



Report of the Africa Regional Fistula Meeting



Accra, Ghana
29 June – 1 July 2004

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Executive Summary

From 29 June to 1 July 2004, UNFPA hosted the second Africa Regional Meeting on Obstetric Fistula, in Accra, Ghana. The conference brought together over 90 participants from 26 countries, including UNFPA staff, government officials, non-governmental organizations, and some of the world's foremost experts in obstetric fistula. The conference took place against a backdrop of rapidly growing worldwide interest in the management of obstetric fistula and was held within the framework of the Campaign to End Fistula, launched by UNFPA in 2003 and which includes a number of partners at global and national levels.

The meeting constituted the largest ever gathering of countries and participants to discuss obstetric fistula. The broad participation provided an opportunity to gain consensus on issues critical to the foundation of the campaign. Of particular importance, the group endorsed the three strategic intervention points of:

- Strengthening prevention
- Building capacity and improving access to treatment services
- Promoting support services before, during and after treatment to ensure social reintegration of fistula survivors into their communities

It was also emphasized that prevention is the key to elimination and that an integrated approach is necessary to ensure that fistula programmes fall within safe motherhood and reproductive health policies, programmes and services at the national level. The three-day consultation also enabled participants to assess the Campaign's progress in Africa, discuss the technical issues relevant to the management of obstetric fistula and most importantly to share country-level experiences and lessons learned. The participants highlighted challenges and possible solutions and agreed on priorities and a course of action for the way forward.

The main recommendations of the meeting were to:

- Integrate fistula into reproductive health and safe motherhood policies and services.
- Continue to develop diverse, multi-sectoral partnerships at country, regional and global levels to ensure a comprehensive and coordinated response to fistula elimination.
- Highlight the issue of fistula to effectively advocate in the areas of universal access to reproductive health, gender empowerment and poverty and promote awareness and behaviour change at community levels.
- Develop consensus on a standard set of objectives and indicators to monitor progress.
- Explore the possibility of setting concrete, timebound targets towards elimination of fistula, including the costing needed to reach these targets.
- Strengthen availability and accessibility of high quality treatment services, including social support services and particularly focus on challenges in the areas of training providers and sustainability of treatment services
- Identify means to fill research gaps in areas such as incidence and prevalence, cultural perspectives, social dimensions, linkages with poverty and operations research

The meeting provided a valuable opportunity to bring all the African countries involved in the Campaign together to network, share information and arrive at consensus around the efforts of the Campaign. Thematic working groups for continuing this vital knowledge sharing and discussion will be created to keep all partners informed and to guide the Campaign as it grows.

Obstetric Fistula

Although it is one of the most severe pregnancy-related conditions, until recently, obstetric fistula remained unacknowledged at the international level. Because it affects women who are among the most marginalized in the world – poor, young, illiterate women in remote areas in developing countries, fistula has remained hidden, even from many health professionals in the countries where it occurs. Partners' combined efforts over the last few years have helped to bring the world's attention to this problem.

Obstetric fistula is a medical condition, but it is closely tied to social and economic factors in both its causes and consequences. Prolonged, obstructed labour without prompt and skilled medical care is the direct cause of most fistula. Its continued existence highlights the failures of health systems to provide high quality maternal health care, including skilled attendance and timely emergency obstetric care. It also reflects underlying socio-economic and gender-based inequities that hinder women from accessing services, even when they are available and of high quality. Moreover, a number of socio-economic factors are associated with fistula, including malnutrition, early marriage followed by early pregnancy, lack of opportunities for women and girls and certain harmful traditional practices. Fistula is also linked to the cycle of poverty, as it often affects the poorest women and increases the depth of their poverty, which prevents them from accessing treatment.

The medical consequences of fistula include permanent incontinence of urine and/or faeces, genital sores and ulcerations, frequent infection and in some cases infertility. It is increasingly recognized, however, that the social consequences of isolation, stigma and abandonment, are equally devastating for women. Social isolation is typically accompanied by a loss of financial support and often inability to work. Fistula, consequently, represents a social crisis not only for women, but also their families and the overall development of their communities.

Fortunately, the medical means to both prevent and treat fistula already exist. Prevention is the ultimate goal, through provision of quality and accessible maternal health care services, particularly emergency obstetric care. Until services are universally accessible, treatment will be needed for those women that experience a fistula. Treatment through surgery is successful in 80-90 percent of cases. This treatment can restore a life of dignity to most women. Yet, the longer struggle lies in addressing the underlying social and economic factors that perpetuate fistula. Empowering women and girls, enhancing their life opportunities and delaying marriage and childbirth will all contribute to reducing the incidence of fistula. Sensitising communities to understand the condition and take action is critical to ensuring that fistula is prevented and that women suffering from it receive the care they need. Considering all of these factors, it is clear that the elimination of fistula calls for a comprehensive response with a participatory approach involving stakeholders from multiple sectors.

The Campaign to End Fistula

In 2001, UNFPA, the International Federation of Gynaecologists and Obstetricians and Columbia University's Averting Maternal Death and Disability Program (AMDD) convened the first meeting of experts in London. The main purpose was to stimulate international action, raise awareness and reflect on strategies and actions to prevent and treat obstetric fistula, particularly in the Africa region. A second meeting was held in 2002, in Addis Ababa, where consensus was reached among stakeholders on a collaborative strategy to prevent and treat fistula in Sub-Saharan Africa. In response, UNFPA launched, in 2003, a global Campaign to End Fistula aimed at making fistula as rare in Africa and Asia as it is in the industrialised world today.

Campaign Structure and Strategic Intervention Points

The Campaign to End Fistula is structured in three programmatic phases: needs assessment, planning and implementation. **Phase 1** - Campaign countries first undergo a rapid needs assessment, to determine needs and map existing services, and findings are used to raise awareness among key stakeholders. **Phase II** - In response to the needs assessment outcomes, each country conducts, together with partners, a six-month planning stage. This phase includes raising awareness among relevant national stakeholders, developing national strategies and forming coalitions to address fistula, as well as building capacity through provision of equipment and training at some service sites. **Phase III** - The planning period is then followed by a comprehensive national action plan which includes advocacy to improve the political environment for addressing fistula; enhancement of accessibility, affordability and quality of health services for both prevention and treatment; community awareness raising on maternal health issues and harmful traditional practices that contribute to maternal mortality and morbidity; and coordination of services to help women with repaired fistulas reintegrate into their community.

The Campaign to End Fistula promotes an integrated approach, which situates fistula programmes within the broader framework of safe motherhood and reproductive health. The strategy reflects the reality that fistula cannot be treated as a stand-alone issue or a vertical programme, but must be a component of maternal and reproductive health policies, programmes and services. The strategic intervention points are: Prevention, Treatment and Reintegration.

Prevention

- Stimulate social and political mobilisation around women and girls' empowerment;
- Advocate for delay of marriage and childbirth;
- Increase access to and utilization of high quality maternal health services including, family planning, antenatal care, skilled birth attendance and emergency obstetric care
- Promote and ensure immediate management of fistula post-partum by catheterisation.

Treatment

- Increase access to and utilization of high quality fistula treatment services, including post-operative care.

Reintegration

- Ensure that treated women have opportunities for improved quality of life, through income generating activities and education;
- Sensitise communities to support women with fistula both before and after treatment;
- Ensure availability of psychosocial support services and

- Provide comprehensive post-treatment counselling on health, particularly reproductive health, future pregnancies, and family planning with provision of contraceptives.

Highlights of Campaign Progress in Africa

Eighteen countries have completed their needs assessments, six are underway, more than nine countries are at an advanced stage of the planning phase and three countries are currently implementing complete programmes. In addition to the 2003 nine-country needs assessments by EngenderHealth and UNFPA, a few countries such as Mali and Nigeria elected to conduct **in-depth assessments** to examine contributing socio-cultural factors and gain greater understanding of needs at the facility and community levels.

Many countries at the planning phase have developed or are nearing completion of **national strategies** to eliminate fistula. Niger and Uganda are notable examples of the importance of **coalition and network formation**, and have brought together major stakeholders to form a sustained platform of collaborative planning and programming.

Preliminary **facility upgrades** and equipment were provided to some countries to jump-start fistula programmes. The support to Point G Hospital in Mali and Monze Mission Hospital in Zambia significantly increased the facilities' capacity. With the newly renovated operating theatre, the Point G Hospital has increased the number of fistula repairs from four to 16 per week.

