THE SECOND MEETING OF THE WORKING GROUP

FOR THE

PREVENTION & TREATMENT

OF

OBSTETRIC FISTULA

ADDIS ABABA

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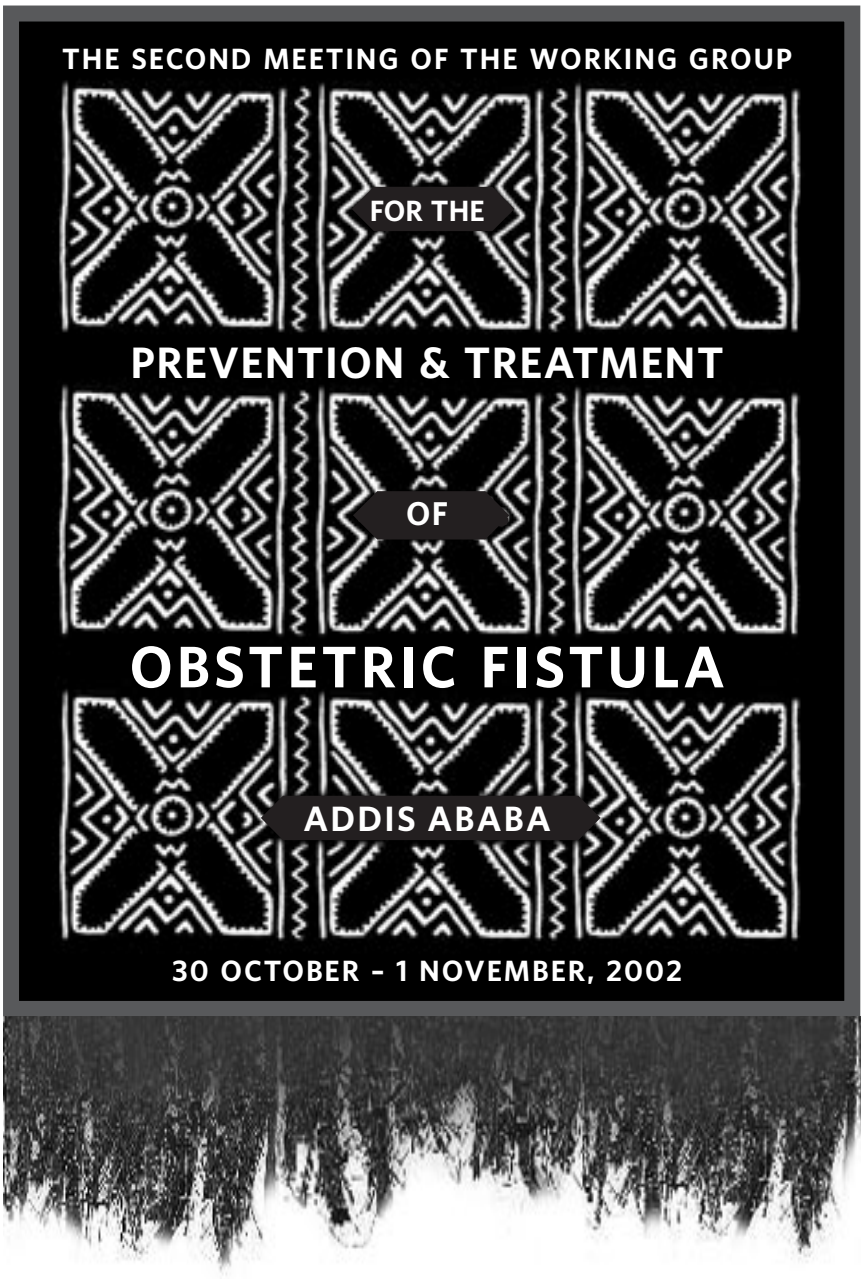
UNFPA



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acknowledgements

Many dedicated individuals and organizations contributed to the success of this meeting—and to those who laid the groundwork for it. We are grateful, first of all, to Dr. Andrew Arkutu for speaking about obstetric fistula long before it was a widely recognized issue and to Dr. Nafis Sadik for bringing the issue to the attention of the multilateral health organizations. At the meeting, the experience and insights of the dedicated surgeons who operate on women with fistula grounded the meeting in a practical and informed discussion. We would particularly like to thank Dr. Catherine Hamlin, Dr. Ann Ward, Dr. John Kelly and Dr. Barbara Kwast. EngenderHealth, the Women's Dignity Project and African Medical and Research Foundation, who carried out the outstanding work on needs assessments. Special thanks to Mary Nell Wegner, Maggie Bangser and Dr. Julius Kiiru for their informative and thorough presentations, and to the UNFPA Country Support Technical Team in Addis Ababa for excellent logistical support.

We are also very appreciative of the outstanding contribution of Amy Pollack, President of EngenderHealth, and of Lord Patel, Vice-President of the International Federation of Obstetricians and Gynecologists, as well as Dr. Doyin Oluwole from WHO Regional Office for Africa, Dr. Luc de Bernis, WHO Headquarters and Petra Ten Hoope, International Confederation of Midwives. Finally we would like to acknowledge the active participation of many UNFPA staff from twelve Field Offices, three Country Support Teams and the Fistula Working Group at Headquarters, with membership from TSD, IERD and Africa Division. Generous funding support came from Columbia University and its Averting Maternal Death and Disability programme, the International Federation of Gynecology and Obstetrics, EngenderHealth and UNFPA.

Very special thanks to Laura Weil, who worked tirelessly to make this report happen.

list of abbreviations

AMDD	Columbia University's Averting Maternal Death and Disability programme
AMREF	African Medical and Research Foundation
CST	Country Support Technical Team(s)
EmOC	Emergency Obstetric Care
FGC	Female genital cutting
FIGO	International Federation of Gynecology and Obstetrics
ICM	International Conference of Midwives
WHO	World Health Organization
WDP	Women's Dignity Project

foreword

I am pleased to issue this report of the Second Meeting of the Working Group for the Prevention and Treatment of Obstetric Fistula. This year's meeting benefited from an exceptional team of experts and generated tremendous enthusiasm for moving ahead. It was attended by representatives from several divisions of UNFPA Headquarters and twelve Field Offices, as well as from some of most important organizations working on this issue: the World Health Organization, Columbia University's Averting Maternal Death and Disability programme, the African Medical and Research Foundation, the International Confederation of Midwives the International Federation of Gynecology and Obstetrics, the Women's Dignity Project, and EngenderHealth.

Much of the meeting was devoted to presentation of needs assessments from 12 African countries. Nine countries were surveyed by EngenderHealth; the African Medical and Research Foundation surveyed Kenya; and the Women's Dignity Project assessed the situation in Tanzania. Dr. Catherine Hamlin and Ruth Kennedy also presented information about the situation in Ethiopia. The assessments provide a clear and informed base—for the first time—on which to build a realistic plan of action to combat fistula in the region. This information should also help to bring the tragedy of fistula out from under its shroud of shame and secrecy. We expect this will result in increased support for many of the best programmes already in place in Africa and in the creation of a regional network for fistula prevention and treatment

In just the past two years, significant progress has been made in raising awareness and mobilizing resources for fistula treatment and prevention. But much remains to be done. We are committed to continuing and expanding this work so that women who suffer from fistula can return to full and active lives, and so that others will be spared from harm.

Mari Simonen
Director
Technical Support Division
UNFPA

overview of key action points from meeting

1. Promote integration of fistula prevention and care into safe motherhood services. Advocating against early marriage and other practices and conditions that lead to maternal mortality and morbidity can improve the lives of women more generally. Moreover, prevention and treatment of fistula is a valuable gauge of the overall strength and quality of a country's obstetric services. Fistula can serve as an entry point for persuading governments to support safe motherhood programs by allocating sufficient funds for skilled attendants to be present at delivery and for timely intervention of obstetric complications. Working with policy makers to prevent fistulas caused by obstructed labour will strengthen emergency obstetric services overall and also help to reduce infant and maternal mortality.

2. Continue work in the needs assessment countries. Benin, Chad, Kenya, Malawi, Mali, Mozambique, Niger, Nigeria, Uganda and Zambia will each receive a one-year $40,000 project-planning grant to develop country projects that build upon the needs assessment results. Planning will begin in 2003 with the final three- to five-year projects beginning in 2004. Ethiopia, Kenya and Tanzania will provide support to these new programming efforts, leveraging their own past experience in combating and treating fistula.

