNFPA staff from Country Offices, technical experts from headquarters and a consultant, who are all indicated in the specific brochures.



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