

FISTULA CARE

FISTULA PARTNERS' MEETING ACCRA, GHANA

April 15- 17, 2008

By



EngenderHealth
for a better life



USAID
FROM THE AMERICAN PEOPLE



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EXECUTIVE SUMMARY

Genital fistula, whether resulting from childbirth complications or sexual violence, is a devastating disability that is both preventable and treatable. Partners across the developing world are working to make motherhood safer and to care for women with fistula. With support from USAID, the AWARE-RH, ACQUIRE and Fistula Care projects brought together their partners for a meeting in Accra, Ghana from April 15-17, 2008. The meeting provided a forum for USAID-supported fistula providers to come together and discuss their needs, challenges, remaining gaps and successes in fistula repair and care.

Several surgeons presented the organization and delivery of quality fistula services in their contexts. Working groups then enabled participants to define the essential elements of a quality of care strategy. Groups focused on fistula prevention highlighted the importance of access to emergency obstetric care services, free cesarean sections, and family planning counseling and services, as well as the correct and consistent use of the partograph. The mass media can be used to spread messages at the community level, and partnerships should be pursued with community groups, community health workers and others facilitating referrals, and programs working to empower women and improve their socioeconomic status. The essential elements of a quality treatment strategy included psychological preparation of the patient, informed consent, treatment of co-morbidities, classification of the fistula, respect for national norms and standards, use of appropriate equipment and material, application of the appropriate surgical technique, and monitoring by providers trained in fistula care. Working groups concluded that a minimum package for reintegration would include counseling, transportation, health education, c-section free of charge, and advocacy within the community. Monitoring is critical for all elements of care.

Participants gave presentations on building the capacity for quality services through training, inviting discussion about current training successes and needs. Participants then turned their attention to the use of data to improve quality and performance. Working groups assisted in defining, refining, and proposing additional indicators for quality fistula services relating to prevention, treatment, reintegration and supervision. The final day of the meeting was devoted to considering factors that contribute to a strengthened environment to support fistula prevention, repair and reintegration. At the close of the meeting, participants worked together to propose actions to be taken at the country and global levels in order to strengthen fistula prevention, use data to make decisions and improve quality, strengthen the environment for fistula service delivery, and increase the capacity of centers to provide fistula repairs.

BACKGROUND

While much progress has been made worldwide in improving maternal health, particularly in ensuring safe and successful childbirth, enormous disparities continue to persist between the developed and developing world. On a global scale, the occurrence of chronic incidence of obstetric fistula in low-resource settings is one of the most visible indicators of this disparity between wealthy and poor.

Over the past ten years, local and international agencies have begun to pay more attention to the issue of genital fistula. In numerous country needs assessment carried out by EngenderHealth and UNFPA, the need to strengthen local capacity in fistula prevention and management has been identified across the board. Since 2004, USAID has provided support to EngenderHealth and its partners through the AWARE-RH, ACQUIRE and Fistula Care projects to implement programs to increase and strengthen the number of sites providing fistula services, as well as to support prevention through advocacy, increased attention to the provision of emergency obstetric care, the use of family planning, and to identify ways to support fistula clients post-surgery to reintegrate into their families and communities, if that is their desire and their need.

With support from USAID, the AWARE-RH, ACQUIRE and Fistula Care projects held a Fistula Partner's Meeting in Accra, Ghana from April 15-17, 2008. The purpose was to advance the state of the art on fistula prevention and care. The meeting facilitated the exchange of successes and challenges experienced, allowing providers, program staff and partners to share nascent or successful programming models and to engage in smaller working group discussions to give guidance on strategies to improve the quality of care, program indicators, research priorities and advocacy needs to support the sustainability of services.

The primary focus of the meeting was to provide a forum for fistula providers – surgeons, nurses, counselors, etc.– to come together and discuss their needs, challenges, remaining gaps and successes in fistula repair and care. While there have been several international fistula meetings held over the past few years, at this meeting the voices of fistula providers supported by USAID, those working on the frontlines in fistula prevention and treatment, took prominence.

The three primary objectives were:

- To share current interventions being used to manage the continuum of comprehensive fistula management services – from prevention to repair to rehabilitation;
- To analyze the successes and challenges of such interventions, and identify the current gaps; and
- To identify gaps in fistula programming and to make recommendations about best practices for addressing those gaps.

Beyond its focus on the landscape of clinical, service delivery and training needs, the workshop participants also considered the ethics of fistula care and

opportunities for research and advocacy. The meeting brought together more than 70 individuals from 16 countries, primarily from the West African region, to provide a real opportunity for south-to-south exchange and reflection on how far we have come and where the movement will go in the next several years. The agenda and participants list for the meeting are attached as Appendix A and B respectively.

THE OPENING SESSION

Opening speech: Mr. Henderson Patrick, Mission Director for USAID/West Africa, opened the meeting and welcomed participants to Ghana. Mr. Patrick noted that the two main objectives of the AWARE-RH project supported by USAID/West Africa are to identify, disseminate and replicate best practices throughout the region and to strengthen the capacity of regional institutions. The project has been supporting work throughout the region to improve maternal health and increase access to family planning, as well as implementing critical initiatives in the prevention of fistula and other childbirth injuries. One key initiative has been the *Community to Facility Continuum of Care Model* which includes strengthening clinical services and addressing demand generation. Key elements of this work include a focus on strengthening the capacity of facilities to provide routine and emergency obstetric care and on educating communities on warning signs, birth preparedness and planning, and community-based health financing. The AWARE-RH project also works to improve the quality of services through improved counseling, facilitative supervision, infection prevention and training in clinical skills with a focus on long-term methods.

Family planning is a critical safe motherhood initiative that enables women and couples to delay first births, space subsequent births, or limit their family size if they so desire. In the context of fistula, it is an important preventive initiative as well as a strategy that can help women ultimately achieve a successful pregnancy after surgery.

In the context of fistula services, AWARE-RH has collaborated with local organizations in Niger and Cameroon to address the challenge of fistula. In Cameroon, they facilitated training in fistula surgery and the establishment of services in collaboration with UNFPA. In Niger, they have supported the work of the Network to Eliminate Fistula (REF) to provide repairs to women with fistula and to decentralize access to treatment to the regional level through training of surgical teams and the provision of equipment and establishment of fistula services at regional hospitals. Throughout the West Africa region the AWARE-RH project promotes changes in law and policy to improve the enabling environment for safe motherhood.

Keynote speech: The Honorable Mr. Abraham Odoom, Deputy Minister of Health, Ghana gave the keynote speech. Fistula is an indicator of a failed maternal health care system. Wherever you find fistula, you will also find women dying from pregnancy and childbirth. Estimates suggest that approximately 2 million women may be living with fistula, predominantly in sub-Saharan Africa, with an additional 50,000 to 100,000 affected each year. In countries with a heavy burden of diseases linked to women and children, the capacity to prevent or manage such problems as obstetric fistula must be a primary health care issue.

Nearly 600,000 women between the ages of 15 and 49 die each year as a result of complications of pregnancy and childbirth, while 50 million women suffer from disabilities that are often long-term or permanent. In sub-Saharan Africa there are 480 maternal deaths for every 100,000 live births, including as many as 1000 in some countries.

Women suffering from fistula are seen working alone, eating alone, and staying alone.

The Honorable Abraham Odoom, Deputy Minister of Health, Ghana

One of the most devastating of the long-term disabilities is obstetric fistula. Prolonged, obstructed labor is the most common cause of fistulae, when the baby's head is jammed against the mother's pelvis, causing the soft tissues to break down. Usually, the baby dies and the mother is left leaking urine or feces or both. In addition to the physical consequences, severe social stigma follows – often divorce and abandonment by spouses and families and varying degrees of social isolation. Yet fistula is a preventable and treatable condition. Access to preventive and emergency obstetric care is essential to prevent fistula. Likewise, addressing malnutrition and reducing early childbearing is an important strategy to ensure that a woman is physically able to deliver a child safely.

The magnitude of obstetric fistula is not known in Ghana, although a current maternal mortality study will provide information on the prevalence of fistula, with results expected by the end of 2008. The Ghana Ministry of Health has launched a project to strengthen fistula prevention and access to treatment in three northern regions where the prevalence of fistula is believed to be high. The Tamale Teaching Hospital and the Baptist Hospital at Nalerigu have been identified as collaborating institutions for treatment services. The project has three foci: awareness creation, identification and treatment of women with fistula; and rehabilitation and reintegration of women who have been repaired into their communities.

In conclusion, Mr. Odoom suggested that there is no reason for a woman to suffer the trauma of obstetric fistula. There is no reason for any woman to live with the indignity and social isolation brought on by this problem, and definitely there is no reason why we should not act when the health system fails any woman simply because of her economic and social circumstances.

MEETING PRESENTATIONS AND DELIBERATIONS

USAID Fistula Program

*Ms. Mary Ellen Stanton and Ms. Patricia MacDonald
USAID/Washington*

Ms. Stanton provided an overview of USAID's proposed response to the recently announced international maternal and child health initiative. By 2013, USAID intends to have supported a 25% average reduction of both under-five and maternal mortality rates in 30 high mortality burden countries; a 15% reduction in child malnutrition in at least 10 of these countries; and increased the number of functional health workers and volunteers serving at primary care and community levels by at least 100,000.

USAID's fistula program is a response to interest expressed by the U.S. Congress in supporting treatment and prevention of obstetric fistula. In 2004, the program began, supporting two countries, expanding to ten countries by 2007. Countries supported include Bangladesh, the Democratic Republic of Congo, Ethiopia, Ghana, Guinea, Niger, Nigeria, Rwanda, Sierra Leone, and Uganda.

Number of Fistula Repairs by Country and Year Supported by USAID				
Country	Oct 04-Sep 05	Oct 05-Sep 06	Oct 06-Sep 07	Oct-Dec 07 (3 mos)
Banglades	20	93	119	44
DRC	0	53	586	103
Ethiopia	0	81	139	0
Ghana	0	21	42	0
Guinea	0	199	292	48
Niger	0	0	27	67
Nigeria	0	0	1,081	271
Rwanda	0	145	147	10
Sierra Leone	0	0	272	85
Uganda	121	335	401	79
Overall Total	141	927	3,106	707

Funding to support this work has grown from \$1.11 million in 2004 to \$11.148 million in 2007. By December 2007 USAID's partners had provided a total of 4,881 repairs in ten countries. This work is carried out in partnership with governments, NGOs, United Nations agencies, universities, and private foundations. The program seeks to link with other initiatives including those for safe motherhood, family planning, and PMTCT.

USAID has identified several programming challenges on which it hoped to receive guidance during the course of this meeting. These include:

- The need to overcome the shortage of surgeons and trainers proficient in fistula repair
- The reality that complicated surgeries generally have a lower chance of success
- The need to address the missed opportunities for prevention of fistula
- The fact that there is limited clinical and other research data on fistula
- The lack of a standardized classification system to facilitate fistula diagnosis, treatment and training
- The need to increase government commitment to eliminate cost as a barrier for skilled care, emergency obstetric care and fistula repair
- The infrastructure needs to adequately support fistula prevention and care including delivery rooms, operating theaters, and bed space in wards
- The ethical issues of informed consent for surgery, choice and understanding of procedures, understanding the reality that treatment may fail and the options available if it does fail, and the need for long-term care.