3. Continue media and advocacy activities. A global advocacy campaign will be implemented simultaneously with country level programming. All UNFPA staff and working group members will be encouraged to deliver presentations about fistula at national and international conferences. In addition, the findings of the nine needs assessments conducted by EngenderHealth and funded by UNFPA will be published and made widely available to policy makers, practitioners and activists. The publication will receive a high profile launch. The working group will also explore further the concept of a fistula awareness month.

4. Improve communication among existing service providers, policy makers, NGOs and other interested parties. Strong communication among fistula treatment providers, programme plannersand activists will be necessary as fistula activities scale up. The working group will reach out to NGOs and women's organizations and will establish steering committees to address specific issues such as prevention and provider training. In the area of training for fistula repair, the work of the steering committees will include the creation of provider training standards and the development of training materials. It might also include a grant for institutions to expand training opportunities.

5. Provide free or highly subsidized fistula services. The poorest women are the most vulnerable to fistula because they tend to marry early, have few educational opportunities and limited access to health care services. They may save their earnings for years just to pay for the transportation to a treatment facility, and then they face the cost of surgery and rehabilitation. Funds must be allotted to enable these women to receive care.

6. Expand the reach of fistula prevention activities to new countries and regions
Continue cataloging fistula activities and services including emergency obstetric care services. Ideally this will result in the establishment of centres for fistula treatment and training in each affected country.

7. Eradicate poverty and improve the socio-economic status of women
The underlying cause for the development of fistula is poverty. This condition inhibits the potential contribution to these girls' economic wealth and ultimately that of their community.

background: about fistula

Obstetric fistula is an injury to the pelvic tissue caused by prolonged, unrelieved obstructed labour that can last up to five days. It is literally a hole between the vagina and bladder or rectum or both that causes total incontinence of urine and/or faeces. Obstructed labour most often occurs when the baby will not pass through the birth canal because it is too big, the mother's pelvis is too small, or in multiparous mothers with a malpresentation. If not treated, this obstructed labour can result in the death of the baby and the mother, or in obstetric fistula for the women who survive. Most women with fistula deliver stillborn babies.

Obstetric fistula is a devastating and preventable tragedy that primarily affects young, poor women who lack the means to access quality maternal care. Women living with fistula are constantly wet from the leaking and often experience genital ulceration, infections and a humiliating odor. About 20 per cent of women with fistula also develop unilateral or bilateral foot drop that limits their day-to-day activities. They are typically shunned by their partners, families and communities because they are considered unclean, and many live in nearly complete isolation. Without financial support, many women with fistula are forced to beg for their living, and they are especially vulnerable to malnutrition and violence.

Poverty is a fundamental cause of fistula. Inadequate nutrition, stunted growth, limited access to health care and traditions of early marriage and pregnancy all contribute to the likelihood of obstructed labour. Traditional practices such as female genital cutting (FGC), especially Type III FGC, can also result in formation of fistula. Fistulas are most common in impoverished communities of Africa and Asia. More than two million women are estimated to live with the condition. And out of every 1,000 births in countries with high maternal mortality rates, another two or three women will be disabled by fistula. In Africa alone, this means 50,000 to 100,000 new fistula patients every year. Women who remain untreated not only face a life of misfortune and isolation, but may also face a slow, premature death from frequent infection and kidney failure.

Fortunately, literature indicates that skilled fistula surgeons can successfully treat 80 to 90 per cent of cases (depending on the type of fistula), and return these women to a full and normal life. However, the African countries with the highest incidence of fistula also lack the facilities and medical skills to provide such treatment. Fistula repair centres operate in only a few countries, most notably Ethiopia and Nigeria, but these centres cannot meet the enormous need for fistula care. As some 1.5 million women and girls await surgery, expansion of fistula repair capacity is urgently needed. Existing centres need to be strengthened and new ones established. Greater awareness of the high prevalence of and difficulties caused by fistulas, as well as an understanding of their cause and treatment, is needed to make this happen.

Fistula was once widespread in Europe and the Americas, but the condition has been eradicated by modern medical care. Because the industrialized world and many developing

countries have been successful in their fight against fistula, it is evident that workable solutions do exist, even in resource-poor countries. The persistence of fistula indicates profoundly inadequate access to emergency obstetric services. Obstetric fistula is an issue inextricably linked to the lower status accorded to women and girls. It is an issue of human rights, and UNFPA is committed to return affected women and girls to a life of dignity and health.

laying the groundwork for action

The tone of the Second Meeting of the Working Group for the Prevention and Treatment of Obstetric Fistula was one of enthusiasm both for what has already been accomplished and for meeting the challenges ahead. In addition to the members present from the original working group, this year's meeting was expanded to include more NGOs and practitioners working on the issue. As intended, the meeting followed up on actions initiated last year and moved forward with an action-oriented agenda.

Much of the meeting revolved around presentation of and discussion about the 12 needs assessments commissioned in 2001 and conducted by UNFPA, together with partners including Columbia University's Averting Maternal Death and Disability programme (AMDD), EngenderHealth, the African Medical and Research Foundation (AMREF), and the Women's Dignity Project (WDP). The assessments were intended to offer a general overview of the experiences of women with fistula and the resources available to them. This is the first time such assessments have been conducted—available services have not been adequately catalogued in any of the countries in Africa. This has contributed to the invisibility of the problem and complicated the delivery of strategic programme support.

While fistula is common in most countries in sub-Saharan Africa and in some parts of Asia and the Middle East, its exact prevalence is quite difficult to determine. In many cases fistula services operate outside of the government health sector and involve visiting foreign surgeons. The extent of the problem uncovered by the needs assessments surprised even several meeting participants who work in Africa. Summaries of the assessments begin on page 22 of this report. The actual reports will be available in hard copy from UNFPA, EngenderHealth, the Women's Dignity Project, and AMREF upon request. Or they can be viewed at the UNFPA website (www.unfpa.org).

A $40,000 project formulation grant for country level exploration and planning will be available to every country in which a needs assessment was conducted. Much of this money will come from a generous grant from the Government of Finland. Grants will be given with the intent of promoting a comprehensive country action plan to address fistula. Projects can include advocacy, training and repairs and awareness raising activities. Several countries submitted their proposals within a few months of the meeting, illustrating their strong motivation to address fistula at the country level. Uganda was the first field office to take advantage of the project formulation grant.

The methodology for the needs assessments varied. EngenderHealth worked in conjunction with UNFPA field offices to visit sites and administer a standard questionnaire to key figures and institutions who work with fistula patients. They also performed qualitative research with patients and survivors. The Women's Dignity Project worked with the Ministry of Health to send out a one-page survey to all district regional and mission hospitals in Tanzania, which received an exceptional 80 per cent response rate, reflecting keen interest in the subject. Referral hospitals were contacted

separately. AMREF used a questionnaire similar to the one used by EngenderHealth.

"I was out giving a health education talk in a village in Rakai district and I wanted to mention that we would have a visiting fistula surgeon coming shortly. I realized that I should talk a little bit about what fistula is since I wasn't sure what it would be called in the local language. Partway through my description a man raised his hand and said, 'But doesn't that always happen in childbirth?' and I suddenly realized that I was in a community where almost every other woman had a fistula...."

—a provider in Uganda

Lessons from the needs assessments

The needs assessments provided valuable information regarding factors that contribute to the incidence of fistula and its impact on women's lives. A brief discussion of common factors garnered from the needs assessments follows:

Poverty. Poverty is a root cause of poor health in general and is linked to fistula on many levels. Poverty may contribute to the formation of fistulas by causing malnutrition that can result in stunted pelvic growth. Poverty may also force girls into early marriage and childbearing. Skilled care at birth and emergency obstetric care in cases of obstructed labour may be too costly for the poor. Poverty also limits women's ability to take advantage of repair services—even though there is a wide range in the cost of surgical repair and methods of cost recovery. In many countries, remuneration is required, often on a sliding scale.