Long-term capacity building is critical to ensuring a meaningful and sustainable response to obstetric fistula. Chad, after completion of its needs assessment, was selected as a pilot country to implement a fistula program. Two surgeons were trained in fistula repair by a team from the Addis Ababa Fistula Hospital and were posted in the two main hospitals in the country, Liberty and Abeche. More than 250 women are treated on a yearly basis. Two additional centres have now also been established.

Partnership development is the cornerstone of the Campaign to End Fistula. At the **global level**, a diverse array of UN agencies and national and international NGOs have joined together to collaborate in the fight against fistula. At the **national and local levels**, similar strong and constructive partnerships of diverse groups have been established. The Malian partnership between UNFPA, the Government of Mali, Delta Survie, IAMANEH Suisse and Medecins du Monde is a notable example.

Advocacy and awareness raising are critical for sensitising communities, mobilizing social and political support and successful fundraising. Media advocacy proved particularly useful in Chad where programs were aired on national radio and TV to foster a political and social environment conducive to the prevention, treatment and management of fistula.

Lessons learned

• **Obstetric Fistula needs to be tackled in a comprehensive way, including prevention, treatment, and social reintegration.** The different dimensions of fistula management are intertwined and should therefore be tackled in a comprehensive and integrated manner. Prevention is key to the long-term management of fistula. Treatment needs to be supplemented with effective social support services. Fistula survivors need to be aware of the need for skilled birth attendance and should have access to a continuum of maternal health care services.

- **Partnerships and national networks or technical working groups are vital.** The momentum generated by fistula has triggered positive reactions from UN agencies, government institutions, NGOs, donors and medical personnel. Development of coalitions and working groups can help to avoid duplication of interventions, inefficient use of already scarce resources and can ensure a coordinated response.
- **Establish the roles and functions of all stakeholders from the beginning through a formal agreement.** Negotiations should be arranged between major partners to foster a common understanding and build a consensus on respective roles and responsibilities based on comparative advantages, culminating in a signed formal agreement.
- **Role of the Ministry of Health and other influential government institutions is critical in mobilizing political support.** At the national level, the Ministry of Health (MOH) and other influential government institutions play an instrumental role in garnering political and governmental support and commitment. To foster ownership from the outset of the programme, it is critical to involve the MOH in all stages of planning, from the needs assessment exercise to the development and implementation of programmes.
- **Advocacy and outreach can help to build awareness.** Recent studies suggest that fistula is known neither in the public sphere nor at the community level. The culture of silence and shame surrounding the condition further compounds the situation.
- **Treatment services should be available before public awareness activities are undertaken.** Once the word about the availability of treatment services is spread, patients tend to flock to the health facilities to seek treatment. This results in an increase in the demand for services, which is not always matched by existing capacity. Therefore, awareness raising activities should be reciprocated by effective capacity building in order to avoid creating unmet demand.
- **Foreign surgeons have played a key role in providing treatment services, but raise issues of sustainability.** The management of fistula requires a specialized expertise from both doctors and support staff. More often than not, the expertise is not readily available in Africa, and mechanisms have been put in place to bring foreign doctors to Africa for training and treatment purposes. While these exchanges are valuable, local and national capacity building will only be sustainable if there is a real transfer of knowledge and know-how.

Key recommendations

Recommendations from the meeting centred around six strategic areas described below. For each, it was concluded that more in-depth discussions should take place. Consequently, working groups will be formed to take further action in defining and sharing knowledge in these areas.

Integration and Partnerships

Partnerships (at global, regional and national levels) and integration of fistula into existing programmes and policies have been strongly emphasized from the beginning of the Campaign. Experiences from several countries have demonstrated that strong partnerships with a diverse and active membership can help to ensure a broad, comprehensive and unified strategy for fistula prevention and treatment. These experiences now need to be documented to share with countries still in the early stages of strategy development. Strategies also need to be developed to reach the long-term goal of integrating fistula into standard reproductive health services, particularly maternal health services. Interventions should build upon ongoing initiatives, such as safe motherhood and adolescent reproductive health, and avoid verticalisation of the issue. Integration of fistula into national policies, such as National Reproductive Health Plans, should be encouraged to support programmatic efforts. Furthermore, linkages between fistula elimination and poverty need to be better understood and interventions must be integrated into poverty reduction strategies. Relevant experiences and concrete, practical strategies for integration need to be documented and shared.

Key points:

- Integrate fistula into reproductive health and safe motherhood policies, services and programmes.
- Develop diverse, multi-sectoral partnerships at country, regional and global levels to ensure a comprehensive and coordinated response to fistula elimination.
- Document and share effective partnership and integration strategies.

Advocacy, BCC and Community Mobilisation

While great strides have been made, there is a continued need to spread messages regarding fistula prevention and treatment and to enlist the support of a variety of actors at global, national and community levels. Fistula provides an entry point for advocacy around the wider issues of universal access to reproductive health services, gender empowerment and poverty. Fistula survivors put a face to these issues and their personal stories can help increase understanding and mobilise support. Accordingly, advocacy for fistula prevention and treatment creates the opportunity to educate, inform and motivate policy makers, communities, and individuals around these issues. Preliminary experiences with national-level advocacy show that linking fistula to social and economic development provides effective messages for securing policy maker and donor support. In addition, mass media can serve as a tool for raising awareness at both the policy and community levels. Greater exploration of appropriate messages and channels for reaching and mobilising communities is needed, as it is clear that community members are vital partners in the fight against fistula.

Advocacy among the donor community will also help leverage resources to support prevention and treatment of fistula. Substantial gains have been made in fundraising, but there are still many countries in need of funds. External donors could be approached to fill the funding gap, however, national sources should also be considered to ensure sustainability and ownership of the initiatives.

Key points:

- Highlight the issue of fistula to effectively advocate and mobilize resources for universal access to reproductive health, gender empowerment and poverty reduction and promote awareness and behaviour change at community levels.

Planning, Monitoring and Evaluation

As the Campaign moves forward from its initial phase, it was agreed that a standard monitoring and evaluation framework, including concrete indicators, needs to be established to measure performance and outcomes. Standardization will ensure comparability both within and across countries and enable the measurement of progress. The indicators should include both impact indicators and process indicators to continually monitor progress. Given the difficulties of data collection, wherever possible indicators that are already part of routine data collection should be used. The framework for structuring the indicators was debated and two suggestions were presented. The first suggestion is to frame results by the strategic entry points (prevention, treatment, reintegration). The second is to centre data on the World Bank's Determinants of Health: Government Policies & Actions, Health Systems and Related Sectors, Households and Communities. The relative strengths and weaknesses of each should be further discussed. Preliminary discussion of indicators took place, but more time and in-depth discussion is required involving all major partners.

Setting of long-term timebound targets that reflect a comprehensive plan to achieving the goal of fistula elimination may also need to be considered. Clear targets with measurable indicators would provide a framework for benchmarking and evaluating progress. Specific targets can also help to mobilise both new and existing partners into action. They could be linked to important international targets, such as the 2015 targets for both the International Conference on Population and Development Programme of Action and the Millennium Development Goals. Costing of fistula elimination, at national, global and regional levels, would further support the achievement of these targets.

Key points:

- Through a participatory process, agree on a standard set of objectives and indicators to monitor progress of the Campaign.
- Explore the possibility of setting concrete, timebound targets towards elimination of fistula, including the costing needed to reach these targets.

Social Support

Strategies to prevent and treat fistula require more than medical interventions, as fistula represents both a social and medical crisis. Fistula's connections with poverty particularly need to be examined, as it often affects the poorest women, increases the depth of their poverty, and prevents them from reaching treatment. Mechanisms to provide social support for women with fistula and to involve communities are key to any strategy for fistula elimination. Community involvement can help to chip away at the social and gender-related factors that underlie fistula. In addition, mobilised communities can actively participate in the prevention of fistula and create a secure and supportive environment for women with fistula. Further, social support programmes to address the social and economic crises that fistula survivors experience are a vital supplement to medical treatment and will assist women to successfully return to their communities. These services might include psychosocial counselling, micro-enterprise loans or grants, income-generation skills training or literacy education. Comprehensive post-treatment counselling on health, particularly reproductive health, future pregnancies, and family planning with provision of contraceptives, can help to prevent the fistula from recurring. To date, little is known about

the difficulties women encounter when returning to their communities and innovative interventions to facilitate their rehabilitation need to be explored and should be guided by the needs identified by the women themselves.