USAID's expectations for the Accra meeting were to focus on the quality of fistula care and treatment. USAID will use guidance from the participants at the meeting to increase access to prevention and treatment services, to preserve and enhance women's dignity and respect, and to strengthen and institutionalize quality improvement systems, while adhering to ethical principles and ensuring help for the greatest number of women.

Strengthening the Capacity of Centers to Provide Quality Services to Repair and Care for Women with Obstetric and Traumatic Fistula

Five panelists were invited to give presentations about the organization of quality fistula services and different models of service delivery. The presentations were followed by a brief question and answer and commentary session. Participants then broke into working groups to further define the essential elements of a quality of care strategy for fistula care.

Panel Presentations:

Organization and Strategies for Obstetric Fistula Services in Mali
Professor Kalilou Ouattara, Urology Department, Point G Hospital, Bamako

“It is better to prevent vesico-vaginal fistula than to have to operate for it.”

Professor Kalilou Ouattara, Point G Hospital, Bamako, Mali

Professor Ouattara began by outlining the basics of quality obstetric fistula care which include primary, secondary and tertiary care. Primary prevention rests on sensitizing the community, training midwives, and providing support to the community health centers. Secondary prevention emphasizes

strengthening emergency obstetric care services, in particular access to cesarean sections, which are free in Mali. Tertiary care rests on ensuring access to repair services at regional and central hospitals. In Mali, obstetric fistula surgeries are provided through 8 regional hospitals and at Point G Hospital in Bamako. A total of 9 surgeons currently provide services in Mali.

In Mali, the aim is to ensure three key components of obstetric fistula care. These include: (1) a lodging place for welcoming women with fistula which counsels and treats as necessary prior to any fistula surgery, (2) dedicated operating theater space or time for obstetric fistula cases, and (3) a place for rest and post-operative follow-up care (10-15 days) which may include physical rehabilitation, counseling and social services.

Professor Ouattara offered the following lessons learned from the experience in Mali:

- To successfully address fistula, programs require:
 - a national strategy
 - a national focal point
 - regional centers for fistula services
 - a network of organizations devoted to addressing fistula.
- There are benefits to the establishment of regional units for the treatment and care of obstetric fistula, as well as the existence of a central unit that can receive referrals of difficult cases
- It is essential to train national surgeons for ongoing fistula surgery

- Strengthening basic and comprehensive emergency obstetric care services is key
- Adequate recruitment and geographic location of ob/gyns and midwives is necessary
- National and sub-regional campaigns to address the backlog of obstetric fistula patients are indispensable
- Treatment should be free of charge
- Involvement of NGOs at all stages of care is essential and beneficial.

Prevention and Treatment of Obstetric Fistula Services in Guinea
Dr. Thierno Hamidou Barry, Kissidougou, Guinea

Fistula prevention and treatment activities with USAID support began in Guinea in 2005. In the first two years, the objectives were to increase access to and use of fistula treatment services, to train providers in prevention, diagnosis, treatment and referral for fistula services, and to increase awareness of the causes of fistula, its treatment and the ways to prevent it. The program in Guinea is focused on ensuring that it is integrated within the Guinean Health system, covers the continuum of prevention, treatment and reintegration, and addresses the basic causes of fistula. In collaboration with the relevant government Ministries, the program is coordinated by three committees: an experts committee on fistula repair that consists of national and international representatives; a second committee that addresses prevention; and a third that addresses reintegration. The fistula program aims to improve democracy and good governance within the health system, ensuring appropriate stewardship of health resources in Guinea. Currently, fistula services are being provided in two centers, one in Conakry and one in Kissidougou.



In collaboration with “*Village Protection Committees*” the program identifies pregnant women within the community and encourages them to attend the prescribed four anti-natal visits, ensures referral for obstetric complications, sensitizes communities on the causes of fistula, and maintains good community statistics on births and maternal deaths. In partnership with the National Safe Motherhood program, the fistula program ensures cascade training at national, regional, prefecture, and health center levels on services appropriate for each level in terms of prevention, treatment and reintegration. Training for fistula surgery has been carried out in collaboration with the Geneva Foundation for Medical Education and Research (GFMER). Other support has included training providers in counseling, nursing care, anesthesiology, logistics management and quality improvement. The project has provided equipment and material as well as food for patients. In partnership with the Ministry for Social Affairs, the

project supports reintegration through psychosocial therapy and counseling, as well as sensitization and advocacy on the part of “satisfied clients.”

One innovative initiative in Guinea is the partnership with the Urban Commune of Kissidougou and the National Directorate of Decentralization to increase community awareness, advocacy and participation in fistula prevention and treatment. With private funding, EngenderHealth has collaborated with the Urban Commune to secure financial resources from the village market to support fistula activities. In addition, members of the community have become host families to fistula clients after their hospitalization and before they return home – many women would find it impossible to return for follow-up care if they returned home immediately because of the distances and challenges with transportation involved.

Dr. Barry indicated that the project has benefited greatly from the strong involvement of government Ministries, expert committees, community support, all important to ensure sustainability. A major challenge is that demand for services is considerably higher than the ability to respond at this time. In addition, there is a need to standardize the certification process for fistula surgeons using international criteria.

Strengthening Fistula Services at Kebbi VVF Center: The Journey So Far
Dr. Hassan L. Wara, Birnin Kebbi VVF Center, Kebbi State, Nigeria

Dr. Wara noted that the VVF Center was started as a unit of the ob/gyn department of the State Specialist Hospital in 1991. The unit was opened by the First Lady of the State in 1992 and commissioned as a full-fledged VVF center in 1995. In the early days of operation, the center experienced challenges including a huge backlog of VVF clients, a lack of sustainability due to frequent changes in government and policies, inadequate manpower and poor motivation, limited funding and poor data management. The Center received support from a private foundation and UNFPA as well as from Dr. Kees Waaldjik, a consultant trainer.



Through the ACQUIRE project beginning in 2006, the VVF center has embraced a holistic approach to fistula care, addressing prevention, repair and rehabilitation. The project is working in five states in Northern Nigeria and has begun to address cross cutting issues in those states such as advocacy, capacity building for fistula surgery, data management and research. The project has collaborated with Dr. Kees Waaldjik to develop experienced fistula surgeons as trainers and these trainers have begun to train additional surgeons and nurses in fistula surgery and management. The project has also conducted training for providers in family planning, infection prevention and counseling, both for fistula service delivery and for family planning. Increasing community awareness and community involvement is an important component to ensure prevention and sustainability.

The VVF center in Kebbi is providing routine repairs. In addition, in order to address the continuing backlog at all sites in the five states, the project has supported a network of fistula surgeons from supported sites to pool their efforts to provide periodic “mini campaigns” at each site. The project has promoted standardized pre- and post-operative management processes for fistula patients, as well as developed follow-up protocols and schedules.

Some of the gaps and challenges that Dr. Wara perceived include the lack of rehabilitation and skills acquisition facilities for fistula patients, the need to upgrade laboratory capacity at service sites, and the need for additional staff, a sustained supply of consumables, and improvements in record keeping. Beyond the fistula center itself, measures to prevent fistula need to be increased, including the provision of free maternal health services and the increase of community awareness about the underlying causes of fistula.

Obstetric Fistula: Prevention, Repair and Reintegration Project, Ethiopia
Dr. Bizunesh T. Tamirat, IntraHealth International, Addis Ababa, Ethiopia

Ethiopia – country profile



- Population 77 million
- Fertility Rate 5.4
- ANC 28%
- Attended delivery 6%
- PNC 5%
- IMR 77/1,000
- CMR 123/1,000
- MMR 871/100,000
- Per capita income 100 USD

USAID currently supports activities to contribute to the reduction of obstetric fistula in Ethiopia through repair and prevention activities. Specific objectives including increasing access to treatment, care and support; integrating and decentralizing fistula repair and care to services at the regional level; building capacity to offer quality comprehensive obstetric fistula services within existing MCH services; bringing about behavior change at all

levels around maternal health. The project is a collaboration between the Bahir Dar Fistula Hospital (affiliated with the Addis Ababa Fistula Hospital and the Fistula Foundation) and IntraHealth International.

At the community level, the focus is on conducting community sensitization activities, training existing community level health workers and detecting and referring obstetric fistula cases. At the facility level, the project seeks to strengthen the capacity of providers, to establish sound referral systems, to ensure facilities are properly equipped and to strengthen coordination and communication among and between the community and community health workers, the health post and health centers, the fistula hospital and project staff. Linking communities and facilities is an important strategy for the project to ensure effective referrals for services. The project has conducted community-facility dialogues to share lessons learned about fistula screening, care, prevention and rehabilitation, and transferring fistula cases to the appropriate level of care.

To date almost 500 women who complained of urinary incontinence have been screened for obstetric fistula and just over half were found to have obstetric fistula. (Almost 200 women were found to have uterine prolapse.) More than 100 providers have been trained in obstetric fistula prevention and referral and 23 nurses and midwives from three health centers and their 15 satellite health posts were trained on basic life saving skills focusing on emergency obstetric care. Almost 1000 community leaders and more than 150,000 community members have received messages about the prevention of obstetric fistula. These messages have been prepared and distributed to all community level health cadres. An Obstetric Fistula Prevention week was celebrated in the presence of women parliamentarians and regional health bureau representatives.

As noted above, one of the main challenges has been the large number of urinary incontinence cases other than obstetric fistula identified. Poor roads and transportation make referral from adjacent regions difficult. Health facilities are poorly equipped and unable to provide basic life saving services and staff turnover is high. There is currently no funding source to support income generating activities as part of post-repair reintegration programs. To address some of these challenges, the project proposes to expand its comprehensive approach to other high prevalence regions, to continue to strengthen basic and comprehensive emergency obstetric care services, to continue to advocate for obstetric fistula with local government authorities and to support capacity building activities at community and facility levels.

The Kitovu Experience in Delivery of Quality Fistula Repair and Care Services
Dr. Maura Lynch, Kitovu Hospital, Masaka, Uganda



Kitovu Hospital in Masaka District has been providing holistic care to the poor and needy since 1955. Beginning in 1993, Dr. Lynch began providing fistula repair services and has been training surgeons in fistula repair continuously. With support from USAID and UNFPA, Kitovu is now able to provide fistula

repair services free of charge and a new 28-bed unit was officially opened in early 2005 with more than 1,300 women served since 2006. Kitovu also provides maternity services for safe delivery by cesarean section after repair.



Kitovu conducts four training work camps each year, with approximately 60 repairs conducted during each workshop. Trainees are nominated by the Ministry of Health and notified by them. Kitovu encourages team training, suggesting that trainee surgeons be accompanied by a theater nurse and a post-op care ward nurse. Unfortunately, trainees are often notified late at their places of work and trainees arrive at the last minute or after examination and assessment of clients have begun. In addition, on occasion,

some trainees have arrived without the requisite level of general surgical skills which makes it difficult to provide them with the additional skills needed for fistula surgery. Dr. Lynch's recommendations to address these issues include:

- The establishment of a waiting list of trainees who have expressed an interest in fistula surgery
- The use of a standardized and recognized training curriculum for repair of both simple and complicated fistula
- The provision of certificates of competency, recognized by the Ministry of Health, upon completion of training

Kitovu Hospital is looking to establish continuous fistula repair services, in addition to serving as a training venue. To do this they need to establish a fully equipped operating theater allocated for fistula surgery, dedicated theater and post-operative ward staff and a physical therapist for post-operative care. Other key needs include funds to assist the hospital to conduct adult literacy classes, to help fistula patients develop other skills (crafts, etc.) and capital to assist patients to start-up business or farming enterprises.