Lack of skilled attendance at birth. In nearly every case of fistula reported, the lack of a skilled attendant, or a doctor, midwife or nurse, led to long labours without appropriate intervention. Unattended labours occurred for several reasons. One is tradition. In many countries, there is a strong cultural value placed on remaining at home to deliver. This may be due to a fear of outsiders (especially men) witnessing the labour, or it may reflect the idea that childbirth is a rite of passage that must be undertaken alone. In many other cases, however, unattended labour is simply the result of too few or inaccessible attendants, especially in rural areas, or a lack of female health workers. Among the solutions suggested in the assessments were deploying better trained attendants to the rural areas, and increasing the salaries of those attendants already living in rural areas as an incentive to stay and work there.

Lack of emergency obstetric care. The assessments revealed multiple cultural and socio-economic reasons why a woman would choose not to seek obstetric care at a hospital. In several countries women said they were uncomfortable being cared for at hospitals, which they associate with death. Some women do not want to be attended by male staff. In certain regions, women thought that hospital staff would not be responsive to their needs, or might even be overtly hostile. Some women, for example, had heard they would not be allowed to deliver in a squatting position, which they consider preferable. Still others feared mandatory testing for HIV. Concerns about cost and transportation also figure into the decision to seek emergency obstetric care. In many cases, even if a woman

"These women are so poor...they come to us with nothing. They have no food to eat, usually no one to care for them while they are in hospital, and malaria, TB, and sometimes other infections. They are almost always malnourished and this is getting worse as the famine grows..."

—a provider in Malawi

desires to seek care at a hospital, she may be unable to do so unless her husband or a male relative agrees.

Lack of transportation. In nearly every country studied, fistulas were geographically concentrated in rural regions, particularly poor and remote areas with limited access to transportation and services. In these areas, transportation to a hospital is extremely hard to find, and once found, can be quite expensive, and often out of the reach of poor women. This situation is exacerbated by the fact that women may lack the power to make critical decisions, such as the decision to seek care, or to make financial sacrifices to procure transportation, even when their survival hangs in the balance.

Lack of awareness among policy makers. Few policy makers realize the magnitude of the problems that women with fistula experience. In several cases, once policy makers were made aware of the problem they were eager to devote energy and resources to finding solutions. Although health care providers are more cognizant of the issue, some of them may also seriously underestimate the struggles that its survivors endure.

A shortage of trained providers for fistula repair. Few trained surgeons, especially in countries where fistula is most prevalent, have the skills and experience to perform successful fistula repairs. This has led to a dependence upon foreign doctors to perform the fistula repairs and has, in turn, created sustainability problems for fistula repair services. Even in countries where fistula treatment is part of the medical curriculum, many doctors choose more lucrative specialties, and prefer to work in cities rather than rural areas. Lacking experience, few practitioners are able to carry out complicated repairs. This lack of providers is not limited to fistula repairs, however. In some countries, nearly every sector of health care is understaffed. In Malawi, for instance, there is a critical shortage of nurses in all specialties.

Limited awareness about repair possibilities. In many countries few women were aware that fistula repairs are possible and available. Consequently, many women have lived with fistula for years. However, when communication and "word of mouth" campaigns were launched—most notably in Chad—women did seek treatment. However, several countries are reluctant to widely advertise repairs, for fear of raising false hopes, and then being inundated with requests beyond their capacity to fulfill. They are concerned about further traumatizing women who may spend the last of their resources reaching a facility only to wait indefinitely to be treated, or to be told that services are no longer available.

Poor integration of services. Although women with fistula may be sexually active, HIV counseling is often not included in fistula treatment. Many providers suggested that HIV counseling would simply add to the "psychological burden" of the patients. However, some facilities, such as the Evangel Hospital in northern Nigeria, do offer voluntary HIV testing and counseling to fistula patients.

Nor is contraceptive counseling typically offered in pre- or post-operative counseling, despite its critical importance to women with fistula. Women with fistula repairs should not get pregnant again right away after their surgeries, and when they do, should have a Caesarean section to avoid a reoccurrence of the injury. The assumptions seem to be either that women will want to become pregnant again immediately or that they are not sexually active. In some cases clients awaiting repairs are not given contracep-

tive counseling even upon request, and are told to wait to resume sexual relations until their fistula has been repaired. This is of concern because in some regions the women may earn their living through sex work, and should have the benefit of counseling on HIV and contraception even before their fistulas are repaired.

Training in income-generation projects is also important. In some countries, women who have been successfully treated are likely to return to their homes and be reintegrated into their communities. In others this is less likely to happen, and women will need an alternate means of supporting themselves.

Marginalization of women with fistula. Fistula victims have little visibility or power. Since the condition is stigmatized, the women who suffer from it often remain hidden. In most of the countries assessed, the women with fistula were quite young. In some countries, most notably in Zambia and Chad, they were also refugees and, therefore, already marginalized. Just as the assessments detailed many common contributing factors, they also offered several common recommendations for actions.

VISITING THE ADDIS ABABA HOSPITAL AND THE VILLAGE OF JOY

All participants were given the opportunity to visit Addis Ababa Fistula Hospital. The hospital tour was led by Dr. Catherine Hamlin, who founded it in 1974 with her late husband Dr. Reginald Hamlin. The hospital is the one of the few in the world that specializes in fistula treatment, and it also serves as an international training centre. Participants toured the operating theatres, recovery rooms, physical therapy centre and cooking areas. They also were able to greet women who had just arrived for treatment following a three-day journey and clients who had been successfully repaired and were ready to return home.

The group also visited the "Village of Joy" (Desta Mender), which was still under construction at the time, but has now opened and serves as a rural oasis for chronic fistula patients. A small number of clients (about 3 per cent of those treated) have been so badly damaged in childbirth that they cannot be cured, and need continual care.

Despite this affliction, almost forty patients have been trained as nursing aides, and they comfort and care for women who have survived with their same condition. Still others cannot do a full day of nursing, so for these some lighter work will be made available at Desta Mender. In 2000 the Ethiopian Government gave the hospital a parcel of 21 hectares (60 acres) of rural land outside of Addis Ababa to build a "self-help" village for these patients. Additional funding was provided by gifts from Australia. The village will initially house 100 women in ten self-contained cottages. Residents will be taught agricultural and craft skills.

strategies to address fistula based on the assessments

Just as the assessments detailed many common contributing factors, they also offered several common recommendations for actions.

Raise awareness. As the assessments revealed, and as has been widely reported, the medical community rarely perceives fistula to be a serious concern. In many cases, health planners grossly underestimate the number of women living with this condition and the devastating impact it has on their lives. Advocacy is needed to better inform providers, politicians and the ministries of health. Publicly defining fistula as a human rights issue will also help to make it a pressing concern both at the ministerial level and for individual practitioners.

It will also be of use to highlight fistula in national reproductive health strategy papers, not only as a component of reproductive health, but also as an issue in and of itself. Fistula can be used to highlight existing sexual and reproductive health policies and to underscore the importance of EmOC. It will also be useful to attract the attention of social scientists to the issues of fistula.

Improve access to maternal health care. New cases of fistula will continue to occur without a concerted effort to improve access to quality maternity care. This includes improving availability and affordability of services. Improving access will entail making sure skilled attendants and emergency obstetric services are available in rural areas, and accomplishing this will require the active involvement of governments and ministries of health. Expanding the roster of practitioners able to save women's lives may require training generalists to perform Caesarean sections. In the short term, it will also be extremely important to ensure that at least a minimum number of facilities have the equipment and supplies necessary to perform Caesarean sections and administer catheters to prevent fistula in cases of prolonged obstructed labor. Incentives for practitioners working in rural areas, and for those who choose to receive fistula training will be helpful.

Moreover, funding schemes are needed to ensure that women who need Caesarean sections are able to receive them. Access to this procedure is especially important for women who have already had fistula repairs. Without the operation, the fistula will very likely reoccur. These interventions alone will make a considerable difference in reducing the incidence of fistula.

Provide fistula services free or at highly subsidized rates. Lack of funds can prevent women in need of fistula repair from accessing services. The poorest women tend to be the most susceptible to fistula because they are the least educated, the earliest to marry, and the least able to access preventive and curative care. They often must save up for years to afford the repair surgery and the expense associated with convalescence in the hospital, in addition to paying for transportation to a treatment site. The cost of fistula repair must be within the reach of all women in need. As is the case with emergency Caesarean sections, funding strategies that make surgical repair affordable to the poorest women are essential.

