

# OBSTETRIC FISTULA AS A CATALYST:

• Partnerships • Strategies • Emergency Obstetric Care • Support Services

**EXPLORING APPROACHES FOR SAFE MOTHERHOOD**

**COMMUNITY-BASED CATALYST APPROACHES**



**Surveillance**



**Safe Motherhood**



**PARADIGM Prevention**

**OBSTETRIC FISTULA**

**MATERNAL HEALTH**



**Groundwork**



**Repair COMPLICATIONS Health Policy GENDER Programmes**

**GLOBAL ACTIVITIES**

**Childbirth**

**COMMUNICATIONS**

**Depression • Life Skills**

**OBSTRUCTED LABOR**

**Early Childbearing**

**Disease Eradication**

**MALE INVOLVEMENT**

**SOCIAL NO STRACISM**



**Interventions**



**Global Fistula Elimination**

Atlanta, Georgia  
October 3–5, 2005

## **Meeting Report**

# **Obstetric Fistula as a Catalyst: Exploring Approaches for Safe Motherhood**

3 – 5 October 2005  
Atlanta, Georgia – USA

### **Objectives:**

To identify aspects of the catalyst approach paradigm that can be applied to obstructed labor and obstetric fistula.

To identify collaborative efforts necessary to strengthen prevention and management of obstructed labor and obstetric fistula.

To develop strategies to utilize obstetric fistula to leverage support for broader safe motherhood issues.

To draft country-specific proposals to pilot and implement recommended efforts.

### **Sponsored by:**

United Nations Population Fund (UNFPA)  
Health & Development International (HDI)  
Centers for Disease Control and Prevention (CDC)

## **Meeting Report**

# **Obstetric Fistula as a Catalyst: Exploring Approaches for Safe Motherhood**

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We greatly appreciate the active participation and the important substantive contributions and insights of all of the experts that attended the meeting. In particular, we wish to thank the presenters (named in the report and listed in the Agenda, Annex A) for the considerable time and effort that went into preparing the plenary presentations, and chairpersons of individual sessions, all of whom contributed importantly to the success of this policy-meeting. Finally, our appreciation goes to Azalia Mitchell and Dr. Anders Seim for writing this report, and to Azalia Mitchell for her efforts as a consultant during the conference.

October, 2005

On behalf of the participants and organizers

## Executive Summary

Experts on reproductive health from Africa, Asia, Europe, and North America, approximately half of them from nine affected countries in Africa and Asia, together with representatives of WHO, three donor-country governments (Canada, Norway, and USA), universities on four continents, a variety of non-governmental organizations (NGOs), and others, some 40 people in all, met at the Emory University Conference Center in Atlanta, Georgia, USA, October 3 – 5, 2005, to explore how interventions against obstetric fistula elimination can be utilized as a catalyst for preventing obstructed labor sequelae and improving maternal health.

The meeting was funded by the United Nations Population Fund (UNFPA), the Government of Canada (CIDA), and Health & Development International (HDI). It was organized by UNFPA, the US Centers for Disease Control and Prevention (CDC), and HDI.

Current efforts to eliminate obstetric fistula were reviewed and discussed in relation to successful disease eradication strategies and public health campaigns in order to identify key necessary components for strengthening fistula efforts at the community, sub-national, national, and international levels. In addition, experiences of utilizing a specific condition or disease to highlight broader issues were reviewed and related to obstructed labor/obstetric fistula and the broader issues of maternal health and gender equity.

Obstetric fistula, “one of the most shocking indicators in the world of a failed health system”, provides a “visible picture of where we have failed” to provide essential health services for women. Efforts to prevent and treat obstetric fistula can advance the cause of improving maternal health. This is key in terms of policy – and it is what makes fistula different and more feasible for advocacy than is maternal death; obstetric fistula is tangible.

**Participants agreed that it will be useful to begin recording and to actively use data on obstetric fistula as a tool for decision-making in affected countries, and for advocacy in affected as well as partner countries.**

**Participants concluded that obstetric fistula can be an important advocacy tool in efforts to achieve better maternal survival in affected countries, and that knowledge about fistula can be a powerful conduit to understanding of and support for developing-country safe-motherhood issues in richer countries.**

**Participants outlined next steps for strengthening the global initiative to eliminate fistula, and to reduce maternal mortality and morbidity through implementation of program elements that were suggested by plenary presenters and in working groups.**

**Seven specific, practical recommendations emerged for affected countries and their external partners.**

**Recommended actions should be seen as additions, and be implemented together with current and previously planned interventions to eliminate obstetric fistula.**