Questions and comments from Participants

Participants were interested to hear more about the connection to democracy and good governance in Guinea and community involvement in Nigeria. Participants commented that in addition to national programs, a sub-regional approach to service provision and training may be appropriate in some instances, recognizing that women are crossing national borders to seek services that are closest to where they live, or where they have heard they can get services. Participants discussed the relative merits of ensuring the involvement of TBAs in safe motherhood and referrals for fistula care. Dr. Bizunesh explained the organization of health services in Ethiopia and noted that the government of Ethiopia does not accept TBAs attending deliveries, but they do support them in helping in community-based education and family planning.

Kate Ramsey from UNFPA noted that currently there is no standardized classification system and that there are at least 25 documented classification systems right now. This makes standardization on guidance and training curriculae difficult. WHO/UNFPA and the Bill and Melinda Gates Institute at Johns Hopkins School of Public Health recently held a meeting in Geneva to discuss the protocol for a multi-centric study *Prognosis, Improvements in Quality of Life (QOL) and Social Integration of Women with Obstetric Fistula after Surgical Treatments: A Collaborative JHU/UNFPA/WHO Study*.¹

Working Group sessions to discuss essential elements of a quality of care strategy

¹ EngenderHealth has embarked on a six country prospective study of the determinants of post-operative outcomes in fistula repair surgery and protocols; see section on Improving Quality and Performance through Research below, page 35. EngenderHealth study instruments have been shared with WHO/UNFPA. The expectation is that the findings from both studies will facilitate discussion about a standardized classification system through a process to be led by WHO and UNFPA.

Participants were organized into working groups to articulate the essential elements of a quality of care strategy for fistula care that could reasonably be implemented in the sites where they work and would encompass prevention, treatment and rehabilitation. Participants were asked to: consider results that could be achievable within a 3-4 year timeframe, embrace evidence-based practice, address the individual needs of women with fistula while at the same time maximizing the public health impact, maximize efficiency in light of limited public sector resources, and integrate with other initiatives whenever feasible.

Prevention:

Three groups focused their attention on initiatives to address prevention. They were asked to consider the following questions:

- Which are the key prevention elements that should be incorporated into a quality of care strategy – at the facility level, at the community level, and at the policy level?
- What are the minimum standards and what should we strive for in prevention?
- Any other guidance on prevention?

At the facility level, participants noted a general lack of staff and equipment needed which needs to be addressed if facilities are to be held accountable for quality services. At a minimum participants felt that the following prevention components should be standard at facility level to ensure quality services:

- **Access to a health facility with emergency obstetric care services that functions 24 hours a day, seven days a week**, with providers trained to do c-sections and with appropriate referral systems in place and functioning to these facilities.
- **C-sections should be provided free of charge.**
- **Correct and consistent use of the partograph** at all levels where delivery occurs and the proper documentation of its use.
- **Family planning** counseling, services and/or referral should be available and accessible.
- **Equipment is available and functioning.**
- **Information systems are adequately maintained.**

Other suggestions to improve quality at the facility level included the use of “focused antenatal care,” building competency at the community health center level of danger signs and procedures for referral, training providers in interpersonal communication skills, emphasizing male involvement and investment in insurance schemes or reduced cost plans for the poorest clients.

At the community level, participants felt that the following prevention components should be standard to ensure quality services:

- Use of **mass media to disseminate messages regarding labor and delivery**. Such messages should include information about family planning, the importance of antenatal care and the use of health care facilities for deliveries.

- **Partnerships** should be established with community health workers, community groups and women's groups to **raise awareness on antenatal care and birth preparedness**.
- Procedures should be established to **facilitate referrals**. One example given was community purchase of ambulances to facilitate transportation of pregnant women to a referral site.
- Programs designed to **improve women's economic status, empowerment and improved social status** should be supported.

Participants further described the need to develop messages for different audiences, including men, mothers, community leaders, and TBAs to build community knowledge of birth planning strategies, obstetric danger signs and harmful socio-cultural practices. Participants recommended investing in community midwives and skilled birth attendants who could conduct normal deliveries and refer high risk cases. They recommended promoting a zero tolerance at the community level for rape. Participants also felt it was important to consider actions at the individual level – to encourage a life cycle approach to reproductive and maternal health.

At the policy level, participants felt the following should be standard components to foster quality services:

- The development and implementation of a **national strategy that addresses fistula prevention**. This should be integrated with other safe motherhood and reproductive health strategies.
- Ensure the provision of **cesarean sections free of charge** for all women who need them. In some countries, c-sections are provided free of charge for fistula clients, but since this is a preventive measure that would negate the need for fistula surgery in most cases, in addition to the benefits for women and their children, it would be cost-saving.
- Ensure the provision of **free maternal health services**. Many participants noted that in principle maternal health services are supposed to be free, but many women find themselves faced with unexpected costs because of shortages at the hospitals or health centers.
- **Promote male involvement** in reproductive health so that they can be effective partners in decisions about birth preparedness and planning.

Other policy components considered important included the need for a multi-sectoral approach at the local level. It is not only the health system that must support a woman's ability to give birth safely; the transportation system and roads must be functioning, water and sanitation systems must be functional, etc. Advocacy with all decision makers (including religious leaders) to improve safe motherhood services and practices is needed. Governments might consider incentives for health workers in hard to reach areas, the deployment of community midwives, and the integration of TBAs and other community health workers into a system that facilitates referrals for high risk cases. Promoting policies that address the education of girls, outreach and education to prevent early marriage, and removing cultural barriers to ensure that women do not need to seek permission to seek care were considered important.

Treatment

Participants were asked to consider the following questions:

- What are the key elements that should be incorporated into a quality of care strategy as far as treatment is concerned?
- What are the minimal standards and what should we strive for in treatment?
- What ancillary surgeries are essential to achieve success for fistula clients and therefore should be supported?
- What guidance would you give on advanced procedures for very complicated cases?
- What guidance would you give for cases that cannot be closed?

Participant responses to the above questions were extensive and are included in a summary form as Appendix C. The key issues identified were arranged into four categories: preoperative, operative and postoperative, and cross-cutting as follows:

For preoperative care, key elements included:

- **Psychological preparation of the patient** through counseling and treatment with respect, dignity and compassion to enable her to make decisions
- **Diagnosis and treatment of co-morbidities** prior to surgery which may require agreement on minimum physical status and minimum laboratory tests required
- **Clinical assessment and evaluation of the fistula** (classification) and associated fistula (e.g. RVF).

For operative care, key elements included:

- **Respecting the national norms and standards** – applies to all stages of care.
- **Availability and use of the appropriate equipment and material.**
- **Choose the surgeon according to the indications/complexity of the surgery.**
- **Application of the appropriate surgical technique.**
- **Antibiotic therapy prophylaxis** (although later on during the discussion on research needs, it was agreed that there was a need to look at the added value of antibiotic prophylaxis.)

For post-operative care, key elements included:

- **Monitoring by a provider trained in fistula care.**

In response to the question about minimal standards of care², participants debated the meaning of “success” because it varies a great deal both from a

² Participants were asked to comment on whether the WHO Guiding Principles for fistula (WHO. 2006. *Obstetric Fistula: Guiding Principles For Clinical Management And Programme Development*. Editors: Gwyneth Lewis and Luc de Bernis) was sufficient. During the discussion, it became clear that many participants had not seen the WHO Guiding Principles. These will be distributed with the meeting report.

patient's perspective and from the perspective of the surgeon. A patient who experiences stress incontinence may not consider the outcome successful. Success may also vary with duration of follow-up, number of surgeries, criteria for case selection depending on complexity according to a standardized classification system that reflects the pathology treated, etc. In general, the recommendation was to remove the subjectivity of the term "success" and refer to rates of fistula closed, stress incontinence, etc. Ultimately, participants indicated that **closing the fistula, restoring continence, and restoring sexual function and reproductive function**, if possible, were the outcomes we should aim for.

Regarding which **ancillary surgeries are essential to support these desired outcomes**, participants recommended the following:

- Urethoplasty (VV)
- Reimplantation of ureters
- Interposition (i.e. pouch, graft)
- Colostomy
- Stress surgery post fistula repair
- Perineal tears, 3rd and 4th degree (resulting in incontinence)
- Flaps and slings as part of fistula surgery
- Vaginoplasty
- C-section post repair – under competent care

For advanced procedures for complicated cases or for cases that cannot be closed, participants stressed the need to **refer the patient to a competent surgeon**, ensure that **informed consent** procedures were followed for any surgery (which should be the case for all surgeries), and **ensure long-term follow-up care**. Participants noted that counseling skills for providers and an environment in which these can be applied are key to communicating with patients about all surgeries, but in particular for complicated cases or cases where the fistula might be inoperable. Participants emphasized the need for an evidence-based definition of an "inoperable case" which again links to the need for a standardized classification system. Diversion may be an option depending on the resources and skills available.

Reintegration

Participants were asked to consider the following questions:

- Which are the key reintegration elements that should be incorporated into a quality of care strategy – at the facility level, at the community level, at the policy level?
- What are the minimum standards and what should we strive for in reintegration?
- Any other guidance on reintegration?

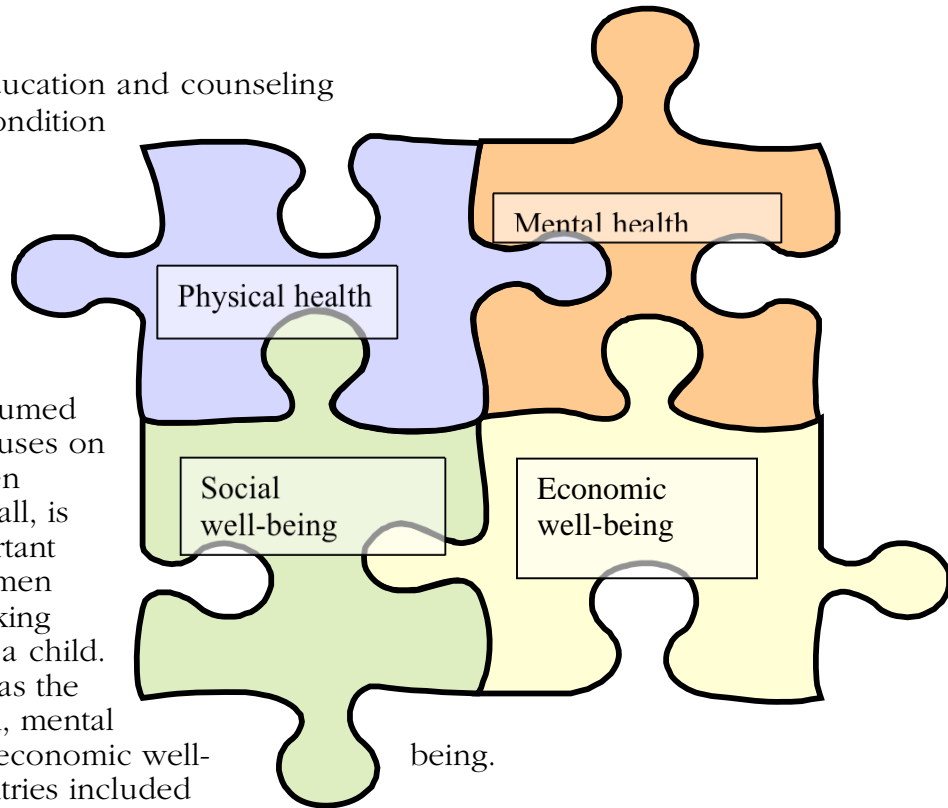
The first comment on reintegration was about the varying definitions of reintegration. There is a need to differentiate between reintegration and empowerment, between social reintegration and family reintegration. There is a

wide variation in approaches, but there is a need to address the poverty of women with fistula.