Develop community level awareness campaigns. Emphasis must be placed on prevention as well as treatment. Radio and local media campaigns can alert communities to the dangers

of early marriage, potential complications of childbirth and the necessity of emergency obstetric care in the case of complications. They can also let women know about the availability of fistula repair. These campaigns could be supported by community-based qualitative research to determine perceptions of fistula patients by the larger community. This will include finding local leaders willing to take a visible role in raising awareness of the problem.

Devise transportation schemes. In most countries there are few sites where fistula repairs are offered. It is difficult for women to find transportation to these sites, and even more difficult for them to pay for it. Several participants told heart-wrenching stories of girls' journeys on foot, horseback and eventually bus to reach a facility that could help them. Working with local truck drivers to help transport women to the hospitals may be one way to improve access to transportation. For women living in high-need areas, group transit options, like buses that depart to the hospital regularly from a referral site, should also be considered.

Explore ways to integrate HIV and contraception counseling into maternity care and fistula repair services. Contraceptive counseling can do a great deal to prevent unplanned pregnancies. Unplanned pregnancies can cause further damage to the pelvis of a woman with a fistula or a recurrence of fistula for a woman whose fistula has been repaired. Offering HIV counseling will help to protect women from becoming infected. Furthermore, consolidating fistula services with HIV-prevention activities may also offer offer an opportunity for fistula repair sites to obtain more funding, since resources for HIV prevention are relatively abundant. Incorporating services for refugees into the scope of this work should be considered as well, as the incidence of fistula among refugees is high in many places.

> *"You know, my dad first heard that this [fistula] could be fixed on the radio and he told me about it...if he hadn't been listening to the radio that day, I would still be leaking."*
>
> *—a fistula client in Uganda*

Promote educational and vocational opportunities for girls. Early pregnancy is one of the greatest risk factors for developing a fistula. It is well documented that girls who have educational and vocational opportunities will delay childbearing, thus reducing their risk for obstructed labour and fistula. These same developmental opportunities should be available to women who have received fistula repairs. These women, in most cases, will need to support themselves. Simply repairing the fistula and returning women to the same conditions that made them ill in the first place may not be enough. The Addis Ababa fistula hospital provides a useful model for literacy and vocational training.

Expand clinical research on fistula repair. While some excellent clinical research exists, there is room for further exploration, particularly regarding pre- and post-operative management of fistula. This may include adapting information systems to capture fistula cases in countries where these systems are well established. There may also be opportunities to promote data collection on fistula in countries where management and health information systems are just developing. The needs assessment in Tanzania revealed that few of the hospitals had information on success rates of surgical repairs. This highlights the need for further monitoring and evaluation of fistula repair services.

highlights from the working groups

In addition to the recommendations based on the assessments, discussion among participants built on the recommendations from the 2001 meeting in London. Working groups on these topics were extremely productive and illustrated the commitment of the participants to create change. The following issues are of primary concern and are targeted for future actions.

Focus on policy. Policies that integrate fistula into existing safe motherhood progammes will help to prevent it becoming a "fashionable" issue with no sustainability. Instead, fistula can be a way to draw attention to the greater unmet need of quality maternal care. Advocacy groups should always be on the lookout to find opportunities in the policy cycle to highlight fistula.

Expand the role of fistula centers. Fistula centres have been a critical component of work to address fistula, serving not only as facilities for surgical repair and psycho-social rehabilitation, but also as centres for advocacy and training. The very presence of fistula centers raises awareness of the problem. Discussion continues about how to best integrate fistula repair services with the general heath sector while maintaining the valuable contributions of these centres. Minimum standards for centres that deal exclusively with fistula, or that offer other services as well should be established. These standards will facilitate selection of new sites that can be promoted as fistula repair hubs. Suggested standards include:

- The ability to provide Caesarean-sections. This serves as a prevention measure for fistula, and it also gives women who have been repaired a place to return to should they become pregnant again.
- Two operating theatres: one for emergency cases, and one for elective procedures.
- Readiness to respond to emergencies 24 hours a day, seven days a week.
- The ability to surgically repair complicated cases.
- A referral system linked to the rural facilities that may be the first point of contact between a fistula patient and the health care system.
- The capacity to serve as training hubs for the country or region.
- A solid and well-trained clinical team.

In addition to these clinical standards, sound management is an essential but often overlooked element of a well-functioning centre. A dedicated manager is needed to write grant proposals, maintain the flow of supplies and the functioning of equipment and the general facility, schedule training trips and liaise with the ministry of health. For these reasons, a management training module should be considered in future training curricula.

Clearly, improved communication and collaboration among the fistula centres and hospitals performing fistula repairs are needed throughout the region. This will facilitate training, research, patient referrals, advocacy and resource mobilization. A mapping and referral system will also aid sustainability. The working group has helped establish communications between some of the centres, but a more comprehensive system should be developed that can serve as a forum to share advocacy materials, successful programming strategies and clinical research studies. The coalition should work to develop a universal management information system to standardize the data collected at each facility and make multi-site research more feasible.

Facilitating communication among fistula providers both nationally and regionally, using some of the methods in practice at the Nigerian National Foundation for VVF and the Women's Dignity Project, will help to coordinate services.

This will include keeping a list of all sites and surgeons performing fistula repairs. Such documentation can also be useful for learning more about the prevalence of fistula. Tracking the caseload of repairs can be used as a gauge to measure the strength of reproductive health and safe motherhood programmes at the country level.

Fistula centres can function as centres for many forms of advocacy as well. For instance, several fistula centres in Nigeria worked with social scientists to form the Nigerian National Foundation on VVF, which has improved communication among fistula centres on a national level and encouraged well-known politicians and entertainers to raise community awareness about the issue. Staff members can also be excellent advocates for the cause. Their contact with the women who have lived with fistula gives them a broad understanding of the condition and its devastating effects on the lives of women and girls.

In Tanzania, fistula centres were seen as only one part of a three-tier referral system. This would include top-tier referral centers to handle complicated cases of fistula with extensive damage and scarring, mid-tier referral facilities able to undertake simple repairs on site and refer more difficult cases, and an entry level that is able to prevent fistula through the management of obstructed labor and possibly catheterization during and after delivery as needed.

Establish universal standards. Coordination of efforts throughout the region and across the globe is becoming increasingly important. Of primary concern is the creation of standards for fistula surgery, training and centres. This will include protocols and guidelines for surgery and pre- and post-operative care.

> *"The definition of a successful repair must go beyond successfully repairing a fistula to include alleviating 'stress incontinence' and creating a lasting positive change in the woman's life".*
>
> *—Maggie Bangser, Women's Dignity Project*

> *"For us, it is a real morale boost to care for fistula clients.....when these ones realize that they are dry and can go on with their lives, they are so happy..."*
>
> *—a nursing sister in Zambia*

Establishing competency-based training standards will encourage a consistent learning process for fistula surgeons. This will allow for the trainees to be sent throughout the region, which can shorten the long waiting lists at several well-known training sites. Competency-based training programmes will also produce surgeons and nurses who are prepared to meet the challenges of providing fistula services. WHO, along with several members of the working group, is developing a manual for training.

Standards of care for fistula will also include a reintegration strategy that can be adapted for use at the local level. Once protocols are developed, they can be implemented by the ministry of health and funded by the government, NGOs or multilaterals.

Strengthen monitoring and evaluation. Existing indicators used to monitor reproductive health and safe motherhood can be easily adapted for use in monitoring fistula. As with any monitoring activity, robust indicators are important. These indicators must be valid, reliable, sensitive, specific, useful, accessible, representative, understandable and ethical to collect. Specific safe motherhood indicators of interest are:

- Percentage of women attended, at least once during pregnancy, by skilled health personnel for reasons relating to pregnancy

■ Percentage of births with a skilled health attendant
■ Number of facilities with functioning basic emergency obstetric care or fistula services per 500,000 population
■ Number of facilities with functioning comprehensive emergency obstetric care per 500, 000 population
■ Geographical distribution of EmOC/ fistula repair facilities

These indicators provide background data that is useful in determining the services available and in estimating the likelihood of fistula incidence. They do not, however, give any descriptive information about the women themselves, and should be supplemented with qualitative data.