**Recommendations**  
**Fistula as a Catalyst Meeting**  
**Atlanta, Georgia, USA**  
**October 3 – 5, 2005**

**The following recommendations came out of the working groups and plenary discussion of the working group reports.**

**1) Measure the extent of the problem.**

- a. Conduct well-designed prevalence surveys in a few countries (2 African and 1 Asian) to form the basis for estimating the extent of the problem in similar settings through modeling. Utilize ongoing population-based surveys where possible, such as national Demographic Health Surveys (DHS), Multiple Indicator Cluster Surveys, etc.
- b. Begin reporting absolute numbers of fistula cases detected and fistula repairs
  - i. Use existing human resources at community level to report on cases (traditional birth attendants (TBAs), village health workers, and district supervisors), and collect data from district level, building on the existing information systems, to develop a country obstetric fistula report.
  - ii. Send reports at least quarterly to a central location (at national and regional/global levels) with rapid analysis and feedback.
  - iii. Develop a universal case definition for use when reporting in a community setting where proper medical examination is not possible. The following definition, currently being used in Tanzania, was considered: *Obstetric fistula exists when a woman experiences constant leaking of urine, even at night, which started after a birth where the baby died.* The Data, Indicators and Research Working Group (see below) will be tasked with developing the case definition, and further research will determine the validity of the definition and whether the selected definition needs refining.

**2) Build consensus on clear indicators for prevention and treatment.**

Proposed indicators include:

- a. Treatment and prevention:
  - prevalence: number of cases existing in a population / number of women of reproductive age\* in that population;
- b. Prevention:
  - fistula ratio: number of new cases / total number of deliveries;
  - incidence: number of new cases / number of women of reproductive age\* in that population;
  - met need for operative deliveries: number of operative deliveries / expected number of births in a population.

**3) Capitalize on local wisdom.**

- a. Utilize wisdom of the women who suffer from fistula.
- b. Address the cultural context by working with opinion leaders, including key members of the community such as religious leaders, grandmothers, village leaders, district counselors, women's groups, and men.
- c. Use available data on the local and national situation to convince local and national religious and political leaders to be advocates for fistula elimination.

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\* The reproductive age range of 12 – 49 has been suggested for obstetric fistula, which often occurs in girls around 13 years of age, although 15 – 49 has traditionally been used when defining “reproductive age.”

- 4) Ensure good overall management and case management.**
- a. Local and national government and their partners need to ensure good management at facility and community levels; ensure that obstetric fistula prevention and treatment is a government priority in the reproductive health or the maternal and neonatal health strategy, plan, and program; assign focal points at national and sub-national levels; make adequate human resources available; and put in place the required equipment, materials and financial resources.
  - b. Case management capacity needs to be geographically distributed, bringing care closer to the affected women.
  - c. Countries should create clear criteria for referral to emergency obstetric care services, for fistula prevention, and to treatment facilities for those who do develop fistula, with variations based upon the context.
- 5) Affected countries should consider implementing a community-based reporting and referral system, at least on a pilot basis. Such implementation should:**
- a. Begin in areas where the fistula problem is severe but where travel-time to emergency services allows realistic hope of demonstrating progress, and ensure that comprehensive emergency obstetric care is available.
  - b. Prioritize and target interventions for prevention and for treatment, based on existing data concerning the number of fistula cases in different parts of the country. Priority should be given to geographic areas reporting the highest number of cases.
  - c. Train those who make obstetric referrals at the community level to develop an individual delivery and emergency evacuation plan with each pregnant woman and other decision-makers within her family. The plan should specify pre-agreed criteria for when, to where, and how the evacuation will take place even if the decision-maker should happen to be absent when a need for evacuation arises; how much it will cost; and how it will be paid for (to allow for saving money in advance if necessary).
- 6) Countries and partners should strengthen the existing global alliance to include a “tight nucleus” within a large coalition.**
- a. Develop the role of the alliance as a member of the Partnership for Maternal, Newborn and Child Health.
  - b. Pull together existing economic and epidemiologic data, and advocacy materials to make these readily available for countries and their partners.
  - c. Develop a common reporting form and a central database.
  - d. Create 4 working groups on the following matters:
    - Partnership
    - Data, indicators and research
    - Costing/economic impact
    - Clinical and training issues
- (UNFPA has agreed to move this recommendation forward in a secretariat capacity. Addis Ababa Fistula Hospital will lead the Clinical group, while CDC will lead the Data group, and WHO has begun work on a draft data form.)
- 7) Frame one clear, agreed message on obstetric fistula that can serve as a catalyst for mobilizing political will and resources for improving maternal health.**

## I. Background

Key experts, together with UNFPA (United Nations Population Fund), CDC (US Centers for Disease Control and Prevention), HDI (Health & Development International), WHO, and a variety of non-governmental organizations (NGOs), three donor-country governments (Canada, Norway, and USA), and others, some 40 people in all, met to explore how interventions for obstetric fistula elimination can be utilized as a catalyst for preventing obstructed labor sequelae and improving maternal health.