Participants noted that this concept might include one or more of the following elements as applied in different programs:

- Physical rehabilitation
- Psychosocial therapy
- Reproductive health education and counseling
- Education about the condition
- Literacy programs
- Handicrafts
- Income generating activities
- Micro-credit/micro-finance schemes

“Focused reintegration,” presumed to mean reintegration that focuses on the needs of individual women rather than a set program for all, is still in its infancy. The important factor is to consider what women want – most likely to stop leaking and for most women to have a child. Reintegration can be defined as the intersection of physical health, mental health, social well-being and economic well-being.



Examples from different countries included community awareness raising to reduce stigma, prevent fistula, and communicate the availability of services, a focus on counseling and psychosocial services, partnering with micro-credit schemes such as cell phones in Sierra Leone, literacy and numeracy programs, village committees and the concept of social immersion as practiced and described in Guinea, the establishment of National Fistula Days to focus attention on the needs of women with fistula, and in many cases the establishment of dedicated reintegration centers where women can stay for varying periods of time.

At the facility level, key components of reintegration would include:

- **Intensive counseling** – psychosocial, reproductive health/health education, clinical counseling. (Participants likened this kind of counseling to that given for those who experience chronic conditions.)
- **Motivational speakers** – the voices of patient advocates and of former fistula clients themselves
- **Peer group counseling** – to facilitate group discussion
- **Literacy and numeracy skills** – partnerships can be established with an NGO or community-based group to help while women are recuperating

At the community level, key components of reintegration would include:

- **Community advocacy** and sensitization
- **Community-based interventions** such as host families and social immersion
- **Fistula advocates** and networks within the community
- **Stigma reduction**
- **Partnerships** – with microfinance organizations and organizations that support income generating activities.

At the policy level, key components of reintegration would include:

- The **involvement of ministries of health and/or social affairs** and other ministries
- The establishment and maintenance of **national coordination bodies** and steering committees
- **Engaging parliamentarians**, especially women
- **Advocacy** – a national fistula day, or bringing attention to fistula on Mother's Day

Participants agreed that a **minimum package for reintegration** would include:

- **Counseling** (psychosocial, stigma)
- **Transport**
- **Health education**
- **C-section free of charge (within the concept of prevention of recurrence as part of successful reintegration)**
- **Advocacy within the community**

Monitoring quality of care for prevention, treatment and reintegration

Participants had also been asked to consider strategies for monitoring the quality of care for prevention, treatment and reintegration. In general, recommendations were similar for each of these elements of care, so we have combined the recommendations here.

- **Ensure supervision systems are in place and functioning** – participants emphasized the need for supervisors to be appointed and working, negative findings be addressed through coaching and mentoring, and activity reports and equipment inventories be routine. There should be quarterly review meetings with site data used to determine how decisions have been made and whether changes are needed.
- **Clarify who takes part in monitoring** -- community involvement, peer-to-peer review processes and patient exit interviews can all help to improve the quality of services. Is there a role for a quality control team? What role do Ministries play in monitoring the program overall?
- **Validate policy documents, disseminate them, implement them and monitor their implementation**
- **Strengthen health information systems**

- **Establish indicators to monitor progress** – what do we want to measure and how often
- **Develop a standardized classification system for fistulae**
- **Active monitoring and evaluation of programs**

Building Capacity for Quality Services through Training

Three participants gave presentations on building the capacity for quality services through training.

Surgeon Training: Understanding the Principles

Dr. Steven Arrowsmith, Mercy Ships and Worldwide Fistula Fund, New Mexico

Developing fistula surgeons is fraught with difficulties. Fistula surgery crosses traditional surgical disciplines. It crosses the boundaries of culture and the medical traditions within each culture and it crosses the thresholds of knowledge. Fistula surgery is complex, it takes time and it is exhausting work.

The ethical issue in fistula surgery (and training) is that the first attempt is the best attempt to achieving closure.

Dr. Steve Arrowsmith, Mercy Ships and Worldwide Fistula Fund

Training surgeons to do fistula repair is a critical step in building the capacity to respond to the needs of women living with fistula. It's also critical to raising awareness of the condition and the response needed. As mentioned previously, fistula surgery crosses traditional surgical disciplines -- there are urologists, gynecologists, general surgeons and other specialists who all do fistula surgery. Regardless of their specialty, the key things that a VVF surgeon needs to know include:

- Patient selection – to be able to determine whether or not the surgeon is capable of repairing the specific fistula and to refer as needed
- Preparation – to ensure that the patient is well enough to withstand the surgery and that the surgeon has assessed well enough what needs to be done
- Surgical treatment – to repair the fistula
- Post operative care – to monitor the patient's progress post-operatively and address any complications that might occur

Fistula surgeons must be able to impart a philosophy of whole person care. Women living with fistula are vulnerable, often bewildered and isolated clients. The surgeon needs to marshal the resources to support the physical, mental, social and economic well-being of these women, as well as advocate for attention to the condition within the health system and within the community.

Fistula training is caught in between the diverse cultures of surgical education. In one cultural sphere, trainees serve as apprentices, observing the techniques and approaches of an experienced surgeon until they are deemed to have absorbed sufficient knowledge to undertake surgery. In another cultural sphere, trainees are taught with the “see one, do one, teach one” approach. There is a need for standardization in both approach and in the content of training, including the development of a standardized classification system, with the focus being on hands-on surgical learning and mentorship. A curriculum should serve as a framework or tool to remind people what they need to do and can provide a list

of competencies to be observed and evaluated. Trainees should be assessed at the end of a training period, but at what point does certification occur and who should be the certifying body? The goal should be that we are building capacity – the end result is trained surgeons – but we need to accept that training is the beginning of a process that should be continuous. It needs to be followed up by multiple points of contact to ensure that trainees reach a higher level of competency and proficiency, and ideally trainees must strive to become trainers.

Fistula Surgery: Optimum Pre- and Post-Operative Care
Dr. John Kelly, Fistula Surgeon, Birmingham Hospital, UK

Dr. Kelly began his presentation by reminding us that there are no robust studies that underlie his presentation, but rather his recommendations are from “accepted practice” to facilitate quality pre- and post-operative care.

- First visit should include a careful history and examination, taking care to respect the dignity of each woman. Rehabilitation (a most important outcome of fistula care) begins at the first visit.
 - Pregnancy history – how many children has the woman had and how many are alive?
 - Gentle vaginal examination
 - If bladder stones are present, counsel the client and explain the importance of removal of the stones to facilitate repair surgery in a few weeks. Discuss and explain any procedures such as colostomy or diversion. Counsel the client regarding HIV.
- Pre-operative care – ensure the availability of water for drinking and soap and water for washing the client and for her clothes.
 - Keep the patient ambulated to address foot drop and to prevent or treat pressure sores
 - Give an enema 24 hours before surgery
 - Agree on anesthesia regimen and what to do if problems arise
- Post-operative care – nurse the patient on alternate sides, change every four hours, and always monitor the drainage receptacles. Encourage the patient to drink fluids. Analgesia should include 50g I.M. of pethidine every four hours. Monitor the drainage of the bladder to ensure that the balloon is not inflated to more than 10 ml, that there are no kinks in the catheter or tubing and that the bag or receptacle is at a lower level than the bladder. It is imperative that the patient be kept clean.
- Prophylactic antibiotics – there are no satisfactory randomized controlled trials relating to the use of antibiotics in fistula surgery. However, if they are given, appropriate antibiotics should be given at induction of anesthesia.

Beware, that in treating a maternal morbidity, we do not end with a mortality.

Dr. John Kelly, Birmingham Hospital, U.K.

The Fistula Care Training Strategy
**Dr. Joseph Ruminjo, Senior Clinical Advisor, Fistula Care Project,
EngenderHealth, New York**

The goal of fistula programs is to initiate and sustain access and develop the capacity of centers to provide quality services for the care of women living with fistula. To do this, it is crucial to pay attention to the quality of training. Dr. Ruminjo described the challenges encountered in training for fistula services. There are many different clinical types of fistula of widely divergent surgical complexity. While there are curricula and reference materials, there is a lack of standardization to those materials, and no current agreement on assessment of knowledge, skills and competence or on the duration of training and training models to be applied. Different approaches and skill sets are required for service provision and for training, even by skilled surgeons. Training site resources vary in terms of personnel, equipment, materials for service provision and for training. Underlying all of these is a dearth of evidence-based clinical and operations research data and as discussed previously, we lack a standardized classification system.

To begin to address these challenges and to achieve the goal, the Fistula Care project has developed a Fistula Training Strategy. The strategy suggests an overall approach to training, key principles and premises. It discusses training systems, training methodology and models. It identifies the cadres to be trained, the criteria for selecting trainees, trainers and sites. It establishes some suggested skill levels to be attained and the process for assessment of competence. It delineates training evaluation and systems for training follow-up and continuing education. The Strategy outlines training for all cadres of providers needed to effectively deliver services to fistula patients, but the focus of the presentation was on surgical training.

The Fistula Training Strategy outlines a uniform approach that is holistic, client-centered and system-focused to facilitate training that contributes to sustainable improvement in quality, availability, access and use of fistula services. The strategy is an outline for more detailed training guidelines and standards that include more technical content. It lays the emphasis on the “Fundamentals of Care” which include informed choice, safety and quality improvement.³

Training is a very expensive undertaking and is only one of the interventions needed to improve performance. Essential to ensuring that trainees are able to apply their skills is a proactive buy-in from sites for sustainability and ownership. It is essential to have institutional and

We should not be trying to train every surgeon from every site. This would lead to poor skills maintenance and trainee attrition.

*Dr. Joseph Ruminjo, EngenderHealth,
New York*

and management commitment to contribute to a supportive work environment that enables trainees early opportunities to apply newly acquired skills. This includes

³EngenderHealth. The Fundamentals of Care: Ensuring Quality in Facility-based Services – a Resource Package. The ACQUIRE Project 2006.

ensuring the availability of general and fistula specific equipment and supplies to provide services, supportive policies and guidelines for services and for clients, and facilitative internal and external supervision that emphasizes mentoring, coaching, joint problem-solving and two-way communication.

The key principles of the training strategy include the following:

- The welfare of the client guides all training
- Adult learning principles and an experiential model should be applied in training
- A combination of didactic and hands-on training is needed
- To the extent possible, we should be training teams for fistula service delivery
- Counseling is an integral part of fistula care
- Training should be competency based, with final assessment to inform the level of surgical complexity that a trainee is competent to repair.