Prevalence surveys are costly, time consuming and difficult to undertake. The results will inevitably be of questionable accuracy or use. However, fistula prevalence can be estimated at 0.3 per cent of births in countries with more than 500 maternal deaths per 100,000 live births. This was of estimating fistula prevalence is based on unpublished research by Dr. Mulu Muleta of the Addis Ababa Fistula Hospital.

Maternal mortality audits and "near miss" audits are both particularly useful in the monitoring of fistula. This encompasses community-based audits, case-reviews and cases in which the woman lived in spite of a near-fatal complication. This will help to provide data about the women who are dying and those who are developing fistula.

Indicators that more specifically address fistula are:
■ Number of pregnant women referred for prolonged obstructed labour
■ Caesarean section rate and the Caesarean section rate for prolonged obstructed labour
■ Number of fistula services or beds per country, per population or per level of care
■ Met need: number of fistulas treated per expected cases of fistula

Existing fistula services must also be carefully evaluated. This will require a standard set of indicators and systematic data collection to be used by all facilities repairing fistulas, including a standardized system for classification of fistulas and monitoring the percentage of surgical success by group. It will also entail efforts to monitor the post-treatment social reintegration of a subset of women.

Monitoring of advocacy activities is also important. This will include identifying countries that have adopted policies, laws and regulations protecting women such as:
■ Raising the age of marriage
■ Promoting and guaranteeing girls' education
■ Improving the socio-economic status of women
■ Providing family planning services and information for adolescents
■ Planning for the equitable distribution of functioning basic emergency obstetric care and comprehensive emergency obstetric care facilities.

Train more providers. Training has many forms in the different facilities in the countries studied. Some charge fees for the training; others require payment only for transportation, food and lodging. However, even this cost may be prohibitive for some candidates.

Training should be comprehensive enough to ensure that doctors feel comfortable undertaking the surgery. Many surgeons believe that the surgery is technically difficult, and therefore they avoid undertaking it for fear of failure. Indeed, the effect of a failed fistula repair can be profound both for the woman and the surgeon. A woman will often spend their entire life savings reaching a fistula centre, and all of her hopes and dreams are pinned upon a successful outcome of surgery.

The disappointment of women who are not successfully repaired can be devastating and can affect the surgeons as well.

Competency-based training will help to alleviate this problem. If a surgeon is not able to perform repairs with a reasonable success rate, she or he will have the benefit of additional guidance to strengthen his or her skills. Turning out competent surgeons who are more likely to practice will dramatically improve the efficiency of training programmes. Historically, specialists have been the ones trained to become fistula surgeons. It may be beneficial to look beyond ob/gyns and surgeons to attract dedicated practitioners interested in receiving training.

Training takes many forms in the facilities throughout the region. In some countries it is part of the medical curriculum. In others, there is only training upon request and may require international travel. A thorough evaluation of the current training programmes in each country will be beneficial in determining which programmes are successful and why. This will lead to the creation of training standards that are practical and feasible, as well as help catalogue the available services.

The needs of providers go beyond simply training. They will require administrative support at whatever facility they practice in. As part of provider training it may be beneficial to have a managerial workshop for those who will be responsible for providing support. Training for all providers should include ways to meet the psychosocial needs of fistula patients. For many providers, their experience simply has not prepared them to provide this type of counseling and support, and they will need help. It is important that providers receive that help in the training sessions.

Training must also include follow-up workshops and support. Providers are easily discouraged after unsuccessful repairs. It takes considerable experience to attain high success rates. Follow-up training sessions to troubleshoot and analyze previous unsuccessful attempts and to gain the skills to undertake more complicated repairs are important in the sustainability of services.

> *When a woman arrives at a repair facility it is as though she has reached Mecca. Her whole life's savings, all of her hopes have been in getting cured and going home. If the surgeon does not care, or is not prepared to do it right the first time, her hopes are shattered. The sorrow of women who are not cured is incredible.*
>
> *—Dr. Ann Ward, Family Life Centre, Nigeria*

Work with the media. Achieving a balance between raising awareness and raising false hopes through media activities remained a controversial issue in the working group. Concern was also expressed that simply portraying women with fistula as victims could further victimize women who are surviving with the condition.

However, the group agreed that awareness of the issue is important, and requires a larger media campaign. It was not determined how to best proceed with the campaign at this time. Several possibilities were raised including a "fistula awareness month". This month would be used to report on the activities and accomplishments of fistula centres and NGOs over the previous year. Ideally, it would show progress from year to year, and keep the issue in the public eye.

Any further campaign will need to carefully determine a target audience and a chronology of the campaign. It will be important to develop a consortium of experts including social scientists, surgeons and opinion leaders to act as spokespeo-

ple. The media campaign has already begun with publications from the members of the working group like the FIGO newsletter, and the UNFPA *State of World Population*. Groups like WDP have also spurred media attention to fistula with the launch of their report. The working group will continue to raise awareness of fistula in technical publications, and the mainstream media.

Mobilize resources to foster sustainability. Sustainability of services will include many of the components already discussed, including human resources, political leadership and revenue. It has been noted that many of the national doctors trained to perform fistula repairs are not utilizing this skill. In some cases this is because they chose other, more lucrative specialties, or because they are unwilling to move to areas where fistula repair services are in high demand. This has led to a dependence upon foreign doctors to undertake fistula repairs. It will be essential to involve local doctors in the development of sustainable fistula programmes. This will require adequate reimbursement, or possibly some kind of incentive scheme, for the doctors involved.

Fistula services should be integrated into safe motherhood programming. This will promote government attention to the problem without it getting lost in the broader reproductive health programme. This will include working to establish or expand national and regional coalitions to lobby for funding commitments and for policies that will benefit women and girls. Groups like women's lawyers associations and religious groups should not be overlooked.

A focus on the managers of fistula services will also be important. Without properly managed programmes, fistula services are not sustainable. Guidelines should be developed to define what the minimum personnel and equipment requirements are for undertaking fistula repairs.

> *"Girls and women with fistula are strong and resilient survivors, not victims."*
>
> *—Women's Dignity Project*

It will be essential to create a source of revenue in order to continue with fistula repairs; this initiative will require innovative financial solutions. The feasibility of providing completely free Caesarean sections and fistula repairs varies from country to country, and among facilities. However, because women needing services are unlikely to be able to pay enough to cover the cost of surgery, services need to be provided at the lowest possible cost. Alternate means of funding must be established; these may come from the national health care budget, particularly from government hospital allocations. Fundraising efforts among private sector donors will also be essential in order to support large-scale improvements and to procure smaller-scale operating funds.

Another possibility for attracting small donations to alleviate the operating costs is a trust fund for fistula repairs. Such a fund could help cover the costs of repairs without putting the burden on the women or the facilities. Free or heavily subsidized repairs will also benefit teaching institutions by expanding the caseload of fistula patients, allowing residents to perform enough surgeries to feel secure and comfortable operating on their own.

Funds for fistula repair services can also come from programmes in related areas, such as human rights and reproductive health. Some countries have found creative ways of using overlapping program funds to recruit, train and compensate staff with crosscutting responsibilities. In Zambia, for example, many nurses that work in and are

paid through an HIV/AIDS programme also treat women receiving fistula repair. These nurses report that they like to care for fistula patients because they have a strong chance for recovery and often leave the hospital ready to start a new life. This comes as a needed morale boost to nurses who primarily care for patients dying of AIDS, patients who are unlikely to leave the hospital alive.

Fistula can also be seen in a multi-sectoral fashion. Working with ministries of transportation and education will bring more attention to the issue as well as make them more sustainable. Specific related policy areas are girls' education and attendance in school, and a realistic look at the implementation of reproductive and sexual health and safe motherhood policies and the impact they have on fistula. Effective policies can be used as advocacy tools in other countries. Additional support for existing policies will be of great use as many countries have strong safe motherhood policies that are not well implemented. Drawing attention to this paradox may prove to be an effective tool in combating fistula.

UNFPA and fistula

Fistula programming represents a new level of collaboration among UNFPA divisions, bringing together a wide range of expertise to work on a single issue. It is a model for all UNFPA programming, one that has already shown a remarkable success in creating and promoting innovative strategies.