Current efforts to eliminate obstetric fistula were reviewed and discussed in relation to successful disease eradication strategies and public health campaigns, in order to identify components for strengthening the fistula efforts at the community, sub-national, national, and international levels. In addition, experiences of utilizing a specific condition or disease to highlight broader issues were reviewed and related to obstructed labor/obstetric fistula and the broader issues of maternal health and gender equity.

Participants outlined next steps for strengthening the global initiative to eliminate fistula and reduce maternal mortality and morbidity through implementation of program elements suggested by plenary presenters, and in working groups organized by topic and then by geographic region.

Obstetric fistula is caused by obstructed or prolonged labor that occurs, by definition, when the birth process does not progress appropriately in spite of strong uterine contractions lasting 24 hours. Of the 135 million women giving birth globally each year, it is estimated that approximately 5% or almost 7 million will experience prolonged or obstructed labor.

In many countries without ready access to emergency obstetric care, women may labor for days. In obstructed labor, the baby's skull is pressed against the mother's pelvis for long periods, and the woman's soft tissues squeezed against the inside of the pelvis receive insufficient blood. If the woman survives, the tissues will slough off after the birth, and a permanent opening, or fistula, is created.

Obstetric fistula can form between either the bladder and the vagina (vesico-vaginal fistula) or the rectum and the vagina (recto-vaginal fistula). The symptoms of fistula include incontinence of faeces, urine or both, with accompanying odour, infections and sometimes infertility. These have a profound effect on the lives of the women who suffer from them: women with fistula often report feelings of shame and isolation, leading to reduced opportunity for community participation and employment. Reports of abandonment by the husband or divorce are sadly frequent. Constant seepage of urine and/or faeces through the vagina has multiple devastating effects on the woman's life.

In addition to younger age and chronic under-nutrition which reduce the size of the birth canal, other risk factors include many previous births (parity > 4), lack of skilled attendance at birth, and lack of access to emergency obstetric care (operative vaginal delivery, symphysiotomy and Caesarean section), and harmful practices in some countries.

The WHO estimates that of the 7 million women who experience obstructed labor each year, ~50,000 will die (~0.7% case fatality rate) and another 50,000–100,000 women will develop a fistula. Currently, it is estimated that more than 2 million women in the world live with fistula and its consequences.<sup>1</sup> The majority of cases are believed to occur in low-resource countries, where women are more vulnerable.

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<sup>1</sup> AbouZahr C Global Burden of maternal death and disability. In: Rodeck C, ed. Reducing maternal death and disability in pregnancy, Oxford, Oxford University Press, 2003:1-11

But obstetric fistula can be prevented and treated by interventions that should be manageable even in low-resource countries. Obstetric fistula sufferers have survived one of the main causes of death during childbirth. Therefore, interventions that prevent obstetric fistula will of necessity reduce maternal mortality, the number of stillbirths, and neonatal mortality, and women living with fistula can assist in identifying the barriers and solutions to accessing life saving obstetric care services.

UNFPA leads a global Campaign to End Fistula that involves a number of partners. The Campaign addresses the problem of fistula by addressing primary risk factors of early pregnancy, increasing access to emergency obstetric care, providing medical treatment to women with fistula and ensuring support services for women to assist their reintegration into society. To accomplish this goal, they outline the following necessary activities:

“To ensure sustainability of efforts, national policies must be created and enforced to: raise the legal age of marriage; provide free or subsidized family planning and high quality maternal health services including emergency obstetric care; and provide resources for fistula treatment. Surgical repair, which has an 88–93% success rate, requires a trained surgeon, a competent nursing staff and an anaesthetist and costs approximately US\$350 per operation. Full treatment also includes post-operative care and provision of social reintegration services.”<sup>2</sup> Note that even a fully qualified surgeon requires specific training in fistula repair.

Obstetric fistula is increasingly recognised as a significant public health issue, but also as an effective entry-point to reproductive health, particularly maternal health, and gender equity. This initiative is designed to contribute to the attainment of the specific Millennium Development Goals of improving maternal and child health, but also to contribute to poverty reduction generally and improve gender equity.

Great progress has been made in recent years, and recommendations resulting from this meeting are being proposed as supplementary and collaborative methods to prevent obstetric fistula and help to more rapidly reduce the number of women living with fistula.

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<sup>2</sup> UNFPA. Planning the campaign to end fistula. Report from a meeting, June, 2004. Available at: <http://www.unfpa.org/publications/detail.cfm?ID=211>

## II. Objectives of the “Fistula as a Catalyst: Exploring Approaches for Safe Motherhood” meeting were to:

- Identify aspects of the catalyst approach paradigm<sup>3</sup> that can be applied to obstructed labor and obstetric fistula.
- Identify collaborative efforts necessary to strengthen prevention and management of obstructive labor and obstetric fistula.
- Develop strategies to utilize obstetric fistula to leverage support for broader safe motherhood issues.
- Draft-specific proposals to pilot and implement recommended efforts.