Key points:

- Ensure that social support services are provided for women with fistula before, during and after treatment including psychosocial, social and economic components through interventions at individual and community levels.

Health system issues

There is strong consensus on the need to strengthen both prevention and treatment services, and address a variety of issues within the health system. These areas include: training for health personnel, standards for training and follow-up supervision, protocols for surgical/medical treatment techniques and post-operative care, data collection, logistics of providing prevention and treatment services, motivation and incentives for providers and commodity security for surgical supplies. Effective methods and interventions for treatment services have been demonstrated in certain contexts, however, new approaches and adaptations may be needed based on country specific situations. Training emerged as a distinct need, due to the high demand which does not match the limited supply of training centres and trainers. While training venues at country-level are under establishment, regional training centres at existing facilities with a strong treatment capability and a high caseload capacity can be created to help absorb the high demand for training. Mali, Nigeria and Benin were noted as facilities that can potentially serve as regional centres, if their capacity is enhanced.

Key points:

- Strengthen availability and accessibility of high quality prevention and treatment services and particularly focus on challenges in the areas of training providers and sustainability of treatment services

Research

Through the recent rapid needs assessments and further in-depth studies, knowledge of fistula has greatly expanded, but there remain many gaps that have not yet been filled. Numerous countries still need to undertake needs assessments in order to reach the goal of completing assessments in suspected high prevalence African countries by 2005. Broadening the perspective of the rapid studies with components to assess socio-cultural dimensions will also enrich the data that is available and ensure that the focus is not purely medical. The experiences of countries that have included this dimension can be shared to support future efforts. While needs assessments have provided a glimpse into the problem, there are still areas where relatively little is known. Data regarding prevalence and incidence remain scarce, and innovative ways to collect it need to be explored. This is particularly important for the long-term elimination of fistula and the setting of viable targets. Pre-existing routine surveys such as the Demographic and Health Surveys and maternal mortality audits may be an effective means of collecting the data. Countries should advocate for a question to be included or even investigate the possibilities of conducting a prevalence study. Also, further research around clinical procedures, social aspects and operational issues would greatly contribute to the prevention and treatment of fistula.

Key points:

- Identify means to fill research gaps in areas such as incidence and prevalence, cultural perspectives, social dimensions, linkages with poverty and operations research

Experiences in Fistula Elimination

A. Needs Assessments: Building the knowledge base

Burkina Faso

Presented by: Ms. Olga Sankara and Mr. Saidou Kabore, UNFPA Burkina Faso

In view of its high maternal mortality ratio and low utilization of health services, UNFPA and the Ministry of Health agreed to study the situation of obstetric fistula through a rapid needs assessment in January 2004. Thirteen health regions were covered by the assessment utilizing a pre-tested questionnaire. The assessment revealed that four facilities had some form of capacity to manage fistula, however, all were facing constraints to providing this care. The equipment in most cases was found to be old and services reliant upon expatriate surgeons – raising questions of sustainability. Success in repairing fistula remained fairly low at only 60 percent for the simplest cases. The Health Information System collects little if any data on fistula, making it difficult to estimate the prevalence. The typical profile of young, married women – often illiterate- remains true in Burkina Faso. It was further found that 75 percent of fistula sufferers experienced two or more days of labour and 25 percent delivered at home. Patients that made it to the facility reported waits as long as 60 months before receiving treatment, and record reviews revealed that some women arrived at facilities but never received the treatment.

The study accordingly recommended improved obstetric care; community involvement and participation in management of fistula; training of trainers in fistula management; integration of fistula management into pre-service curricula; free treatment of fistula; and enhanced advocacy campaigns on fistula.

Eritrea

Presented by: Dr. Charlotte Gardiner, UNFPA Eritrea

Eritrea's maternal health status also indicates that fistula may be a problem. There remain wide rural and urban disparities for maternal health care with only 10% of births in rural areas attended by a medically trained provider, compared to almost 90% in the capital. To better understand the situation and the perspective of fistula survivors, the needs assessment in Eritrea included guided focus group discussions in addition to a survey of the six zones by inviting the women to six sites/facilities. Prior to the assessment, a mass radio campaign was conducted to attract fistula survivors to participate, resulting in the participation of 82 women. As most rural women in Eritrea do not listen to radio, the study encountered some limitations in drawing participants.

The study revealed that 37.8 percent of fistula patients depend on their parents and close relatives for survival; 14.6 depend on beer selling and farming while 47 percent are housewives. Almost 60 percent developed the fistula with their first delivery and close to 90 percent of those experienced a stillbirth. Capacity to treat fistula was discovered to be almost non-existent with neither available facilities for fistula repair nor skilled health workers to provide services. Similarly at the community level, there was little to no awareness of the issue. Prospects for change are positive, and the Eritrean government is supportive of the initiative and communities seem willing to collaborate. The Ministry of Health is currently advocating for a stand-alone fistula centre which may be difficult to sustain in the long-term; thus until now, the sites for establishing treatment services have not yet been determined.

Mauritania

Presented by: Madame Ba Khady Sy, UNFPA Mauritania

In Mauritania, a large proportion of women still have limited access to emergency obstetric care services. For instance, only 35 percent of the need for EmOC is currently being met and the caesarean section rate of 0.53% remains well below the minimum acceptable level of 5 percent. For the needs assessment, the three regions with the highest suspected prevalence of obstetric fistula were selected – regions with poor EmOC access and high levels of poverty. Mauritania's assessment was comprised of three questionnaires for facilities, key informants and patients. The assessment revealed limited knowledge of fistula among health workers – only one out of four health workers knew about what it was. Two hospitals occasionally conduct fistula repairs although none of the obstetricians have had any formal training in the special techniques. Fistula patients often wait up to nine months before they are treated and after the operation spend only 48 hours in the hospital, well short of the recommended 10-14 days of post-operative care. In the process of conducting the assessment, a large backlog of fistula patients were identified and immediate support is needed to provide these women with treatment.

Recommendations from the study propose a three-pronged strategy emphasising both preventive and treatment measures, advocacy at community and national levels and reintegration programmes for treated survivors. Additionally, plans are in place to integrate all fistula-related interventions into ongoing emergency obstetric care programmes.

Ghana and Rwanda

Presented by: Ms. Mary Nell Wegner and Mr. Joseph Ruminjo, EngenderHealth

The needs assessments in Ghana and Rwanda were carried out by EngenderHealth, with support from AMDD, within the context of emergency obstetric care using primarily qualitative methods. The rapid studies included observations at public and private facilities; reviews of theatre logbooks; and provider, administrator, and client interviews utilising an 11-question survey.

Ghana

The assessment in Ghana revealed that there is limited knowledge of fistula in the population and delays in seeking care are common. It was suspected that the prevalence has decreased, but it was also noted that the condition is likely more widespread than acknowledged. Identified cultural barriers to fistula prevention included perceptions of fistula as punishment for infidelity, the need for women to seek permission to access care, and the continued use of traditional healers. In the six treatment facilities visited in Ghana, eight providers were performing repairs, while more surgeons were undergoing training. Good collaboration exists among various partners involved in fistula management including the Worldwide Fund for Fistula and the Archdiocese of the Cape Coast; and among these partners plans for development of a treatment centre are currently underway. Constraints to improving treatment include the limited number of providers interested in the issue, the lack of expertise among interested personnel, and the limited theatre space in facilities, as well as specific regional deficits in skilled personnel.

Rwanda

In Rwanda, years of conflict have had a severe impact on the health system resulting in only 14 obstetrician/gynaecologists for a population of 8.1 million and a maternal mortality ratio that is among the highest in the world at 1,071 per 100,000 live births. The needs assessment uncovered barriers to fistula prevention including cultural beliefs such as fear of being seen in labour and unaffordable costs of transport and care. Poor quality of maternity services also results in women's low return rates after initial ANC visits and a low desire to deliver in a facility. Furthermore, it was also revealed that many women are often unaware that they have a fistula. Only two Rwandan doctors are able to repair fistula although several rotating expatriates are available in the country.

The assessment recommends that fistula management be included in national Reproductive Health policies and standards. Country-specific systems for recognition, referral, and management of fistula must also be developed. To strengthen human resource capacity, recommendations include increasing training opportunities to improve basic quality of care and EmOC services and identification and further training of interested physicians and nurses in fistula management. At the community level, the report recommends community-based research to guide birth preparedness and fistula awareness-raising campaigns; and cautions that increased awareness must be matched with availability of services.