UNFPA's commitment to ending fistula was evident throughout the meeting, which was the first international gathering of UNFPA representatives from several branches of the organization to address this issue. The needs assessments generated considerable enthusiasm, and suggested potential for UNFPA offices to take a leadership role in the next steps. Country representatives from the 12 needs assessment countries met with headquarters staff to refine the broader organizational action plan for moving forward. Further research will be needed to determine UNFPA's most effective role at the country level.

Several UNFPA country representatives remarked that the needs assessments helped to bring the issue of fistula to their attention. Several said they had not previously realized the extent of the problem within their countries. Increased awareness of the problem heightened their motivation to address it in programming. CST advisors from Dakar, Addis and Katmandu were also present at the meeting to help stimulate action and guide a region-wide plan of action.

The Fistula Campaign concept

UNFPA originally determined that a coordinated effort to reduce the prevalence of fistula through prevention and treatment could be coordinated under the umbrella of a fistula campaign. Dr. France Donnay, Kristin Hetle and Mari Tikkanen presented the concept on behalf of the UNFPA interdivisional working group on obstetric fistula. The vision for the campaign includes training, service delivery and advocacy components.

The goals are to prevent new cases of fistula by delaying early marriage and improving access to emergency obstetric care, to improve access to high quality treatment for affected women, to ease social integration of women who have been repaired as well as those who remain affected, and to raise awareness of the problem on an international level. The campaign is to be carried out in stages, possibly culminating in a fistula month. The fistula month was seen as a way to increase the number of surgeries completed in a month's time as well as to draw attention to the issue. It was determined, however, through a very lively discussion, that a surgical fistula month was not technically feasible. It was also decided that more groundwork is needed to inform any future campaign. Considerable coordination among existing agencies will be necessary. More effort will be required to catalogue the existing services and develop communication networks before embarking on a comprehensive campaign. However, all parties agreed that the idea of a campaign is one to be reconsidered in the future.

The Knowledge Sharing Asset

In order to facilitate the process of knowledge sharing about fistula, a pilot project to design and create a knowledge asset on fistula has been established by UNFPA. A knowledge asset

is a database of information designed to function as a clearinghouse for information and easy access to step-by-step programming guidance and resources. A network of experts on obstetric fistula from both field offices and non-UNFPA parties participated in contributing information and experiences to this pilot project. The information is being organized and will be displayed in a question and answer format on an interactive, web-based platform designed by the Knowledge Sharing Branch of UNFPA.

At the meeting, the knowledge asset and its use was demonstrated. Because the knowledge asset is intended to be a continuously evolving, dynamic exchange of information, a general invitation was extended to all attendants of the meeting to join the network of contributing experts.

summaries of needs assessments

The following are summaries of the needs assessments presented at the meeting. All were conducted by EngenderHealth except for Tanzania, which was conducted by Maggie Bangser of Women's Dignity Project, and Kenya, conducted by the African Medical and Research Foundation. Full reports are being distributed widely to the press and policy makers, and can be viewed at www.UNFPA.org/publications.

Benin

Since Benin's democratic elections in 1996, traditional ideas on reproductive health appear to have softened, and some health indicators are improving. Until recently, C-section was not even considered an accepted form of delivery, but now represents about 3 per cent of all births. Several organizations (including UNFPA Benin) have also been able to make reproductive health a central theme of their programming. The aim has been to improve conditions for women, men and adolescents by integrating family planning and reproductive health into programme areas, creating services to spread information about low-risk sexual activity and collecting data on fistula to develop and plan interventions. The Ministry of Health says it supports any action that will lead to the reduction of maternal mortality and morbidity, which includes addressing fistula.

Discussions with UNFPA staff, district administrators and health care workers at four hospitals around the country (two public, two private) suggest that fistula is not yet acknowledged as a critical issue in Benin. Of the four sites visited, three offer fistula repair surgery. Fistula is seldom recorded in provider logs; nor has information on prevalence or incidence ever been gathered. Few local qualified personnel are available to operate on existing cases and the majority of facilities visited rely on the services of expatriate doctors. While fistula has been recognized and repaired for many years, it has been deemed by some providers as "luxury surgery," since women rarely die from the condition, though they often live as outcasts in their communities. For this reason, fistula is perceived as more of a social than a medical concern.

Key Findings and Recommendations:

- Take advantage of existing research capacity to collect qualitative data to better understand the circumstances of clients' lives.
- Initiate information campaigns to raise awareness about prevention and treatment of fistula, as misconceptions about the condition abound.
- Train local specialists in fistula surgery so services can be offered on a continual basis.
- Develop a national referral system for fistula services in the context of maternity care.
- Explore the idea of creating a regional training centre for fistula repair based at the Brothers of St. Jean Hospital in Tanguiéta. Benin already has strong resources for training in surgery and public health and a reputation as a "teaching" country.

Chad

Chad is emerging from 30 years of war, which impacts the level and accessibility of care available to women in this desperately poor country. Although only 241 cases of fistula were reported last year, suspected prevalence is much higher, given the overall state of maternal health in the country. HIV affects about 4 per cent of young women, 88 per cent of deliveries take place at home, and only one per cent of women give birth by C- section. Women marry very young, rarely use contraceptives and are reluctant to be treated by male health care providers. Women who are able to seek treatment do so in a context where severe staffing shortages often mean that surgeons with no prior training attempt to repair fistula and end up complicating already difficult cases. However, there are signs that maternal health is becoming an increasingly important issue at the national level. The Chadian Parliament has initiated a process to enhance the protection of its citizens' reproductive health rights. Fistula is also getting more attention, including a pilot project in N'djamena's public hospital to treat and operate on fistula clients. In addition, two doctors spent August 2002 in Addis Ababa to receive formal training in fistula repair.

Key Findings and Recommendations:

■ Due to cultural, economic and practical reasons, most women prefer to deliver at home and mistrust of hospitals is common.

■ Gather data from communities to paint a more accurate picture of the impact of fistula and encourage local leaders, parents and district level officials to become involved in increasing awareness about preventing and treating fistula.

■ Staff shortages — especially of female providers — are common. Sponsor more fistula repair training for current staff, recruit more providers and motivate women health care providers to work in remote areas.

■ Lack of surgical skills sometimes results in aggravating damage to patients.

■ Investigate incorporating fistula repair training in medical school curricula and establishing a national fistula centre at Hôpital de la Liberté.

Kenya

Although Kenya has a high maternal mortality ratio and HIV prevalence, some of its reproductive health indicators (including skilled attendance at delivery and contraceptive prevalence) are better than many other countries in the region. Nevertheless an estimated 3,000 new cases of fistula develop each year, with only 7.5 per cent of them treated annually. The number of reported fistula operations has, however, increased more than tenfold over the last decade, from only 36 in 1992 to 479 in 2001. Interest in fistula among health managers, providers and NGOs is low. Kenyatta National Hospital specializes in the treatment of fistula, and visiting physicians from AMREF offer repairs at five other sites in the country. Other provincial and some district hospitals offer some treatment services as well.

Key Findings and Recommendations:

- Improve the status of women, by encouraging education, discouraging early marriage and abolishing female genital cutting.
- Advocacy activities should target policymakers, providers, professional associations and the general public that include messages about prevention and treatment.
- Train more providers. This can include integration of fistula into the medical curriculum at the university, and also training clinical officers in emergency obstetric care.
- Improve reproductive health services in general. Supplies and equipment are badly needed, as well as trained staff.
- Establish three regional fistula centres, at Machakos, Kisumu and Kenyatta Hospital.

Malawi

Findings from visits to six service delivery sites conducting fistula repair, three public and three private, suggest that obstetric fistula is a large and growing problem, exacerbated by poverty and famine. Despite a prevalence of obstetric fistula described by one provider as "undoubtedly high," the issue is not visible on the national policy front—perhaps masked by other urgent conditions, such as hunger and the spread of HIV/AIDS.

HIV prevalence is estimated to be 15 per cent among women age 15 to 24. Contraceptive prevalence rate for modern methods has more than tripled since 1992. The percentage of attended births delivered within a facility is significantly higher than in neighbouring countries, and most women also seek antenatal care.

The government, recognizing that maternal health needed to be made a priority, began a "Safe Motherhood Initiative" in 1995, with a goal of reducing maternal and infant mortality by improving access to quality care. One key objective is to improve transportation by providing more vehicle and bicycle ambulances, a process key leaders in communities often supervise. The programme also aims to improve attitudes and skills of health care providers. At the local level, village committees are in preliminary stages, or planned, to address safe motherhood, effective transportation plans and the updating of birth attendants' knowledge.