Training must ideally translate into improved performance, so the selection of surgical trainees should be conditioned by the service need or demand and institutional support. Individuals must have an interest and commitment to providing services, with an intention to remain in the service for a reasonable minimum length of time, and the motivation and ability to immediately apply their new skills upon return to their post. The minimum educational requirements should be as per the policy of the local Ministry of Health, but we recommend that a fistula trainee should be a doctor with a minimum of three years of surgical experience. This could be a specialist or a general physician. In some instances, where specific country policies allow, it may also be possible to train a paramedical staff person.

The strategy defines the skill levels to be attained by fistula surgeons over time:

- Initial skill acquisition level – to make a diagnosis, to classify fistula and understand when referral is needed; to recognize the service systems needed.
- Competence level – to diagnose, classify and do fistula surgery. Fistula repairs vary greatly in complexity and difficulty so the strategy recommends gradual, progressive increases in skills acquisition and surgical efficiency in three stages. Individual country programs may vary in recommendations, but all stages of competence should start with an intensive hands-on surgical skills training, followed by progressive increases in numbers of fistulae repaired and degree of surgical complexity.
 - Stage 1 – intensive training plus additional 100-300 simple cases
 - Stage 2 – intensive training plus additional 100-300 simple and moderate complexity cases
 - Stage 3 – intensive training plus 300-600 cases, simple, moderate and complicated cases to achieve proficiency.
- Proficiency level – able to do most of the complicated cases, safely, efficiently and in correct sequence for the key steps; to deal with

unexpected complications intra and peri-operatively. It is beneficial to add a trainers' skill set at this stage.

Not all fistula surgeons can be trainers. To qualify as a trainer, the strategy suggests a minimum of Stage 2 competency. But also important is the acquisition of training skills, respecting training principles and criteria. The individual should be able to use and adapt training materials for central training and/or structured on-the-job training. S/he should be currently employed by the state or government or have the MOH support and recognition for the training provided. The individual should ideally work at a site providing routine repairs at least once a week and should have a knowledge of varied approaches of surgical management for different circumstances and complications. The trainer should take responsibility and accountability for improving their own level of skill with support as needed from the institution and administration.

Similarly, a "master trainer" is a master trainer by virtue of skills, not by designation. A master trainer must have proficiency level in fistula surgery, but must also be highly experienced in service delivery and training, with advanced training skills to enable him/her to train trainers and to develop training courses and materials. The individual must have access to training center material resources and have a large caseload of at least 100 cases yearly to maintain skills.

Following-up trainees is crucial and integral to the success and quality of training. This requires both administrative follow-up and supervision and clinical skills follow-up.

The strategy also sets out criteria for the selection of fistula training sites. The site must exhibit accepted medical standards and supportive policies, be fully equipped with general and fistula specific equipment, with adequate supplies, emergency medications and staff to be able to handle all complications from fistula surgery or anesthesia. The infrastructure must include appropriate work spaces, amenities and utilities, including exam and procedure rooms with privacy, a theater and wards (ideally dedicated, but may be shared), running water, power, teaching equipment, supplies, reference materials and a space for didactics and practicum. The site must have a trainer, either resident or visiting, and collateral staff able to support the training. Finally, the site must have an adequate caseload to facilitate training to the standards identified earlier.

The Strategy suggests how to apply the four levels of training evaluation⁴, reaction, learning, application and results. Finally, the Strategy suggests supplemental training at the skills building or awareness raising level to position fistula within a broader context. This might include safe motherhood interventions, cross-cutting issues such as quality of care (counseling and informed decision-making, infection prevention procedures and management of medical waste), community outreach and referral systems, traumatic fistula and

⁴ Donald Kirkpatrick's learning evaluating model: Kirkpatrick DL 1998, "Another look at Evaluating Training Programs. ASTD Alexandria, USA.

gender-based violence, and the broader context of poverty, women's rights and health equity.

Questions, Answers and Comments

There was general agreement that there is a critical need to focus on training additional ob/gyns, nurses and midwives to ensure that prevention is available. In addition, there is a need to increase the numbers of surgeons and other health care providers capable of responding to the needs of women living with fistula. In general, the approach should be to train local surgeons and teams wherever possible. A recommendation was made that formal training programs need to be instituted within faculties of medicine, and should include on- the-job training, although there was no consensus on this point. There was a general call for addressing the issue of certification.

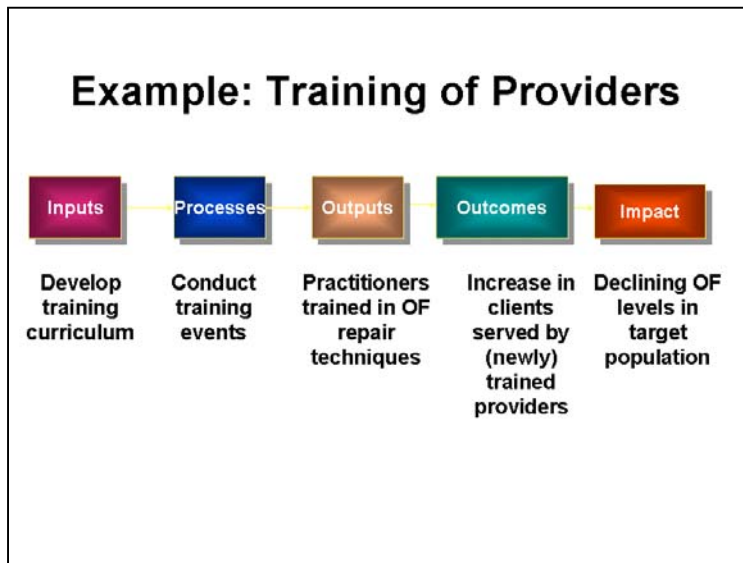
All agreed that it was imperative for those surgeons who have been working in fistula for long periods of time and have case data, to publish this data, and to pass on their learning and knowledge to future generations of surgeons. Finally, one participant reminded us all that training is necessary but not sufficient to ensure services. It is essential to ensure that equipment, consumables, facilitative supervision, etc. are available to support someone in applying their skills.

Improving Quality and Performance through Data

Three participants gave presentations on improving quality and performance through data.

Selected Indicators for Obstetric Fistula Programs

Dr. Florina Serbanescu, Centers for Disease Control, Atlanta, on behalf of the International Obstetric Fistula Working Group: Data, Indicators and Research Committee



Dr. Serbanescu began by reminding us that there is very little reliable information available on fistula anywhere in the world on incidence, prevalence, treatment or other aspects of care. Much of the available information cannot be generalized because it is small scale or facility-based. She described the main data sources for monitoring and evaluation of obstetric fistula programs: facility-based

routine data; facility-based surveys; cross-sectional population-based surveys; and qualitative studies such as needs assessments and focus groups. She provided an overview of the steps in determining appropriate indicators beginning with a results framework for maternal health. She provided an overview of the components of a program and potential indicators, using training as an example.

The Data, Indicators and Research Committee began with the classification of obstetric fistula indicators into focus areas: prevention, treatment, reintegration and cross-cutting. Within each focus area, indicators were further classified by categories: access, utilization of services and training. A list of indicators had been rated in terms of relative importance: core indicators which countries should report; additional indicators that would address special needs, contextual issues or capabilities; and extended indicators that would focus on very specific issues. The list of suggested indicators is attached as Appendix D.

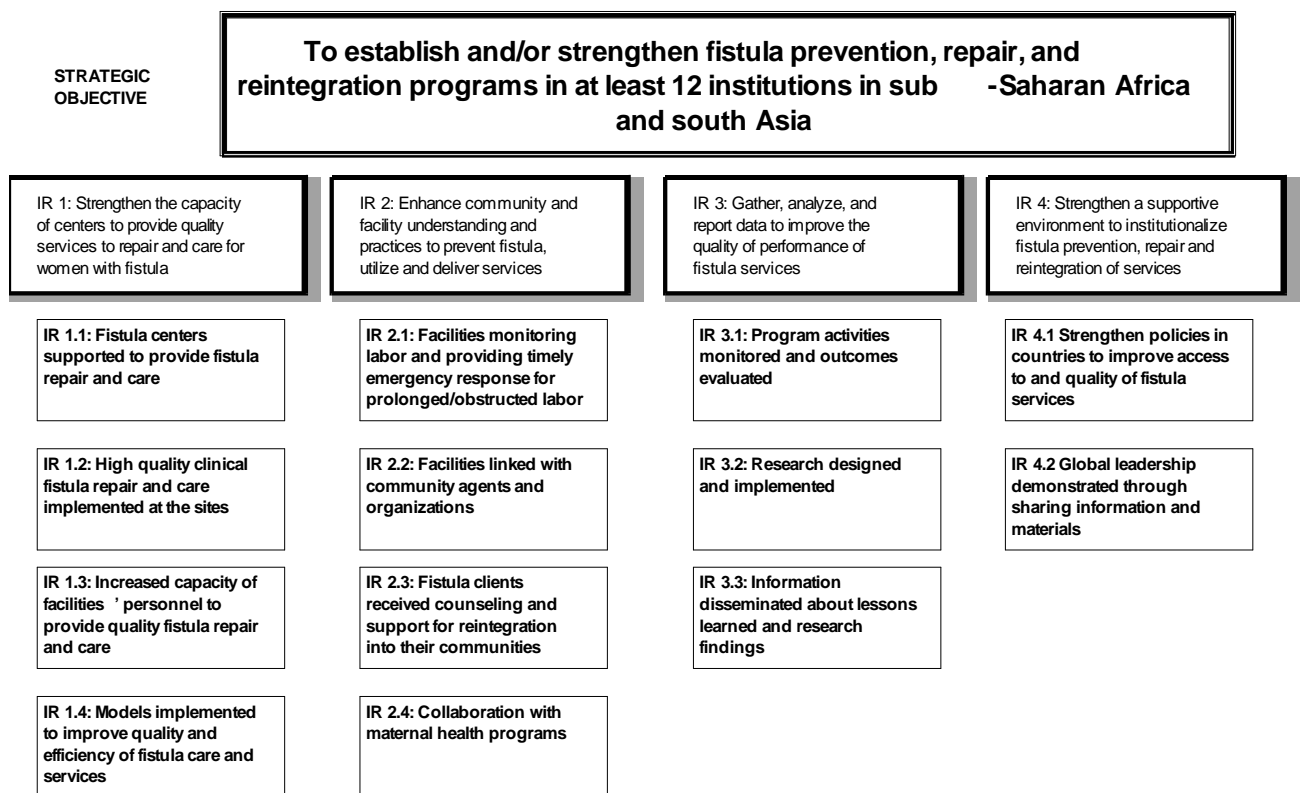
The next steps of the process will be to draft sections of a compendium for broader group review and to publish the report on the internet. A training workshop will be planned for policy makers, program managers, and clinicians. It is expected that the indicators will then be refined, field tested and validated.

Fistula Care Indicators

Ms. Evelyn Landry, Senior Monitor & Evaluation and Research Advisor, Fistula Care, EngenderHealth, New York

Ms. Landry introduced participants to the results framework for the Fistula Care (FC) Project and the related indicators. This presentation would set the scene for working group discussions later in the day for participants to provide guidance on refining or proposing additional indicators to assist in monitoring the quality of fistula services supported through USAID programs. Participants addressed indicators relating to prevention, treatment, reintegration and supervision. Please see after the next presentation summary for the results of those discussions.