Kenya

Presented by: Ms. Judith Kunyiha-Karogo and Dr. Stephen Wanyee, UNFPA Kenya

Following the rapid assessment conducted by AMREF in 2002 and presented at the October 2002 meeting in Addis Ababa, it was decided that it was necessary to take a deeper look at the situation to identify gaps and capacities to guide the planning of a national strategy. Covering four districts with high levels of maternal mortality, the assessment entailed a community-level assessment of socio-cultural factors through interviews and focus-group discussions as well as surveys at relevant facilities. The assessment revealed that there are two specialised fistula centres as well as five outreach centres managed by AMREF. Treatment is subsidized (US\$65 as compared to US\$200) although still unaffordable for most, and the success rates are high. Currently, the two facilities have reached a capacity of 500 repairs each year, out of an estimated 3000 new cases annually. There are few trained specialists (less than 10), operational costs are high, and patients experience delays in accessing treatment services. Ongoing initiatives provide a strong environment for strengthening prevention, including the Safe Motherhood Initiative (SMI) and corresponding policies and community-level advocacy by NGOs such as SETAT. In addition, five regions benefit from surgical outreach visits financed by AMREF. Nonetheless, there are still prevention gaps such as the limited number of trained service providers, the high number of deliveries conducted at home or with a TBA and gaps in SMI coverage. The assessment summarized factors that contribute to the continued incidence of fistula, such as rugged physical and expansive landscape; harmful cultural practices (e.g. the first child must be born in the house of the father); and poverty, which forces women to seek a cure from traditional sources. Fortunately stigmatisation of women with fistula does not appear to be common, with the exception of one district.

The assessment recommends a series of short, medium and long-term interventions. In the short term, the focus for treatment is to scale-up capacity building initiatives; to increase access to treatment through subsidies and provision of supplies; while prevention efforts will emphasize life saving skills training, enhancement of supervision systems and behaviour change communication campaigns. The assessment further recommends in the medium to long term a focus on sustainability with policy interventions to integrate fistula management into safe motherhood initiatives, integration of fistula into training curricula, and enhancement of institutional preparedness through increases in staffing levels and use of the partograph. Finally, the assessment emphasised the need to enhance partnerships, including government and civil society.

B. Planning and partnership formation

Network formation in Niger

Presented by: Mr. Ali Djibo, Ministry of Public Health, Government of Niger, and Ms. Nathalie Maulet, UNFPA Niger

Within the Campaign to End Fistula and through a widely participatory process, UNFPA spearheaded the development of a broad-based coalition of key stakeholders, culminating in the formation of the Network for the Elimination of Fistula in Niger. The network has ensured the coordination of stakeholders' interactions, systematic sharing of information, joint planning and programming resulting in concerted actions towards the elimination of fistula.

The functioning of the Network has been successful due largely to clear definition of the group's role and specific objectives. The objectives are to:

- Ensure information sharing on issues related to obstetric fistula;
- Ensure complementarity of interventions through the development of an effective multi-sectoral collaboration;
- Advocate for the cause of fistula and the promotion of Emergency Obstetric Care services and
- Mobilise political and financial support for fistula and EmOC programs.

Several critical steps were identified in the process of network formation:

Lobbying: Intensive advocacy activities to mobilize support and sensitise potential partners was the first critical step that triggered positive reactions from major stakeholders.

Consensus building: Once partners had been identified and their commitment enlisted, a fistula workshop was organized to build national consensus on the framework of the network and its operating mechanisms. Network members agreed on a monitoring system and hold meetings on a regular basis to follow-up on network activities.

Official launch of the Network: The launch of the Network was sanctioned by an official constitutive act passed by the government. An office was set-up and the Network became fully operational with a long-term strategic plan.

Structure and organization of the Network: The Network has set up an office comprised of representatives of the Ministry of Health, Ministry of Social Development and national NGOs and associations. A permanent council is charged with the responsibility of overseeing the day-to-day management of Network activities. A plenary meeting is held on a quarterly basis to discuss strategic issues, planning, and monitoring and evaluation aspects of the Network. Technical working groups were established along thematic lines (Research, Communication and Training) and meet on an ad hoc basis. UNFPA and external partners provide technical assistance and financial support.

Partnership building in Uganda

Presented by: Ms. Aisha Camara, UNFPA Uganda

In Uganda, current data suggest that only thirty-eight percent of women have skilled attendance at birth and 70 percent of Ugandan mothers experience their first pregnancy by the age of 19. A rapid assessment was carried out in November 2002, as part of the UNFPA-EngenderHealth nine-country needs assessment on obstetric fistula, and was followed by an in-depth assessment.

The in-depth assessment and the ensuing national strategy were developed with the oversight and involvement of a National Technical Working Group composed of major stakeholders. The group is also charged with the responsibility of overseeing the implementation of the national strategy.

Partnership development in Uganda consisted of identifying key institutions and structures, developing and adopting appropriate strategies and systematizing partners' interactions to ensure a coordinated response. The partnership established in Uganda fostered joint planning and programming, a participatory approach through the involvement of key stakeholders and concerted action for the elimination of fistula nationwide.

Partner identification was a critical step in the development of a genuine and representative network of relevant institutions. A broad-based and diverse partnership was formed at the national level featuring government institutions, civil society organizations and the international community including donors. Uganda favoured a multi-sectoral approach to ensure a comprehensive and multi-dimensional response in tackling obstetric fistula. Stakeholders raised two fundamental questions – how can obstetric fistula be prevented and treated effectively and what are the most critical institutions to involve in this task?

The strategies adopted consist of integrating fistula into safe motherhood programmes, identifying potential hospitals to be strengthened and equipped and providing support to centres for the training of trainers, as part of a long-term capacity building strategy. The involvement of the First Lady in the official launch of the programme raised the profile of fistula as a national priority.

Lessons learned from Uganda can assist others in moving the process forward. First, existing opportunities to meet with partners, such as annual programme reviews, are important venues for initial sensitisation. A small, but diverse Technical Working Group that works closely together, has clearly defined terms of reference and meets regularly is an effective way to ensure a unified national strategy and collaborative implementation. Further, involving well-known figures, such as First Ladies, can be helpful for national advocacy and developing political will.

National strategy development in Nigeria

Presented by: Dr. Lucy Idoko, UNFPA Nigeria

According to the in-depth assessment conducted by the National VVF Foundation, in 2003, the fistula prevalence in Nigeria ranges from 800,000 to 1,000,000 cases with an incidence of 20,000 new cases each year. The condition predominates in the northern part of the country and is worsened by the prevailing culture of silence and influential socio-cultural factors that have a negative impact on women lives. As a result, most women with fistula are not aware that treatment is available and those who are, live in extreme poverty and cannot afford the costs of services. While 80 to 95% of fistula cases result from obstructed labour, it is estimated that 5% are due to “Gishiri cut” (a blind incision to the anterior vaginal wall that is performed for a variety of reasons including to widen the birth canal and relieve obstruction during labour).

Further to the groundbreaking needs assessment conducted in partnership with EngenderHealth and the subsequent in-depth assessment carried out by the National VVF Foundation, Nigeria worked with a diverse group of stakeholders to develop a comprehensive national strategy for the long-term elimination of obstetric fistula in the country. Through a participatory approach, the development of the National Strategy featured key institutions and stakeholders namely relevant

government ministries, the National Poverty Eradication Agency, development partners, relevant NGOs, professional associations, experts, research organizations, universities and teaching hospitals. The strategy adopted a multi-disciplinary and multi-sectoral approach and was the culmination of key stakeholders' consensus.

The estimated prevalence of obstetric fistula and its determinants were strong justifications for the development of a concerted national response to address the issue. The national strategy was developed in line with the National Reproductive Health policy and was inspired by health sector reform, which calls for comprehensive and strategic programming. The imperative of a coordinated national response, the need to move from policy to action and the federal government's commitment to fistula guided the national strategy development process.

The strategy consists of 6 major components:

Advocacy and resource mobilization: This dimension of the strategy focuses on increasing awareness of obstetric fistula among policy makers, and traditional and religious leaders while at the same time securing commitment and support of political leaders and decision makers at the highest level. It also aims at leveraging resources for prevention and treatment services and rehabilitation of fistula patients.