Key Findings and Recommendations:

- Local cultural beliefs about witchcraft and gender roles sometimes prevent access to transportation and emergency care.
- Some policy makers do not consider fistula a major problem in Malawi, whereas providers report that it is a significant and increasingly common condition.
- Severe staffing shortages have caused the closing of both new and established health centres, and compromise quality of care in other facilities
- Nonetheless, sites visited conduct one to 12 fistula repairs per month, and none require women to pay for services
- A collegial network among doctors, medical officers and nursing staff has contributed to good surgical outcomes, and should be encouraged and supported.
- More information should be gathered about girls and women living with fistula at the community level and the current health management information system should be adapted to capture fistula-related information at the national level.
- Standardize protocols and guidelines for fistula surgery, as well as pre-operative and post-operative care.
- Ensure that fistula training always includes more than one person per site.
- Zomba Central Hospital is a good candidate to become a national or regional fistula repair training centre.

Mali

Only two sites in the country have specialists who are able to carry out fistula repair surgery on a consistent basis: University Hospital of Point G in Bamako and the Regional Hospital of Mopti. Both rely heavily on private donations for funding fistula repair. As elsewhere in the region, women who develop fistula tend to be young, poor, uneducated and often do not have support from their families; nor do they have access to a facility where they might be able to receive quality care during labour and delivery. Circumstances for labour and delivery differ tremendously by location, with the majority of women in the capital city delivering in a facility. Outside of Bamako, women have little control over where they give birth; the decision is usually made by a family member.

Some attempts are in place to help women who have undergone successful surgery to regain confidence and reintegrate into their communities. A local NGO helped fund the building of a shed at the Regional Hospital of Mopti, where women can make and sell handicrafts that might allow them to earn some income. At University Hospital of Point G, the First Lady of Mali has helped construct a centre called Oasis, which is intended to give other fistula clients similar opportunities. To date, however, the centre has only been able to offer temporary housing to women waiting for treatment.

Key Findings and Recommendations:

- Root problems, such as limited educational opportunities for girls, should be addressed.
- Community level campaigns should be undertaken to raise understanding of fistula and to reduce the stigmatization of those who live with the condition.
- Training of additional providers to work throughout the country would be helpful since the majority of clinically trained midwives practice in the capital.
- Advocacy at the national level should attempt to bring more attention to fistula within the broader context of promoting reproductive health and address the issue of poor referral systems.
- Create a fund or financial strategy to support women who need repairs and devise a re-integration plan for women following repair.
- More collaboration among institutions providing repairs, both within and outside of the country would be helpful, as providers report that the quality of fistula repair is not consistent.
- Consider creating a national fistula centre at University Hospital of Point G.

Mozambique

After visiting two out of the three sites that offer fistula repair in Mozambique, it appears that there are far more women with fistula than the current roster of providers can care for. Although the providers try to cover adjacent regions, they are overwhelmed by the numbers and realize that they are not reaching many of the women in the greatest need. As elsewhere in the region, fistula appears to primarily afflict younger women, some of whom have very small stature and live in areas where transportation is not available. The country's large size makes access to services a challenge, which, along with poverty, the rural distribution of the population and an often fractured health-care infrastructure, combine to keep basic health care out of reach for many Mozambicans. The stigmatizing of fistula clients is profound and extends even into the wards where clients are treated.

Rates of antenatal visits are high, but the vast majority of women do not begin seeking care until they are into their sixth month of pregnancy. Approximately 41 per cent of births occur in facilities—more in Maputo city than elsewhere—but even so, the death rate for mothers and newborns in these settings is alarming. A national C-section rate of 1.12 per cent clearly signals the need to address maternal care within facilities. As with the rest of the region, HIV/AIDS has already had a dramatic impact on health and longevity. HIV prevalence is thought to be approximately 12 per cent among pregnant women.

Key Findings and Recommendations:

- Stigma around fistula is widespread, and affects potential providers as well as clients. A campaign that describes fistula as a human rights issue would be helpful in changing attitudes.
- Cultural beliefs and lack of transportation are obstacles to emergency obstetric care.
- In some parts of the country, waiting homes for pregnant women considered to be high-risk have reduced delays in getting emergency obstetric care.
- Physicians able to repair fistula are in desperately short supply. With only three doctors consistently providing repairs, and often traveling to various sites to do so, the sustainability of their efforts is in question.
- An incentive system should be initiated to interest physicians in learning fistula repair and providing services. Training of surgical assistants in fistula repair should be investigated as well.
- HIV/AIDS and family planning counselling is almost nonexistent for fistula clients, although many hope to get pregnant again.
- The national government is making progress in rebuilding its health care infrastructure, but needs short-term external support.
- Because the country is so large, more than one training centre may be needed to serve as a national referral site.

Niger

Women in Niger have the highest fertility rate in sub-Saharan Africa. Most deliver at home and are encouraged to do so, either unassisted or without the help of a trained provider. Entrenched traditions sometimes prevent women from leaving their homes, which may help explain why only 30 per cent seek antenatal care and the Caesarean section rate is 2 per cent. Visits to five sites and discussions with providers, district officials and NGO staff indicate that obstetric fistula in Niger is an exceptionally common phenomenon. Its occurrence is frequently linked to traditional practices prevalent in the rural areas where most fistula cases develop. Twenty-two per cent of women diagnosed with fistula have undergone some form of genital mutilation. In addition, most women with fistula are young and may well have been married from the time they were 13.

Only three sites in the country offer fistula repair and only six surgeons are known to have the necessary training. A sizeable backlog of clients exists in the capital, Niamey, as many women are referred there for treatment. In the city's National Hospital, 47 women, some of whom have been waiting for more than 10 years, are living in one of the facility's pavilions. In general, government funding appears to have diminished for health and education. However, a division of the Ministry of Health now pays for Caesarean sections needed by women who have had fistula repair.

Key Findings and Recommendations:

- The government is not actively involved in fistula repair or prevention programmes. However local NGOs are working in various ways to address women's rights and reproductive health issues.
- Better and more training to more fistula repair providers, with a focus on remote locations is needed. Staffing shortages undermine the capacity of hospitals and local health units.
- Community awareness campaigns should be implemented, as cultural concerns and traditional practices put women at risk for fistula and may prevent them from receiving emergency obstetric care.
- Better transport and communication between health care sites is needed.
- Without help in reintegrating into their communities, and in finding ways to support themselves, fistula repair clients may turn to risky commercial sex. Attention should be given to training women in income-generating activities.
- Hôpital de Lamordé, with a chief urologist who was trained in Addis Ababa and is eager to train others, is a strong candidate for becoming a fistula treatment centre.

Nigeria

Visits to 12 sites around the country produced a complex picture of the frequency, prevention and treatment of fistula, with significant differences noted between the situation in the north and south. Between 100,000 and one million Nigerian women are estimated to live with the condition. About 58 per cent of women deliver at home, 11 per cent without any assistance. In recent years, many women have started delivering their babies in churches. Although the delivery care they receive there is unskilled, they believe that in church they will be protected from "spiritual attacks" by satanic forces or witchcraft enacted by jealous or wicked neighbours. Another contributing factor to the development of fistula is the use of the gishiri cut, a type of female genital cutting that cuts the vagina rather than the vulva, practiced among some groups in Nigeria.

The government has created a national task force on obstetric fistula and supported initiatives to train nurses and surgeons, advocate for women, create community awareness programmes, gather data about fistula, and rehabilitate and re-integrate fistula patients back into the community. In spite of these efforts, the fistula situation in Nigeria is growing more serious.

Key Findings and Recommendations:

- Since many women deliver at home, provide more training, equipment and referral capabilities to birth attendants and encourage them to work in remote regions.
- Communication campaigns should be launched, using radio programming in locally spoken languages and taking advantage of traditional leadership structures to raise awareness about the links of poorly managed deliveries and some cultural practices to fistula.
- Education and vocational training for girls and women, which tend to delay early marriage, should be promoted by a wide coalition.
- Free or subsidized treatment for fistula should be provided since it is currently out of reach of most clients, many of whom have been abandoned by their husbands and have neither money for surgery nor transportation to repair facilities. This may result in more capacity for treatment.
- Training of all levels of staff providing fistula services should be increased, since the lack of trained personnel as well as a shortage of supplies undermines the ability of facilities to provide quality care. Training should address the perception that health care workers at hospitals are insensitive or hostile.
- Fistula treatment sites should include counselling centres for both HIV/AIDS and contraception, since counselling about these key reproductive health issues is not well integrated into treatment.
- Research about fistula patients and treatment should be broadened and evidence-based protocols created to fill gaps in knowledge. The country has several facilities that offer promise as training centers.