Figure 1: Fistula Care Results Framework



Processes to Improve the Quality of Fistula Services
Dr. Sita Millimono, Medical Associate, EngenderHealth, Guinea

Dr. Millimono began by reminding participants the quality improvement serves to protect the health of both clients and health personnel, facilitates cost savings by reducing waste and repeat procedures, attracts potential clients and increases the utilization of services. The basic principles that apply include:

- A focus on the clients' rights and needs
- Participation of health personnel and a focus on their needs
- A focus on improving processes and systems
- Paying attention to costs and efficiency
- Continuous development and reinforcement of capacity
- Continuous attention to improvement

Dr. Millimono described the COPE⁵ approach used in Guinea to engage all site staff in assessing the quality of the services from the perspectives of clients' rights and providers' needs, identifying problems and developing action plans to address them. The approach is amplified by client flow analysis, client interviews, community discussions, and regular medical monitoring and supervision visits. Facilitative supervision and medical monitoring are crucial to quality services and effective communication among all levels of service providers; they assure compliance with standards, norms and guidelines and that staff have the necessary knowledge and skills to carry out their assigned tasks, as well as provide an opportunity for orienting new staff and coaching and mentoring to address weaknesses. Together the use of the COPE approach and facilitative supervision enable joint identification and resolution of challenges and problems, reinforce the team concept, assist in creating a culture of continuous quality improvement and enable the supervisor to focus attention on problems that the providers themselves cannot resolve.

Working Group sessions to define, refine or propose additional indicators for quality fistula services

Participants were organized into four working groups to assist in defining, refining or proposing additional indicators for quality fistula services relating to prevention, treatment, reintegration and supervision. The following is a summary of the recommendations made by the working groups.

Treatment Indicators

The Fistula Care project developed a quarterly data reporting form for each country/project supported site to use for reporting on 9 treatment-related indicators. The current list of indicators for treatment and the comments from the two working groups include:

⁵EngenderHealth. COPE® Handbook: a Process for Improving Quality in Health Services, Revised Edition. 2003.

Fistula Care Treatment Monitoring Indicators	Feedback/Comments
1. # of women arriving and seeking fistula repair	No comments
2. # women requiring fistula repair surgery	No comments
3. # of women receiving surgery for fistula repair	<p>Refine indicator to say number of women receiving surgery <i>at this facility</i>. Some women are referred to other facilities when and if the surgeon does not have the skills to conduct the repair surgery.</p> <p>There was some discussion as to whether sites should report on <i>irreparable cases</i> and women who were <i>not operated upon</i>. There was comment about the challenge caused by the changing denominator as one worked their way down this form</p>
first repair	
second repair	
> 2 repairs	
4. # of women discharged after receiving fistula surgery	
Outcome of fistula repair surgery	<p>Agreement that we should not use the terms success and failures when talking about the outcome of surgery.</p> <p>The two groups had different opinions about how to classify outcome of surgery. One group recommended including the outcome (dry or with stress incontinence) disaggregated by the number of previous repairs), as the potential for “successful” outcome diminishes with successive surgeries.</p> <p>The other group recommended classification of surgery outcome as number with a closed fistula followed by number with a closed fistula who are dry (at time of discharge).</p> <p>One group wondered about the importance of reporting on stress</p>

Fistula Care Treatment Monitoring Indicators	Feedback/Comments
	incontinence.
5. # of women who have a closed fistula and are dry	
6.# of women who have a closed fistula and remaining stress incontinence	
7.#f women whose fistula was not closed	
8. # of women who received fistula surgery and were discharged, who experienced a complication up to the time of discharge (as opposed to the definition of complications as up to 42 days post-procedure)	See comments below
anesthesia-related	
post-operative (fever, UTI, bleeding, etc.)	
death	
other (specify)	
9. # of women who remain in post-op care and were not discharged this quarter	

Other comments/recommendations were:

- Include an indicator to account for any women who needed surgery but were referred to another facility.
- Include an indicator to describe the etiology of the fistula: obstetric, traumatic, or surgical.
- Count of women with RVF repairs and those with 3rd and 4th degree perineal tears.

Some women who turn up at workshop settings but are not operated on for one reason or another do not have any data captured at all, not even how many they are in sum (an example was given from Nigeria).

Reporting of complications:

Some further clarifications about the definition of a complication and types to report were discussed. Recommendations included:

- Expansion of definition of a complication: A complication is a medical **or surgical** problem requiring intervention or management beyond what is normally necessary. A complication is an adverse event associated with surgery or anesthesia –i.e., it would not have happened if the patient had not been operated upon. Pre-existing conditions such as diabetes and heart disease may affect complications rates.
- The list of major complications was reviewed and accepted by the group.

- Bleeding should be defined as necessitating intervention
- Anesthesia complications should be a separate category
- Complications to add to the list may include: urine retention, urethral stenosis, hemotometra (rare)
- There is continuing clinical debate whether there is a cause and effect relationship between stress incontinence and fistula surgery. Additional procedures, e.g. planned colostomy and diversions, should not be reported under complications but as necessary interventions.
- Importance of level of detail to report on complications in the context of heavy workloads of physicians was discussed in one group.
- Diagnosis should ideally be lab based, rather than clinical; but it is challenging to establish even a minimum package for laboratories in our resource poor settings.

Prevention Indicators

Two groups reviewed and discussed 12 of the 20 indicators from the OFWG (we selected those which could be measured at the facility level; many of the prevention indicators require population-based assessments) and 5 proposed by Fistula Care; see Appendix D for a list of the OFWG indicators. The indicators and comments from the groups about the OFWG indicators included:

Selected OWFG Indicators	Feedback/Comments
Access: Availability	
P.2 Proportion of comprehensive EmOC facilities that are functioning 24/7 of all EmOC facilities	Some countries are currently using this indicator but only feasible in some countries
P.3 Availability of community outreach efforts on awareness of pregnancy complications, obstructed labor and OF	Used in some countries
Access: Information	
P.10 Met need for obstructed labor	Not used
Access : Quality	
P.11 Functioning service delivery points prepared to provide at least 3 FP methods	No comments
P.12 Service delivery points that experience a stock-out of each method at any point during a given period	No comments
P.13 Facility readiness to perform a cesarean within 2 hours of an obstetric emergency	Used in some countries
P.14 Case Fatality Rate for Obstructed Labour	Used in some countries
Use of Services	
P.16 Institutional deliveries	No comments
P.17 Births attended by skilled personnel	No comments
P.18 C-section rate	Used at the facility level

Selected OWFG Indicators	Feedback/Comments
P.19 % of women who survived obstructed labors with or without cesarean section who are appropriately managed according to catheter protocol (WHO guidelines)	Not used
P.20 Correct usage of partographs according to agreed criteria	Used in some countries

FC Proposed Indicators for Prevention	Feedback/comments
# of community outreach activities and # persons reached about prevention of obstetric fistula (OF)	Considered a burden to collect
# of FC supported sites provided with technical assistance to improve EoC services	Too general
# of clients served with FP services at FC-supported sites (any clients including fistula clients)	Fine; clearly defined
% of births at FC supported sites which are c-sections	No comments
% of women presenting at FC supported facility for which labor has lasted >24 hours (expect to see this number decrease over time as a result of community outreach and other BCC efforts)	May be too difficult to interpret
% of women discharged after fistula repair who are counseled about care for their next pregnancy and delivery	

Suggested prevention indicators for Fistula Care supported programs include:

- % of correct use of the partograph
- # BEmOC sites referring to CEmOC sites for prolonged labor
- Access, demand and postnatal care indicators

Reintegration Indicators

One small group reviewed and commented on 8 of the 9 reintegration indicators from the OFWG; see Appendix D. There was overall agreement during this session and a previous session on defining the services of reintegration that reintegration needs to be defined.

Selected OFWG Indicators for social reintegration	Feedback/Comments
Availability	
SR1. Proportion of fistula treatment facilities that provide or refer patients to	Need to clarify definitions of reintegration, referral systems, (e.g., life

Selected OFWG Indicators for social reintegration	Feedback/Comments
reintegration services, such as literacy training, life skills, micro-credit.	skills and microcredit as “empowerment” vs. “reintegration”) – not collected yet
SR2. Proportion (%) of fistula treatment facilities that offer family planning services for fistula patients.	FP services can mean counseling, with or without provision of methods. Could be easy to collect, but need clear referrals and links between fistula ward and FP clinic
Use of Services	
SR3. Proportion (%) of women treated for OF who received psycho-social counseling services.	Define types and timing of counseling (e.g, peer support, group support, health education, pre-surgery, post-surgery)
SR4. Proportion of women treated for OF who received FP services, including method or prescription for a method.	Question whether FP use indicator is important for reintegration (this is also a prevention indicator on the OFWG prevention list)
Training	
SR5. Number of providers trained in counseling for women living with OF	Training process indicator could be clarified to measure competency, attrition rate of trained providers
Family/Community support living with fistula - stigma reduction	
SR6. Proportion (%) of women treated for OF who had access to treatment with the support of a family member.	more likely as part of a special study – define types of family (birth family, family married into)
SR7. Proportion (%) of women seeking OF treatment who report experiencing stigma or discrimination from their community prior to fistula treatment.	fine as a special study, good indicator for fundraising and advocacy
SR9. Proportion (%) of women treated for OF who report increased participation in community life after fistula treatment.	For special studies – very good indicator. Better as a qualitative measure than a proportion. How long after care should this be followed up?

Monitoring and Supervision

One group met to discuss the current supervision practices (both internal and external supervisors) and to comment on the supervision and monitoring check list Fistula Care has developed. Those who participated in this small group reported different experiences: some facilities have informal systems or supervision is nonexistent. In other facilities there are regular management meetings and medical review meeting to review trainings, surgeries, types of repairs, outcomes, challenges and recommendations. External supervision does occur, either annually or on an ad-hoc basis with varying frequency. External supervision usually is done jointly by the external visitors (e.g., health management teams, Mercy Ships HQ, EngenderHealth, UNFPA) and site staff.

Feedback on the monitoring checklist included:

- How often would it be used? By whom? How long would it take at a site?
- The checklist is very long; recommend that this type of supervision checklist be used only annually
- Each facility should review current monitoring and needs assessment tools, and assess and harmonize tools.
- Suggest conducting peer review among peers who agree on the criteria
- Service delivery and infection prevention guidelines are referenced – Recommend having consensus about the guidelines, flexibility to reflect local guidelines, and provide the guidelines to the facilities
- Questions about available drugs, equipment, consumables are useful, and the tool can be used to advocate for inputs to facilities
- Recommend additional questions on dignity, cleanliness, quality of outpatient examination, referral systems, confidentiality and photos/media
- Assistance needed to implement (training on how to use, how to score) – it could be a lot of work for the external team, but not too much for any single provider at the site being assessed

Improving Quality and Performance through Research

Determinants of Post-operative Outcomes in Fistula Repair Surgery: A Prospective Facility-based Study

Mark Barone, Senior Medical Associate, EngenderHealth, New York, presented by Ms. Evelyn Landry, EngenderHealth New York

EngenderHealth, with support from USAID has embarked on a multi-center research study to assess the determinants of post-operative outcomes. Ms. Landry presented a short overview of the study. There are limited reliable data about the association of clinical, social and demographic factors with outcomes of fistula repair surgery. Most studies have collected data retrospectively, so results are limited to information available in the records being reviewed. As a result, collection of consistent information from multiple sites/countries is unlikely and additional indicators that could provide a more nuanced description of fistula clients and the care they receive are not available.