Social Mobilization and BCC: Developing and sustaining community dialogue and participation from civil society is the mainstay of social mobilization efforts in Nigeria. In addition, BCC activities will be developed and implemented with a focus on promoting positive attitudes around fistula in the general population and behaviours that reduce the incidence of fistula such as increasing girls education, delayed marriage and childbirth, promotion of universal access to EOC services, skilled attendance at birth and gender equality and empowerment of women.

Human resource development: The strategy also focuses on development of stable human capital by equipping health providers with the relevant skills and expertise to manage fistula and with social workers with the skills to assist patients in reintegration. At the institutional level, a decentralised management style along with the development of incentive schemes to motivate health workers involved in fistula repair will ensure an effective and sustained national response to the issue of obstetric fistula.

Infrastructure development: Three functional fistula training and research centres will be established and additional treatment facilities strengthened, namely specialised hospitals, general hospitals and district hospitals. Adequate medical supplies for treatment as well as basic and comprehensive emergency obstetric care were identified as critical components of long-term capacity building efforts.

Research: Activities will focus on community-based research to determine the magnitude and distribution of fistula cases and understand the socio-demographic profile of fistula patients and their rehabilitation needs. Operations research will also be conducted to improve performance of the health system and optimise programme implementation approaches.

Coordination and Management: Given the multi-sectoral involvement, there is a need to determine roles and responsibilities of each sector based upon each partner's comparative advantage. Also, a monitoring and evaluation plan is key to effective management and would ensure that the implementation stays on course.

Key also to the strategy was the setting of concrete and time-bound objectives. Over a period of 5 years (2005-2010), the strategy aims to:

- Reduce the incidence of fistula by 80%;
- Clear 80% of the backlog of fistula patients;
- Increase access to fistula treatment services by 300% from current levels;
- Ensure the rehabilitation and reintegration of 90% of repaired clients into their communities;
- Mobilise and consistently make available at least 80% of resources required for Obstetric Fistula interventions in the country;
- Increase the proportion of skilled health personnel actively involved in the management and rehabilitation of fistula clients by 200%;
- Reduce behaviours that increase the risk of Obstetric Fistula by 50% and
- Conduct operational national research on fistula and use it to influence policies and programmes.

Taking Action on Fistula in the context of poverty, gender and rights in Tanzania
Presented by: Ms. Dorothy Temu-Usiri, UNFPA Tanzania

The dangerous nexus between fistula and poverty is an important focus of efforts in Tanzania. At the primary education level, only 6% make it to secondary school. The maternal mortality ratio is high (529/100,000) and is compounded by decreasing skilled attendance at birth. The legal age at marriage is estimated at 14 years and the country, despite its economic performance, is aware of growing inequalities at the social level. Despite initiatives taken to reform the health sector, the health system suffers from serious deficiencies and a lack of funds.

From 2000 to 2001, the Women's Dignity Project (WDP), UNFPA and the Ministry of Health in Tanzania joined together to conduct a fistula survey to map existing services and determine needs. The study found that six major centres were providing repairs on the perimeters of the country through both local and visiting surgeons. Cost and distance formed major impediments to accessing this treatment, as well as the low levels of public information on the services. The Women's Dignity Project is championing the fight against fistula in the country using the findings from this survey and others. WDP interventions are focused on the following critical areas:

- Capacity building of doctors/facilities to provide care;
- Establishment of a national referral system for fistula;
- Broad dissemination of information on fistula;
- Development of strong alliances with the MOH, media, health professionals and NGOs;
- Linking fistula directly to poverty reduction strategies and resource allocation and
- Research studies to reflect the voices of poor women.

The WDP commissioned a study and a literature review on poor women and health services in Tanzania. The findings are influencing policy dialogue and resource allocation in relation to basic services for the poor. According to poor women, the most critical areas with regard to health services are access, cost and affordability, quality of care and governance and accountability.

Access to health services: EmOC services are severely lacking in remote areas, which prevents patients from accessing services. Limited transportation options also affect access to treatment, with girls and women travelling up to 1000 km to reach a treatment facility. The prohibitive cost of transport and prevailing socio-cultural norms further impede access to services.

Governance and accountability: A good governance system is critical to the sound management of the health sector. In Tanzania, community involvement in the planning and financial management of health services is extremely limited. There are neither reliable mechanisms to enable poor women to voice their concerns nor proper management information systems to ensure appropriate collection and utilization of user fees. It is also difficult to financially monitor the health sector, due to limited access to information on budgets and public expenditures.

Cost and affordability: Women often cannot reach services due to costs. Specifically, the study found that poor women are often discriminated against because they cannot pay. According to policy, maternal and child health care should be free, but this is not practiced and poor women are usually unaware of their entitlements. Consequently, women cope by selling critical assets, borrowing money, taking children out of school and even cutting back on food.

Quality of care: Poor quality of services further prevents women from accessing care. Women may reach the facility to find services unavailable due to a lack of basic equipment and supplies, drugs and human resources. In addition, poor people are frequently overlooked or treated last. Weaknesses due to corruption and bribery and the lack of cooperation between public and private sectors were also identified.

C. Providing Fistula Treatment Services

Babbar Ruga Fistula Hospital, Nigeria

Presented by: Dr. Kees Waaldijk, Babbar Ruga Fistula Hospital

The Babbar Ruga Fistula Hospital is one of the largest centres in the world providing fistula treatment services and training in fistula management. Dr. Kees Waldjik, the main fistula surgeon, runs the hospital and has developed a series of techniques for fistula training and repair.

Treatment

The treatment at the Babbar Ruga hospital begins with insertion of a catheter as soon as the patient experiences urine incontinence, and remains for four to six weeks combined with a high oral fluid intake. The hospital has experienced a “spontaneous” cure in 20% of the patients using this method. A range of providers involved in obstetric care, such as midwives, nurses, and doctors, can provide catheter management care in a variety of settings, including homes, primary care centres and hospitals.

If the fistula does not heal through catheter management, the hospital recommends repair through vaginal operation with two possible approaches depending upon available expertise. Where expertise in fistula surgery is lacking, the standard management procedure of waiting three months would be applied. However, if expertise in fistula surgery is available, an early repair could be performed as soon as the wound edges are clean. The hospital has estimated the early repair closure rate of 90-95%, a higher rate than that for delayed repairs. For both approaches, patients would receive two weeks of post-operative care, supplemented by counselling services

to prevent recurrence. To ensure proper healing it is also recommended that women abstain from sexual activity for at least three to four months.

Fistula Centres

To ensure smooth functioning, the hospital recommends a separate unit including a hostel, a separate ward, an operating theatre and dedicated staff specifically assigned to fistula treatment services. In some cases, the fistula unit could be integrated within a hospital and then one fixed day a week devoted to fistula surgery. However, if the number of operations performed annually exceeds 150-200 surgical interventions then a separate centre is recommended.

Training

For training of fistula surgeons, the hospital requires each doctor to perform a minimum of ten repairs and have a minimum of three years of surgical experience. To become a fistula trainer, a surgeon must have performed a minimum of three hundred repairs. Training of nurses is critical for pre and post-operative care. To ensure high quality, the hospital trains small groups of 5-10 nurses at a time.

Addis Ababa Fistula Hospital, Ethiopia

Presented by: Ms. Ruth Kennedy, Addis Ababa Fistula Hospital

One of the only specialized fistula hospitals in Africa, the Addis Ababa Fistula Hospital (AAFH) began operations in 1974. The overall goal of the hospital is to provide services for those suffering from childbirth and related injuries and ensure the successful reintegration of ex-patients into their communities with dignity and a sense of self worth. As regards treatment services, the hospital is involved in the following:

- Provision of physical social and psychological assistance to fistula patients;
- Capacity building of healthcare professionals both in-country and out of country;
- Provision of pre-natal shelter for high risk women and post-operative care to repaired mothers and
- Awareness raising on the dangers associated with unsupervised pregnancy and labour.

The AAFH performs an average of 1,200 repairs a year. In addition it is a major training centre, providing fistula treatment training to 12 Ethiopian and 12 non-national surgeons each year and continuously to former patients to work as nursing aides. Despite the high caseload, there are still many women that are unable to reach the centre. In response, AAFH will establish satellite centres at five regional hospitals with thirty bed wards and an annexed operating theatre. Each of the five centres will have a coordinator and a midwife who will monitor the activities of these outreach centres. AAFH will also use the satellite centres as a base to inform remote communities about fistula prevention and treatment.