Tanzania

Information on fistula in Tanzania was gathered through a brief survey on the subject that was sent to all district, regional and mission hospitals in mainland Tanzania. Referral hospitals were contacted separately. About 80 per cent of hospitals responded, indicating a strong interest in the subject. As many as 1,200 new cases of fistula are thought to occur each year in the country.

According to two separate studies in Tanzania, fistula clients are older than in some other countries (median age 22 and 24, respectively). Almost all come from poor families, lack access to adequate health services and information, and cannot pay for medical treatment. Evidence suggests that some women get their fistula in hospital settings due to poor emergency obstetric care.

One study in Tanzania revealed that over three quarters of fistula patients felt ashamed of themselves and had their lives serious impaired by leaking and stigmatization. Despite adverse conditions, many girls and women with fistula mobilize scarce resources to find medical care. However, many are denied treatment because of they do not know it is available, or lack funds for transportation and treatment.

Key Findings and Recommendations:

- Six hospitals in Tanzania, concentrated on the country's perimeter, perform most of the country's fistula repairs, leaving women in the interior with few options. Consider building capacity of hospitals in central Tanzania to do simple repairs and assigning visiting surgeons to these underserved areas.
- Ensure that fistula care is highly subsidized or free. Although 32 hospitals subsidize operations, and three offer free treatment, the cost of surgery coupled with transportation (many women travel 500 kilometers or more) is prohibitive for many.
- Increase capacity for prevention and early management of fistula at all hospitals, and develop a three-tier national referral system for fistula care. Under this system, major centres would handle complicated cases and training; second-tier facilities would build capacity for uncomplicated repairs and refer other cases; and smaller facilities would concentrate on improving their emergency obstetric care services.
- Provide more training to appropriate and geographically distributed health workers. Only 12 Tanzanian doctors have been trained in fistula repair— almost half of the repairs are done by visiting surgeons.
- Accurate and timely information on fistula prevention, impact and repair needs to widely distributed.
- Nineteen of the hospitals surveyed reported shortages of equipment and supplies.

Uganda

Interviews, observations and discussions at four fistula repair sites (three private and one public) yielded a consistent picture across the country: a growing number of women with fistula, a short supply of physicians with the skills to repair them, few and insufficiently equipped operating theatres, and a reliance on visiting doctors to treat the large numbers of women awaiting surgery.

Key Findings and Recommendations:

- Strong cultural value placed on home birth leads to delays and complications. Antenatal visits could be used to advise patients about danger signs and encourage them to plan for transportation should emergency obstetric care be needed.
- The social conditions of fistula patients at the community level should be researched. Many lack resources to pay for repair.
- HIV/AIDS and family planning information and services should be integrated with care of fistula patients
- Foster more interest among doctors in fistula surgery, which is perceived as being difficult and often unsuccessful. Currently, volunteer physicians, who visit sites once or twice a year, are relied upon heavily.
- Investigate the feasibility of training medical officers to perform basic repairs and provide emergency obstetric care.
- The idea of making Nsambya Mission Hospital a fistula training repair centre warrants further exploration as well.

Zambia

Despite Zambia's vast size, only one facility (at Monze) is able to provide repairs on a continuous basis. No national prevalence statistics on fistula are available, but findings suggest that it is reasonable to think that the problem of fistula may be slightly less prevalent in Zambia than other countries in the region and that not all women with the condition are seeking services.

The impact of HIV/AIDS has lowered the average life expectancy in Zambia from 55 in the early 1980s to 37 in 1998. Not surprisingly, women's health has not improved during recent years. However, contraceptive use grew from 15 per cent in 1992 to 26 per cent in 1996, and a large majority of women get antenatal care. About 47 percent of deliveries are attended by a skilled health worker. The National Health Strategic Plan for 2001-2005 aims to address reproductive health through the assessment and restructuring of basic health care. Interventions are focussed at the district level, with an emphasis on serving the most vulnerable. The Ministry of Health supports several community projects now under way, with a particular emphasis on making pregnancy safer.

Key Findings and Recommendations:

- Severe staffing shortages of doctors and nurses are compounded by insufficient resources for material and equipment. However, innovative techniques by one surgeon have improved outcomes in Monze.
- HIV/AIDS support is used to offset some costs for care to fistula clients
- Fistula clients tend to be young; a significant number are refugees. A more in-depth assessment to get a clearer picture of the prevalence of fistula and its relationship to HIV is needed.
- Advocacy is needed within the local medical and nursing training facilities to build awareness of and interest in fistula.
- Transportation in this vast country is difficult and expensive. Devise innovative transportation schemes to get women to Monze Mission Hospital, the best candidate for a fistula care training centre, and build capacity for district-level hospitals to perform simple repairs.

meeting agenda

WEDNESDAY, 30 OCTOBER Chair

Hilton Hotel Ballroom

9:00 –10:30	Welcome Address, Introductions and Meeting Objectives Distribution of Needs Assessment Briefs (France Donnay) Doyin Oluwole
10:30- 1:00	Tours begin of Addis Ababa Fistula Hospital or Village of Joy — participants divided in 2 groups UN Conference Centre: Conference Room 3
1:00-2:30	Lunch (Boxed lunch for those attending the Village of Joy)
2:30-3:15	Discussion of Tours and Presentation: Ethiopia (Catherine Hamlin) Barbara Kwast
3:15-3:30	Coffee Break
3:30-4:15	Needs Assessment Presentation: Kenya (Dr. Kiiru)
4:15-5:00	Needs Assessment Presentation: Tanzania (Maggie Bangser)
5:00-5:45	Questions and Discussion
7:30-9:30	Dinner at the Hilton Hotel Harar Grill offered by the meeting organizers

THURSDAY, 31 OCTOBER Chair

UN Conference Centre: Conference Room 3

9:00 –10:30	Introduction to methodology and Needs Assessment Results: Uganda, Zambia, Malawi, Mozambique (Mary Nell Wegner) Amy Pollack
10:30-10:45	Coffee break
10:45-11:30	Needs Assessment Presentation: Nigeria
11:30-1:00	Needs Assessment Presentations: Chad, Mali, Niger, and Benin
1:00-2:00	Lunch
2:00-3:15	Introduction to the Fistula Campaign with questions (France Donnay, Mari Tikkanen and Kristin Hetle) Naren Patel
3:15-3:30	Coffee Break

THURSDAY, 31 OCTOBER, *continued*

3:30-5:00

Working Groups on Fistula Campaign

Small group sessions:	Facilitators:	Caucus Room:
Media Awareness	Micol Zarb/Mary Kanu	1
Ensuring Facility readiness	John Kelly/Ruth Kennedy	2
Physician/Nurse Recruitment	Naren Patel/Petra ten Hoope	3
Prevention activities	Maggie Bangser/Nana Tanko	7
Monitoring and Evaluation	Luc de Bernis/ Joseph Ruminjo	8
Sustainability	Andre de Clercq/ Dr. Kiiru	9

5:00-6:30 Reports from small group sessions and discussion - Petra ten Hoope

7:30-9:00 Reception at Hilton Hotel Harar Grill offered by UNFPA and EngenderHealth

FRIDAY, 1 NOVEMBER Chair

UN Conference Centre: Conference Room 3

9:00-10:30	Site Selection for establishing fistula centres - Nafis Sadik
10:30-11:00	Coffee Break
11:00-12:30	Finalizing Fistula Campaign Plan
12:30-1:30	Lunch
	UNFPA Country Staff Meeting and Knowledge Asset Presentation
1:30-2:30	Creating a Regional Plan of Action for the Prevention and Treatment of Obstetric Fistula - Daniel Sala-Diakanda
2:30-3:00	Closing Remarks
3:30- 5:30	Visit of Fistula Hospital/Satellite Centre

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