This study is being carried out in 6 countries—Bangladesh, Guinea, Niger, Nigeria, Rwanda and Uganda. The primary purposes of the study are to determine factors that predict outcomes (closure, continence, and complications) of fistula repair surgery and to examine socio-structural factors associated with fistula. Factors to be examined include socio-demographic and other background information, circumstances surrounding the development of the fistula, anatomical and clinical characteristics of the fistula, pre, intra and post-operative techniques, provider training, experience, qualifications, and how fistula repair services are organized.

A total of 1,439 women will be recruited into the study. Patient enrollment began in January and February 2008; a total of 130 women had been enrolled as of March 30th. Given the limited previous research on factors affecting fistula repair outcome the study is exploratory in nature. The results may directly inform future fistula repair services. The study will also generate new ideas clinical research to improve fistula treatment. The data from the study will be useful for discussion, modeling and/or validation of classification systems. We will not be developing a classification system as part of this study, however it is anticipated that the results from this study will assist in the development of a standardized classification system that allows for the predictability of prognosis along with the UNFPA, JHU and WHO collaborative study (*Prognosis, Improvements in Quality of Life (QOL) and Social Integration of Women with Obstetric Fistula after Surgical Treatments*). This study, which will be done in collaboration with medical institutions in seven high fistula prevalent countries (Bangladesh, Benin, Ethiopia, Mali, Niger, Nigeria, Sudan, and Tanzania) will examine post-operative prognosis, (building from/similar to the EH/FC and USAID study), and expand the focus for improvement in quality of life, social integration, and rehabilitation of fistula patients after surgical treatments.

Dialog with USAID: Fistula Research Priorities
Dr. John Yeh, USAID/Washington, USA

The purpose of Dr. Yeh's presentation was to review potential areas for obstetrical fistula investigation and to seek guidance from participants on a possible ranked list of feasible and high impact studies that could be accomplished in a reasonable timeframe. As noted previously, there is a lack of published data about many social, demographic and clinical factors. Most studies have gathered data retrospectively by individual clinicians resulting in a lack of consistent information from multiple sites or countries and additional indicators that could provide a more nuanced description of fistula clients are needed. Prospective studies are needed to assess the association of current clinical practices at study sites with the outcome of repair surgery, as well as to answer pressing clinical, epidemiological and operations research questions to inform future interventions and further research in fistula treatment and prevention.

The focus of the presentation was on feasible and high impact studies which could be accomplished in the next 3-5 years with attention to optimal clinical regimens. For example:

- criteria to identify and grade complexity (in the absence of a standard classification system) and optimal pre-operative evaluation;
- the use of prophylactic antibiotics – what is the optimal regimen before, during and after surgery;
- the role of catheterization in management, perhaps requiring a randomized controlled trial of duration, open versus closed drainage, bed rest versus encouraging women to be ambulatory; and
- how to optimize cost-effectiveness of care, for example in duration of hospitalization for post-operative care.
- With regards to stress incontinence after fistula repair, what is the incidence, what might be pre-operative predictors of stress incontinence and what are the most effective management strategies?
- For repeat fistula, what are the causative associations and what repair algorithms should be used to avoid complications?
- What is the incidence of fistulae that cannot be repaired and what are the best strategies for management?

There are new technologies that should be assessed through research, including urethral plug for stress incontinence, fistula plugs for small VVF and RVF, as well as other emerging technologies. From an epidemiological standpoint, we need more information on the circumstances surrounding the development of the fistula, including iatrogenic cases and the availability of and access to obstetric services. In the case of traumatic fistula, we need case studies of what surgeons are seeing in the field, description of range of cases seen and whether approaches, principles and techniques for repair and outcomes are significantly different than for obstetric fistula. In terms of short-term interventions, it is

important to know the optimal timing of surgical repair, the role of early catheterization in fistula management as prevention or treatment, and the best program models for elective c-sections post repair.

There was no disagreement from participants about the ideas presented. The two main issues which were discussed in more detail were studies needed to assess the use of antibiotics and drainage practices. There was agreement about the need for well designed studies as well as concerns expressed by some about the amount of time and effort required in collecting data. Some participants were interested in less clinically focused studies: multidisciplinary studies to assess impact of treatment on desire for fertility and difficulty in sexual relations would be useful; also examine the social cost to patient regarding the length of time for postoperative care.

Strengthening the Environment to Support Fistula Prevention, Repair and Reintegration

The final day was devoted to considering factors that contribute to a strengthened environment to support fistula prevention, repair and reintegration. The discussions began with a presentation from Ms. Maggie Bangser on the experience in Tanzania, a good case study for a strengthened environment.

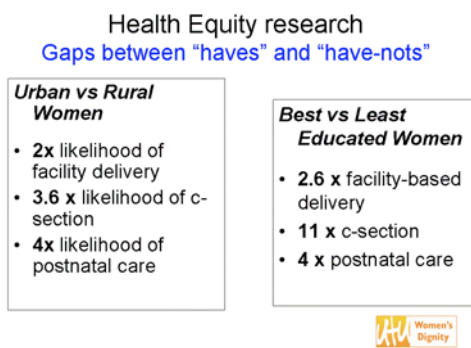
Dancing the Dance: Fistula and Health Equity in Tanzania

Ms. Maggie Bangser, Women's Dignity Project, Tanzania, presented on her behalf by Karen Beattie

“Women's Dignity” promotes citizen engagement to enable all Tanzanians, particularly marginalized girls and women, to realize their basic right to health. The organization is particularly committed to enhancing the rights of girls and women living with obstetric fistula. Its programs support citizens to access and use information to promote their health rights; ensure policies, programs and services promote the dignity and rights of the poor, particularly girls and women; and engage communities as meaningful participants in processes for social change.

Women's Dignity links fistula and health equity, like partners in a dance. Fistula is a clear marker between the “haves” and the “have nots” exposing the failure to prioritize marginalized girls and women, to allocate resources to meet their basic needs and to implement promises made in national and international policy circles. “Health equity” is defined as the fair and just distribution of resources and entitlements for marginalized people, requiring the prioritization of resources to under-served locales (such things as skilled providers, emergency obstetric care services, and functioning referral systems), as well as ensuring effective allocation and use of health budgets, citizen involvement in priority setting for health care and establishing mechanisms of accountability for negligence, abuse and poor quality care.

To address these issues, Women's Dignity has three strategies: to build the evidence for addressing the linkage; to facilitate and encourage citizen debate; and to build a movement for health rights. In building the evidence, Women's



Dignity examines the underlying conditions that lead to fistula, maternal mortality and morbidity, and ill-health of the poor. The findings are used to identify changes for health policy and practice. This has included mapping fistula care in Tanzania and the production of several research and policy analysis papers. These research findings are shared with the community to engage citizens and their local leaders, increasing knowledge and accountability.

Using film, photography and popular media (radio and TV spots), as well as working with local journalists, and encouraging women's voices in the media, Women's Dignity improves citizens' access to information, enabling people to articulate their views and mobilize broad public debate. The messages include information on health rights and maternal health, on threats to women's health, and on showing that change is possible.

To build a movement for health rights, focused on women with fistula, quality maternal health and health rights for the poor, Women's Dignity has focused on establishing strategic partnerships. This has culminated in the existence of a National Fistula Program in Tanzania that includes hospitals, the Ministry of Health, NGOs, the media and donors. It focuses its efforts on training providers, ensuring service delivery, establishing effective referral systems for repair, and conducting research and advocacy. Similarly, a Health Equity Group has been established of like-minded NGOs, whose objective is to monitor services, track health budgets, educate Members of Parliament and launch public campaigns to create awareness. Finally, Women's Dignity has established partnerships with international organizations to share lessons learned, including WHO, UNFPA and EngenderHealth.

After almost ten years, progress has been made. Partnerships on fistula and health equity have been effectively established and are functioning and broad-based. The link between fistula and health equity has been articulated and understood, although there is still a long way to go. The activities are moving from evidence to action through media and through strategic advocacy and bridges have been built across the community, district, national and international levels. Further progress has been challenged by weak basic health systems resulting in weak maternal health services; massive HIV/AIDS funding is pushing other health needs of the agenda, including maternal health; a nascent and reticent "public voice" limits the effectiveness of advocacy and there is still some government resistance to NGOs and citizen driven accountability places an obstacle to policy dialogue and real change.

Community-based Prevention of Fistula

Ms. Gwendolyn Lusi, Heal Africa, Democratic Republic of Congo

Ms Lusi described the work of Heal Africa in North Kivu. Of sixty-three VVF patients seen at HEAL Africa in March, 43 were the result of obstructed labor, 13 were the victims of gang rape and torture, and 7 were the result of surgical error. It is important in establishing services to take into account difference in perspectives that women have in seeking access to obstetric care. Health providers will identify the importance of procedures, personnel, equipment, etc. while women are concerned about who will take care of their families, how to get to the facility, how to pay, and that many women, including their own mothers, have received care locally from a midwife without complications.

To address these perspectives Heal Africa works both at the facility level and at the community level. They train health workers – nurses, surgeons and midwives, and equip health centers. They equip health centers and providers

with items needed for safe delivery and services, including delivery tables, mattresses, cesarean kits, generators, etc, using local supplies and equipment to the extent possible. Equally as important is to train traditional helpers who, as a



result, refer deliveries to health centers. Traditional helpers receive kits and uniforms after training and completing a test of their skills. Once trained, Heal Africa has found that traditional helpers serve to sensitize other traditional helpers from different villages to come for training. Heal Africa also forms “Nehemiah Committees” at the community level and work with leaders in the community to reinforce messages of zero tolerance of sexual violence, and to promote safe motherhood and family

planning. They have also formed Solidarity Groups where mothers of childbearing age are formed into maternity insurance groups to receive funds collectively for income generating activities. Solidarity groups have also served as foster mothers taking care of orphaned children. Women fistula patients sew baby layettes for newborns, which usually do not have clothes because of the poverty in the area. Heal Africa’s message is “don’t get bogged down” but rather to think creatively about how to maximize the resources available to you.