Despite its outstanding performance, the AAFH is faced with logistical constraints such as shortage of beds, which hampers its normal operation. Coping mechanisms are in place to mitigate the problem and patients are compelled to share beds when admitted to the hospital. Possible solutions are being sought and patients are now being sent to Desta Mender as an alternative to the increasing demand for treatment services.

Point G Hospital, Mali

Presented by: Dr. Kalilou Ouattara, Urology Service, Point G Hospital

The health system in Mali is structured in three levels. The first layer consists of centres at the community level (Centre de Santé Communautaire), which provide basic treatment services. The

second level of the health system is composed of referral centres and regional hospitals at the district and regional levels. The higher level of the pyramid is comprised of national hospitals, which can perform complicated surgical interventions.

The Point G hospital, part of the upper tier of the health system, started providing fistula treatment services in 1906. A national doctor who is an expert in fistula surgery, Professor Kalilou Ouattara, currently runs the fistula treatment services. The fistula unit at the Point G hospital has four surgeons specialized in fistula repair and a reasonable number of nurses and qualified paramedical staff, allowing each surgeon to perform five repairs a day. Equipped with 40 beds, the fistula ward (“Centre Oasis”) is in excellent condition. It serves as a pre and post-operative care unit as well as a rehabilitation centre for the promotion of income-generating activities. Consultations are underway between the relevant technical ministries on the possibility of building a new facility to increase the capacity of the centre. The new operating theatre (specifically dedicated to fistula repair), renovated and equipped by UNFPA, has a brand new operating table, an autoclave and the requisite surgical kits.

The upgrading of the Point G Hospital had a far-reaching impact on the hospital’s performance, which saw its capacity increase from four to 16 repairs a week. Prior to UNFPA assistance, the facility devoted one day of the week to fistula repairs. In view of the hospital’s performance, the Point G has been identified as a potential site for a regional training, research and treatment centre for the Africa region.

Monze Mission Hospital, Zambia

Presented by: Dr. Sarai Malumo, UNFPA Zambia

The Monze Mission Hospital is the largest provider of fistula services in Zambia. It is equipped with 250 beds, one surgeon, five medical doctors, five clinical officers and one obstetrician/gynaecologist. This Catholic Mission hospital serves also as a referral unit for obstetric and gynaecological services.

Within the context of UNFPA's efforts in the Campaign to End Fistula, support was provided to Monze Mission hospital in the form of supplies and equipment, which strengthened its capacity to provide treatment services and improved the work environment. As a result of this support, the demand for services increased. The hospital also became committed to increasing its fistula caseload. The hospital was a good candidate for this support due to its comfortable layout for patients, caring and committed staff, and awareness of their services at the community level.

A key lesson learned was that a small amount of support could greatly improve conditions at existing service sites. Some identified constraining factors however, will have long-term implications for future progress. Notable among them is the fact that the hospital is not centrally located. The situation is compounded by the lack of qualified local surgeons and necessary equipment and the long waiting period for accessing treatment services. Furthermore, hidden costs to facilities such as transport, provision of supplies for washing and personal hygiene, and nutritional support were identified.

D. Social Support and Community Involvement

Experiences of FORWARD in Nigeria

Presented by: Dr. Rahmat Mohammed, FORWARD

FORWARD (Foundation for Women's Health, Research and Development) has been active in the field of fistula since 1984. In 1999, it began a project in Northern Nigeria with the goal of "raising the level of women's health, education and economic and nutritional status as a necessary foundation for their active participation in the sustainable development process." The project's objectives are:

- To strengthen existing community-based health services;
- To provide rehabilitative care for fistula survivors;
- To improve the socio-economic status of women through strengthening of adult literacy programmes and vocational training and
- To increase community awareness on reproductive health and rights issues.

While all of these components can contribute to fistula elimination, the second, specifically focused on obstetric fistula, aims to provide surgical repair and aftercare for women. After receiving treatment, women are housed at the rehabilitation centre for nine to 12 months where they are provided with education, income-generating activities and psychosocial support. The women also participate in daily activities such as food preparation and vegetable cultivation. Following their stay at the centre, clients are given a loan of materials for income-generation that is paid back in instalments at zero percent interest. The project also follows up with women in their villages to document their situation and provide any necessary support. Clients continue to be active in the project's activities by sharing their experiences with other women and conducting outreach programmes.

Despite positive initial outcomes, inaccessibility remains a major challenge, due to washing out of roads during the rainy season, unreliable and infrequent public transport in some communities, and long distances to health facilities for maternal health services (up to 50 km). Lessons learned from these initial experiences show that efforts should continue to address obstetric fistula with a holistic approach, recognising the underlying factors such as lack of education for girls, early marriage and maternity and ensuring the integration of health and development.

Delta Survie's experience in Mali

Presented by: Mr. Ibrahima Sankaré, Delta Survie

Delta Survie, an NGO working in the region of Mopti, focuses on the social and economic rehabilitation of women who have received fistula treatment. In the region, stigma and misperceptions surround the condition. The consequences of these societal misperceptions include marginalisation, religious exclusion from prayer, reduced access to financial resources, and psychological trauma. To tackle these problems, Delta Survie with partners has embarked on a project of social and economic rehabilitation for treated women. The strategy is to provide treated women with training in textile production, and then offer the opportunity to work at an artisan textile workshop. The sale of the textiles is expected to eventually make the endeavour financially self-sufficient. Simultaneously the project is sensitising women with fistula and their families on fistula prevention and treatment. To date, 75 women have been trained at the workshop and almost 200 sensitisation events have been held. Delta Survie has found that the workshop provides a real opportunity for women to find dignity in their lives, to earn an income and be independent.

Some challenges have been encountered in implementing the project. The current structure is best suited for women whose stay at the hospital is three months or more, as high turnover makes it difficult to create ownership and maintain skills. Bringing women together in one location poses the risk of ghettoization of the area, which may have particular impact on women that remain at the centre for long periods of time. A proper evaluation of the project's impact would be difficult as there is no current follow-up component for when women return home. Sustainability, particularly financial, is also an issue compounded by the difficulty of finding a market for the centre's products.

The Case of Setat in Kenya

Presented by: Ms. Lilian JC Plapin, SETAT

Setat was started in 1998 by seven women in Pokot that were disturbed by the suffering of girls with FGM, particularly at the moment of childbirth. It began as a self-help group that centred on a revolving fund used for empowerment activities and sensitisation about FGM. As a result of their work around FGM, the patriarchal system's detrimental effects on women were exposed – including social, economic and health issues. The organisation then committed itself to integrating health activities into their mandate, particularly to offering services to women with obstetric fistula. With funding from the Sentinelles Foundation, Setat has identified 130 cases of vesico-vaginal and recto-vaginal fistula and 109 have been operated successfully, with four additional women having undergone several operations without success. The organization does close monitoring and follow-up to ensure that the women and girls have fully recovered and are able to join the social mainstream.

The organization also undertakes activities that can contribute to preventing fistula. SETAT has 'rescued' 130 girls by helping them to return to school. Their parents are also counselled to accept and share the costs of their education. During holidays girls are trained in income-generating skills. Also, Setat is working with 27 youth groups on social and economic empowerment issues. Constraints encountered include the harsh terrain, the just concluded elections, cultural practices, community attitudes and the lack of funds to do aggressive advocacy.

Experiences of DIMOL in Niger

Presented by: Ms. Salamatou Traore, DIMOL

In Niger, many women with fistula, even those successfully treated, have opted to reside near health facilities due to the exclusion from their communities. To provide women with the ability to start a new life, the NGO Dimol began to work on social and economic rehabilitation for women with fistula. Dimol first researched the situation to determine who the women were, why they are excluded and by whom, and what they need to reintegrate into their community. Using these findings, a project was developed that included counselling for women, training in income-generating activities and the provision of transport and start-up funds. Initial results from the project were disappointing, with nine out of 21 women that went through the programme reappearing at the hospital in Niamey.

In response to these findings, Dimol added a component to the project, whereby a team composed of an attending practitioner, a social worker and a representative from Dimol accompanies the treated woman to her village. During the visit, the team conducts the following:

- Meetings between local and medical authorities, including the community health nurse;

- Public meetings to discuss topics such as: early marriage, importance of antenatal consultations and assisted childbirth, girls' education, post-operative care, STIs and HIV/AIDS and the causes and consequences of obstetric fistula and
- Discussions with the family, including the husband and in-laws on fistula, and particularly an explanation of instructions for post-operative care.

During the mission, the team also works with the woman and her family to plan for a six-month return visit for a medical examination and to provide contraception. Dimol may also conduct follow-up missions to the village.

Some constraints have hindered the process, such as road impassability, women becoming pregnant again too early, and false information. However, overall, results have been positive. To date, none of the 59 women that benefited from accompanied reintegration have returned to the facility in Niamey. In addition, the project has the added benefit of strong community involvement and participation.

E. Advocating for the Prevention and Treatment of Fistula

Media Strategies in Chad

Presented by: Dr. Sephora Kono, UNFPA Chad

As part of its comprehensive national strategy, Chad has conducted awareness raising activities involving several types of media. The large rural population (80 percent), the low rate of girls' education and correspondingly high rates of illiteracy were taken into account when designing the intervention. Based on these factors, radio, which is popular in rural communities, supplemented by television, was chosen to spread public awareness messages. The strategy also called for working closely with print media. Activities included working with journalists to ensure media coverage of fistula prevention and treatment activities, production and broadcast of radio and television shows, placement of the topic on existing national radio series, televised debates on the issue and production of a video to support IEC activities.

Overall, these actions contributed to greater awareness and knowledge of fistula at several levels of society. Particularly, there was increased understanding that women with fistula are not to blame for their condition. Subsequently, demand for treatment services increased - 228 cases of fistula were treated in two years – and demand is constantly on the rise. The messages also attracted civil society partners, such as faith-based organizations.

Radio was found to be an especially effective tool for reaching the population, and rural radio stations were able to reach some of the most remote regions. Testimonials and personal messages strengthened the impact of the messages. It was acknowledged that while media is an effective tool for breaking the silence and dispelling misperceptions, it is crucial to ensure that services are available first to prevent false hope for a cure among women with fistula. Among decision-makers, television appeared to be a more effective method for advocacy. While journalists assisted in the process, prior training in population and reproductive health issues would have improved the accuracy and clarity of the coverage.

The high costs were highlighted as one constraining factor. Television shows were expensive and reached very few viewers. In addition, radio costs were higher than expected due to the weak power of the national radio signal and subsequent need to use the four regional radio stations. However, the switch to rural radio may have created more favourable conditions for

accessing remote villages, due to the far reach of its teams. It also allowed for involvement of local authorities at the production stage. Despite the high cost of television broadcasts, it may have long-term financial benefit due to its impact on policy-makers.

Experiences of Political Advocacy in Benin

Presented by: Dr. Edwige Adekambi, UNFPA Benin

In order to gain widespread political and financial support in the fight against fistula, Benin advocated with government and partners using the RAPID (Resources for Analysis of Population and its Impact on Development) advocacy method, which highlighted the linkages between development and fistula prevention and treatment. The rapid needs assessment conducted by EngenderHealth/UNFPA in 2002 and the outcomes from the Addis Ababa Meeting in 2002 provided vital information to guide the process and to demonstrate the impact of obstetric fistula on economic and social development in Benin. Once these arguments were developed and stakeholders identified, meetings were held to disseminate the results. Individual formal and informal meetings complemented these broader dissemination meetings.

The key element to this strategy was the development of messages showing the linkages, both cause and effect, between the national social and economic context and maternal mortality and morbidity. Fistula survivors' exclusion from society was stressed as well, focusing on their inability to participate in economic development. In addition, it was important to identify existing capacities and recommend concrete interventions for the prevention and treatment of obstetric fistula, with a special emphasis on prevention.

As a result, a diverse group of stakeholders agreed that in the short-term the issue needed further investigation to identify and implement suitable strategies. This agreement resulted in the completion of an in-depth study, greater awareness of the issue, and formation of a diverse partnership. Furthermore, fistula is now integrated in the National Reproductive Health Plan and partners are working together on a unified national strategy. To move the process forward, next steps include involving community leaders, ensuring implementation of existing laws, and continuing to mobilize resources. Through the process, alliances and partnerships emerged as vital and should be strongly encouraged. Data collected through studies was crucial for preparing arguments and ensuring credibility of proposals, and has important implications for results-based management.

F. Moving towards Elimination by Improving Maternal Health

The Case of South Africa

Presented by: Mr. George Nsiah and Dr. Lillian Marutle, UNFPA South Africa

Fistula is no longer considered a major public health problem in South Africa, largely because health services, and especially emergency obstetric care services, are widely available. Twenty years ago South Africa experienced poor delivery outcomes due to improperly trained and unskilled personnel. One of these poor outcomes was obstetric fistula. Inequalities due to gender and poverty, and health care access were barriers to change. Discriminatory laws further institutionalised some of these inequalities and disparities.

Opportunities for change then arose due to a new, more favourable policy environment, including the government's recognition of the need to provide essential obstetric care to prevent maternal death and disability. The government took a positive, proactive approach by training primary and community health care nurses, instating a maximum ten-minute ambulance response

time, providing free services for pregnant women and children less than five years old, and prioritising health by allocating sufficient resources. These policy changes were supported by a high level of community awareness and responsiveness.

Despite significant advances in reproductive health care, however, some challenges remain, namely: inequities in resource distribution; inability to pay for services compounded by poverty among indigenous populations; low level of male involvement; and lack of data at the national level. Further, the HIV/AIDS epidemic continues to have an impact on overall progress in the health sector.

Notably, the actions taken in South Africa have included the integration of obstetric fistula treatment within the reproductive health system (e.g. in training); continuous improvements to the health care system and local-level monitoring; as well as ensuring local and community involvement. The successes achieved so far provide confirmation that maternal death and disability, including fistula, can be significantly reduced with a comprehensive response at all levels that works to ensure accessibility for all.

Working Group Highlights

Costing

The group's discussions were based around the draft of a resource requirement guide for obstetric fistula that is currently being developed. The document outlines what resources are required to tackle the problem of obstetric fistula in a country. It describes the human and material resources required to carry out a needs assessment in a country, train medical staff, furnish a clinic to carry out fistula repairs, etc. The resource requirement guide is accompanied by a costing tool which attaches a price tag to the identified resources.

Among the groups recommendations:

- The guide should clearly distinguish between one-time, investment costs and recurrent/operating costs
- It should include information on the resource requirements for advocacy, sensitisation and IEC/BCC
- Recurrent costs should include facility operating/maintenance costs
- Training should include follow-up and supervision
- Eventually, the guide should also spell out the resource requirements for fistula prevention (strengthening of emergency obstetric care, etc.)

Discussion: It was strongly recommended to include monitoring and evaluation as well as data collection in a country's fistula program (and in the resource requirement guide). It was emphasized that deeper discussion and reflection will be needed to integrate the cost of fistula programs into national budgets. Only by integrating fistula program costs into national budgets will it be possible to ensure sustainability of actions and to avoid the problem of donor fatigue. An appeal was made to any program that has cost data to provide these to UNFPA HQ so that the resource and costing guide can be improved.

Indicators for Obstetric Fistula

The group agreed that a standard set of indicators is needed to ensure comparability of impact across countries. The identification of indicators was based on the four different strategic components of fistula management: early prevention, immediate prevention, treatment, and reintegration. A variety of indicators were suggested including the following:

- Early Prevention: legal age at marriage, age at first childbirth;
- Immediate prevention: indicators of skilled birth attendance, rate of caesarean section, and the process indicators for EmOC;
- Treatment: indicators regarding the availability of skilled providers, proportion of women receiving treatment, rate of success in repair and
- Reintegration: availability of reintegration services at treatment facilities, proportion of treated women that are integrated into their community.

Ultimately, the group recommended further discussion of the issue, beginning with consensus on results before defining indicators.

Discussion: During discussion, the participants recommended the following:

- Indicators must account for access, availability and utilization as well as of quality.
- There is a need to define both impact indicators (e.g. number of registered fistula cases) and process indicators (e.g. new cases received and treated).
- Indicators should be tied to indicators regarding coverage of basic comprehensive EmOC.
- The World Bank Determinants of Health Framework might be more conducive to integrating fistula.

Training and Treatment

This group focused on the major health service needs and the structure for ensuring sufficient training and supervision in fistula prevention and treatment.