Working Group sessions to discuss country plans and ethics

Participants were split into working groups to propose actions that could be taken at the country and global level towards achieving the Fistula Care results. Working groups were asked to suggest three to five specific activities to achieve any of the following they would like to include in their programs, or to be addressed globally:

- **Fistula prevention strengthened**
- **Data used to make decisions and improve quality**
- **Strengthened environment for fistula service delivery**
- **Increased capacity of centers to provide fistula repairs**
- **Ethics in fistula care service delivery**

Fistula Prevention Strengthened	
Actions to be taken	Countries
Improve access to emergency obstetric care with a focus on training doctors and midwives in monitoring labor, use of the partograph and the provision of basic and emergency obstetric care.	Bangladesh, Guinea, Ethiopia, Mali, Nigeria, Rwanda, Uganda
Train health facility staff in interpersonal communications	Nigeria
Establish referral networks for emergency obstetric care	DRC, Ethiopia, Guinea, Rwanda, Uganda
Create protocols or job aids for providers in how to deal	Uganda

Fistula Prevention Strengthened	
Actions to be taken	Countries
with obstructed labor in partnership with MOH to provide standardized practice guidance	
Within fistula centers, incorporate emergency obstetric care and family planning services and link with community-based skilled birth attendants	Bangladesh
Strengthen capacity of and incentives for TBAs to serve as referral agents to facilities	Nigeria
Engage NGOs and community-based outreach workers in prevention activities to educate women and school children on the use of services	Mali, Nigeria, Ethiopia
Establish village safe motherhood committees, male involvement activities, and work with satisfied clients. Develop national advocacy groups for prevention and for reintegration	Guinea
Create mass media messages and information campaigns through radio, drama, community meetings, targeting community leaders (political, religious, education, etc.)	DRC, Ethiopia, Guinea, Uganda
Advocate for free maternal health services for women	Nigeria
Empower women economically through income generating activities	Ethiopia

Data used to make decisions and improve quality	
Actions to be taken	Countries
Train personnel in data collection and maintaining accurate service data on fistula. Raise awareness among personnel in fistula centers of the importance of this data to improve quality. Provide timely feedback on data.	Mali, Uganda, Rwanda, Bangladesh
Use data collection to tailor messages in communities	Uganda/Rwanda
Conduct data audits at the facility level – monthly and/or quarterly meetings to review data to determine trends and improve quality	Nigeria, Guinea

Strengthened Environment for Fistula Service Delivery	
Actions to be taken	Countries
Advocacy activities: Facilitate ownership of program through Ministries and other national programs. Support the national league to end fistula. Advocate for National Fistula Day with parliament. Advocacy with women parliamentarians for resource allocation. Develop advocacy champions Women with fistula to serve as advocates within their communities	Guinea, Uganda, Nigeria, Rwanda

Strengthened Environment for Fistula Service Delivery	
Actions to be taken	Countries
National network of fistula services through National Fistula Task Force	Bangladesh, Nigeria
Form Uganda Fistula Providers' Association of surgeons, nurses and others to meet annually to share lessons learned, pool resources as needed.	Uganda
Fistula to be part of provincial health inspection (review) which brings together all heads of zones once a month	DRC
Policy to support free fistula management and repair services	Mali
Preparation of strategic fistula management plan	Rwanda

Increased Capacity of Centers to Provide Fistula Repairs	
Actions to be taken	Countries
Standardize certification of surgeons	Guinea
Raise the profile of fistula surgery within ob/gyn programs and provide structured training. Share information on global trends with surgeons and nurses through international journals for example	Bangladesh, Nigeria
Ensure continuous training of multi-disciplinary fistula surgery teams and provide facilitative supervision for those teams.	Mali, DRC, Nigeria
Develop a list of committed providers who want training and a database of those who have been trained and their skill level.	Uganda
Train paramedical staff to follow up women, nurses, anesthetists, counselors	Guinea
Equip and/or rehabilitate fistula centers	Nigeria, Uganda
Develop a regional training curriculum on fistula management for nurses	ECSA (Tanzania)
Advocate for funds/resources for fistula	Nigeria, Bangladesh, Uganda
Create a map of fistula distribution	DRC
More surgical outreach camps	Uganda
Upgrade Ruhengeri to a treatment site and national hospital to a training site	Rwanda

In addition to the country discussions above, one working group had been asked to consider the ethical issues in fistula service delivery. Questions asked included the following:

- 3-5% of cases cannot be repaired. What should be done to address the needs of these women?
- Some women experience multiple repairs. What are the conditions under which a second, third or fourth repair should be undertaken and by

- whom? What processes need to be in place to facilitate this decision-making?
- What advanced procedures should be supported and by whom? What processes need to be in place to facilitate this decision-making?
 - What are the relative costs?
 - Will certification assist in ensuring that women receive appropriate care? If so, recognizing that fistula surgery is done by individuals with a broad range of specialties, who should provide the certification – a university, the Ministry of Health, an international society, other? How would this work?
 - What informed consent procedures should be considered routine in fistula surgery?
 - Any other ethical issues?

This group reported that following a meeting held at Duke University in 2007, a Fistula Surgeon's Code of Ethics had been developed and it was proposed that the new International Society of Fistula Surgeons should consider adopting this and it should be included in fistula training curriculae. Other issues addressed during the discussions included the following:

Informed choice and informed consent are concepts that need special attention at multiple points of interaction with fistula patients. These include before surgery to discuss options, for photography, for research, for media attention, for stories, etc. There is a great challenge about how the woman with limited literacy and conceptualization about treatment options and different local and global media will actually make a fully informed choice, and what part of the decision will ultimately fall to the providers after good-faith attempts.

A standardized classification system, once developed, should include an evidence-based definition of what is an irreparable case. The diagnosis would need to be made by the most skilled person in the surgical team. It is important that each surgeon and surgical team recognize and accept the limits of their skills and ability for complex fistula surgery, and know what other options are available locally or nationally or within reach. Hospitals will also decide whether to refer or defer if there is someone else more experienced to be available in reasonable time and distance, although it was pointed out referring some of these women to a different culture/setting would be equivalent to referring them to the moon. It was suggested that ethics committees might be established to help deal with addressing the needs of women who cannot be repaired.

Even for irreparable cases, it is important for the client and the provider to understand there are still other options for assistance, including counseling, vocational training, treatment of co morbidities and, ultimately, considerations for diversion. But diversion should not be the first and easy option, and should take into account the long-term circumstances of the woman: clinical, logistical, cultural-social and access to necessary supplies and support. The model of "fistula-villages" is not necessarily the ideal long-term and sustainable solution for these women, and cannot be considered true reintegration, but is the only option for some of these women.

Expatriates who come in as 'fistula tourists' probably have good intentions to begin with, but they may have expertise in a particular surgical area that is not in synch with what is a priority in the local context, i.e. a solution looking for a problem. Surgeons may for example do diversions as the very first option because they have expertise in that area; they should try to submit their expertise and collaborate in the local context and under local expertise and their clinical hosts, committing enough time to learn and be of real benefit to the women they propose to assist.

TBAs, nurses and midwives need to be specifically trained to establish a special relationship with patients who are coming to deliver, instead of creating a negative attitude.

Some final thoughts on models that might be replicated:

In Zambia and Mozambique, the Ministry of Health is upgrading clinical officers to "licenciates" who can specialize in ob/gyn, including some who do fistula surgery. Their main role is to work on prevention and they work mostly in rural areas where doctors and nurses are hard to find. It was suggested that this model might be something to explore.

In one area of Ethiopia, fistula has essentially been eradicated through community action.

In Darfur, 16 former fistula patients have been trained as midwives to support fistula patients, but they are not formally allowed to work as midwives because of their lack of formal training. Is this something that should be explored?

CONCLUSIONS AND NEXT STEPS

This meeting provided a forum for a first meeting of USAID-supported fistula providers to come together and discuss their needs, challenges, remaining gaps and successes in fistula repair and care.

Over the course of the three day meeting participants heard about the organization and delivery of fistula services from a variety of countries, deliberated on defining essential elements for a quality of care fistula strategy, discussed training needs, assisted in defining, refining program monitoring indicators, and identified key actions which would contribute to a strengthened environment to support fistula prevention, repair and re integration.

Over the course of the next several months the Fistula Care team will be meeting with country partners to refine/develop strategies to strengthen fistula prevention, use data to make decisions and improve quality, strengthen the environment for fistula service delivery, and increase the capacity of centers to provide fistula repairs.

Appendix A: Meeting Agenda

Meeting Agenda April 15-17, 2008 Airport West Hotel, Accra

Tuesday, April 15, 2008

7:45 a.m.	Registration (continued from previous evening)
9 .00 a.m.	Welcome and Introductions Dr. Isaiah Ndong, Vice President, EngenderHealth
9.15 a.m.	Official opening and keynote speech The Honorable Mr. Abraham Odoom, Deputy Minister of Health, on behalf of the Minister of Health, Ghana
10.00 a.m.	Welcome to participants on behalf of USAID/West Africa Mr. Henderson Patrick, Mission Director
10.30 a.m.	Break
11.00 a.m.	Where are we now? An Overview of Fistula Repair supported by USAID 2004-2008 Ms. Mary Ellen Stanton, Senior Reproductive Health Advisor, USAID and Ms. Patricia MacDonald, Senior Technical Advisor, USAID
11.3 0 a.m.	Objectives and Expectations for the meeting – a Roadmap to 2012 Karen Beattie, Project Director, Fistula Care, EngenderHealth
12 p.m.	Lunch
1 p.m.	Strengthening the capacity of centers to provide quality services to repair and care for women with obstetric and traumatic fistula – Panel presentation <i>The Panelists will speak on the organization of quality fistula services and different models of service delivery</i> Dr. Thierno Hamidou Barry, Guinea Dr. Hassan Wara, Nigeria Dr. Maura Lynch, Uganda Dr. Bizunesh Tesfaye Tamirat, Ethiopia Professor Kalilou Ouattara and Dr. Traore Awa Marcelline, Mali
2.45 p.m.	Break
3.15 p.m.	Working groups <i>Working groups will define the essential elements of a quality of care strategy for fistula care, including prevention, treatment and reintegration</i>
5.00 p.m.	Close for the day
5.30 p.m.	Welcome reception

Wednesday, April 16, 2008

8.30 a.m.	Regroup and summary of previous day
9.15 a.m.	Building capacity for quality services through training – Panel presentation <i>The Panelists will speak on training strategy, training curriculae and certification, training of trainers, surgeons and ancillary personnel, and training for pre- and post-operative care.</i> Dr. Joseph Ruminjo, Kenya Dr. Steven Arrowsmith, USA Dr. John Kelly, United Kingdom
10.15 a.m.	Questions and comments
10.30 a.m.	Break
10.45 a.m.	Improving quality and performance through data – Panel presentation <i>The Panelists will speak on the work of the Data, Indicators and Research Working Group of the Obstetric Fistula Working Group, core indicators used in USAID programs and processes and tools for supervision and monitoring quality and performance.</i> Dr. Florina Serbianescu, USA Ms. Evelyn Landry, USA Dr. Sita Millimono, Guinea
11.45 a.m.	Questions and comments
12.15 p.m.	Lunch
1.15 p.m.	Working groups <i>Working groups will respond to questions posed regarding key indicators and monitoring processes for a quality of care strategy.</i>
3.15 p.m.	Break
3.30 p.m.	Improving quality and performance through research – Presentations and discussion <i>Presenters will review current research and USAID priorities for future research</i> Ms. Evelyn Landry, USA Dr. John Yeh, USA
5 p.m.	Close for the day

Thursday, April 17, 2008

8.30 a.m.	Regroup and summary of previous day
9 a.m.	Strengthening the environment to support fistula prevention, repair and reintegration – Presentation and discussion <i>The Presenter will discuss what it takes to strengthen the environment for fistula services, providing a country case study.</i> Ms. Maggie Bangser, Tanzania
9.40 a.m.	Working Groups <i>Working groups will be organized by country and by specific issues to identify actions that can be taken at the country and global level towards the Roadmap to 2012</i>
10.30 a.m.	Break
10.45 a.m.	Working groups continue
12.00	Lunch
1 p.m.	A Road Map for Fistula Care to 2012 – Highlights of recommendations made and additional contributions – Presentation and discussion <i>Participants will review recommendations made during the meeting and contribute further suggestions for Fistula Care priorities through 2012</i>
2 p.m.	Closing session
3 p.m.	End of meeting