The group identified several steps for training of providers in the treatment of obstetric fistula:

- Establish a committed team;
- Ensure an enabling environment for the repair of obstetric fistula, including the availability of:
 1. Patients in sufficient numbers for hands-on training;
 2. Equipment, supplies and medicines;
 3. Committed and qualified human resources;
 4. Resources to assist in subsidizing the costs for the patients and
 5. Space for providing services [mobile teams are limited in their ability to train].
 - Organize training of trainers
 - Ensure the necessary supervision of trainees

It was strongly recommended that governments be enlisted to support the organization of training in order to ensure sustainability. Advocacy to engage government partners and ensure their active participation may be necessary.

Discussion: In the plenary, several points were raised to expound on the discussions of the working group.

- Training must be considered at three strategic points: 1) prevention to ensure that costs of treatment do not increase and to improve accessibility, 2) treatment 3) coordination and follow-up to ensure that the non-clinical aspects are taken into account and that training in counselling at all of these levels is included.
- All medical personnel, not only surgeons, must also be considered for the trainings.
- Many were interested in defining the minimum and maximum durations for training, the requirements for trainers, and the specifications for each type, which will be standardized through the upcoming manual under development at WHO.

Social Support

The group focused its strategies on individual and community directed efforts, and divided implementation to meet needs prior, during and after treatment.

Before treatment: Strategies should involve identifying and recruiting patients through sensitisation activities at community level, using all potential channels of communication (e.g. radio, peer educators, treated women with fistula, community participation efforts, drama, etc.) being sure to use messages centred on the cultural, traditional and community values. It is also vital to direct advocacy efforts at the community leaders and existing community-based groups. Services can also be directed towards recruited women at this time including housing, food assistance, psychological care, social protection and counselling to inform women about the treatment they are about to undergo and what will follow the treatment.

During treatment: Women should receive psychological care and support during this time to strengthen their self-confidence.

After treatment: A set of activities can be developed to strengthen women's capacities and competencies, taking into account the specific characteristics of women, including age, socio-economic status, literacy, marital status. Income generation activities, including skills training, that are appropriate in the context of the community, can assist women particularly to improve their revenue and facilitate their assimilation back into the community. It is also vital to sensitise and mobilise the community to accept treated women, ensuring the involvement of men, young people and women's groups.

Discussion: It was particularly noted that the community-level should be focused on increased utilisation of reproductive health services to prevent fistula while also incorporating specific messages regarding fistula. The entire community should be targeted, rather than special groups. Specific attention should be paid to not creating demands that cannot be satisfied.

Community-level Advocacy

Advocacy at the community level was closely tied to social support. The group focused on outlining the following steps for sustainable, appropriate community-level advocacy:

- Advocacy should focus on prevention, and be continuous;
- Community members should be involved from the beginning in order to develop specific, targeted messages for different audiences that take into account the cultural context;
- Using these messages, appropriate and sustainable advocacy interventions should include community members at key points in implementation;
- Develop a monitoring and evaluation plan to determine the impact of the strategies and messages.
- There is a strong need to develop advocacy activities surrounding the treatment and the social reintegration of women – areas that still need further development.



Annex: AGENDA

Day 1 - Tuesday, 29 June

Opening Session

Chair: Mr. Moses Mukasa, Representative, UNFPA Ghana

09:25-09:30	Opening Remarks	Mr. Moses Mukasa, Representative, UNFPA Ghana
09:30-09:45	Welcome Address	Ms. Fama Ba, Director, Africa Division, UNFPA
09:45-09:50	Meeting Objectives	Dr. France Donnay, Chief, RH Branch, Technical Support Division, UNFPA
09:50-10:05	Statement from Government of Ghana	Mr. Moses Dani-Baah, Deputy Minister of Health, Government of Ghana
10:05-10:15	Closing remarks by the chair	Mr. Moses Mukasa

Session 1: The Campaign to End Fistula

Chair: Fama Ba, Director, Africa Division, UNFPA

Rapporteur: Ms. Dorothy Temu-Usiri, UNFPA Tanzania

11:00-11:30	Global Campaign to End Fistula: Overview and Linkages to RH	Ms. Kate Ramsey, Technical Support Division, UNFPA
11:30-12:00	Africa Regional Strategy Against Fistula and Update and Africa Campaign	Mr. Yahya Kane, Africa Division, UNFPA

Session 2: Country Updates

Chair: Mr. Uche Azie, Director, UNFPA CST Harare

Rapporteurs: Mr. Nestor Owomuhangi, UNFPA Uganda and Dr. Dian Sidibé, MOH Mali

14:00-14:30	Findings from Recent Needs Assessments: Obstetric Fistula in Burkina Faso: Scope of the problem and capacity of health facilities to manage fistula Fistula Needs Assessment in Eritrea Situation Analysis in Mauritania	Ms. Olga Sankara and Mr. Saidou Kabore, UNFPA Burkina Faso Dr. Charlotte Gardiner, UNFPA Eritrea Ms. Ba Khady Sy, UNFPA Mauritania
14:30-14:50	Ghana and Rwanda Needs Assessment findings	Ms. Mary Nell Wegner and Dr. Joseph Ruminjo, EngenderHealth
14:50-15:10	Management of Obstetric Fistula in Kenya: Strengths, Weaknesses and Proposed Interventions	Dr. Stephen Wanyee and Ms. Judith Kunyiha-Karogo, UNFPA Kenya
16:00-16:20	Network for the Eradication of Fistula in Niger	Mr. Ali Djibo, Ministry of Public Health, Government of Niger and Ms. Nathalie Maulet, UNFPA Niger
16:20-16:40	Processes of Partnership Building: The Uganda Experience	Ms. Aisha Camara, UNFPA Uganda
16:40-17:00	Strategic Framework for the Prevention of Obstetric Fistula in Nigeria	Dr. Lucy Idoko, UNFPA Nigeria

Day 2 - Wednesday, 30 June

Session 3: Country Updates

Chair: Mr. Essan Niangoran, Representative, UNFPA Nigeria

Rapporteurs: Dr. Fatma Mrisho, UNFPA CST Addis Ababa and Ms. Karoline Fonck, UNFPA CST Dakar

09:00-09:20	Training and treatment services	Dr. Kees Waaldijk, Babbar Ruga Fistula Hospital
09:20-09:40	Addis Ababa Fistula Hospital Activities	Ms. Ruth Kennedy, Addis Ababa Fistula Hospital
09:40-10:00	The Issue of Fistula in Mali	Dr. Kalilou Outtara, Point G Hospital
10:00-10:10	Clinical perspective of Fistula	Dr. John Kelly
10:10-10:30	Taking Action on Fistula in the context of poverty and women's rights: The Case of Tanzania	Ms. Dorothy Temu-Usuri, UNFPA Tanzania
11:00-11:20	Social Support Programmes	Dr. Rahmat Mohammed, FORWARD
11:20-11:40	Media Strategies for Raising Awareness of Obstetric Fistula: The Case of Chad	Dr. Sephora Kono, UNFPA Chad
11:40-12:00	Political Advocacy for the Prevention and Treatment of Obstetric Fistula: The Experience of Benin	Dr. Edwige Adekambi, UNFPA Benin
12:00-12:20	Moving towards elimination in South Africa	Mr. George Nsiah and Dr. Lillian Marutle, UNFPA South Africa
10:40-10:50	Implementing the Global Programme in Zambia	Dr. Sarai Malumo, UNFPA Zambia

Session 4: Technical Breakout Sessions

Rapporteur: Dr. Edwige Adekambi, UNFPA Benin

14:00-16:00	Simultaneous working groups:	
	Indicators for Obstetric Fistula	Ms. Kate Ramsey, UNFPA NY
	Social Support Services for Fistula Survivors	Dr. Rahmat Mohammed, FORWARD – Nigeria and Mr. Ibrahim Sankare, Delta Survie – Mali
	Community Advocacy Against Fistula	Mrs. Salamatou Traore, Dimol – Niger and Mrs. Lillian Plapin, SETAT – Kenya
	Costing for Fistula Management	Ms. Eva Weissman, UNFPA NY
16:30-17:30	Reports from group sessions	

Summary / Closing Session

Chair: Mr. Moses Mukasa, Representative, UNFPA Ghana

18:30-18:35	Recommendations	Dr. France Donnay
18:50-19:00	Closing Remarks and Vote of Thanks	Mr. Moses Mukasa

Day 3 – Internal UNFPA meeting