The three-day meeting focused on identifying key elements necessary for a strengthened fistula elimination campaign. Day One consisted of a series of presentations while Days Two and Three focused heavily on discussion and working group sessions to move the Campaign to End Fistula even further forward.

## III. Summary of Presentations

During the morning session of Day One, **Dr. Colin Bullough from University of Aberdeen** provided a valuable overview of current knowledge on the epidemiology of obstructed labor and obstetric fistula based on a literature search he had done for this occasion. He highlighted the lack of available data regarding obstetric fistula and discussed, among other things, various possible indicators for use in surveys to monitor fistula elimination efforts. **Dr. France Donnay from UNFPA** provided an excellent overview of The Campaign to End Fistula, which seeks to bring together the efforts of the many individuals and organizations that have been working on the issue, to bring greater attention and resources to fistula prevention and treatment. Brief presentations on ongoing national and organizational fistula elimination efforts were also provided by country-delegates and NGOs. **Mary Ellen Stanton from USAID** provided a fine overview of policy issues pertaining to obstetric fistula, and especially pointed out various ways in which current trends in bilateral and international development assistance are relevant for efforts to address obstetric fistula in particular as part of broader reproductive health issues.

The afternoon session of Day One consisted of plenary presentations by five presenters. This session was organized to frame discussion surrounding the issue of “What works.” What models and strategies have been labeled successful, and are there elements of these success stories that could be applicable to help speed elimination of obstetric fistula? The final two presentations of the afternoon provided concrete examples of successful programs that used a community-based catalyst approach.

*Note:* The term “catalyst” was used in two different ways during the meeting itself, and it is therefore being used in two ways in this report. It has already been used in the sense that work to prevent fistula has a catalytic effect on the prevention of maternal mortality. It is also used in reference to a specific approach with a significant community-based component that can be used to help address fistula.

**Dr. Ruth Levine from the Center for Global Development** presented the results of a study that looked systematically at health and development programs in developing countries to demonstrate that public health campaigns have been successful in improving health. The “What Works Working Group” brought together 15 experts from developed and developing countries to assess large-scale health projects described in the form of case studies nominated by experts from all over the world. They selected seventeen notable successes, and identified some common elements found in all of these programs.

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<sup>3</sup> Seim AR. Time for an additional paradigm? A catalyst approach to public health. WHO Bulletin; 2005 (May); 83(5): 392 – 4.

The study revealed three major surprises: 1) The power for success of partnerships / alliances between national governments, funding agencies and technical institutions; 2) Most of the successful programs were public – led by national governments; 3) Much of the success rested on changes in health behaviors.

Below are the six core elements of “success” as identified by this working group:

1. Predictable, adequate funding
2. Political leadership and champions
3. Technological innovation within an effective delivery system
4. Technical consensus about the appropriate biomedical or public health approach
5. Good management on the ground
6. Effective use of information
  - a. Measuring the extent of the problem
  - b. Monitoring for constant readjustment of strategy
  - c. True, independent and credible evaluations of programs (results cannot be contradicted by policy makers)

### **Discussion :**

Community ownership and flexibility were also identified by the participants as key elements in successful programs. There was acknowledgement that while we know, clinically, what to do in terms of maternal health, quite a bit remains to be understood concerning public health interventions needed in order to apply this clinical knowledge into practice on a large scale.

**Prof. Jeremy Shiffman, Syracuse University**, presented “Generating Political Priority for Maternal Mortality Reduction: Relevance for Obstetric Fistula.” Prof. Shiffman presented background evidence on studies from five countries: Honduras, Guatemala, Indonesia, India and Nigeria. These studies responded to his question of why there has not been significant progress in achieving safe motherhood, globally. Shiffman posits that the missing element is political priority. He defines political priority as “the degree to which political and social leaders at national and sub-national levels identify a cause as a concern, and back up that concern with the provision of financial, technical and human resources commensurate with the severity of the problem.”

Shiffman stated that the existence of a crisis in and of itself is insufficient to generate action. In order to achieve action, strategic negotiation of the political landscape is necessary. He designated the following factors as being crucial to shaping political priority in relation to obstetric fistula: 1) Development of clear indicators; 2) Attention-generating focus events; 3) Availability of clear policy alternatives; 4) Presence of political entrepreneurs; and 5) Coalescence of the policy community. He also noted emerging findings which show that respecting of local wisdom, pressure by civil society, and horizontal diffusion of priority so that policy officials within a country and in different counties can influence and learn from one another, may also be important factors.

During discussion, it was concluded that the following were also important in creating a political priority:

- In some settings / locations, religious leaders have more influence than political leaders.
- Competition could be used very effectively in combination with horizontal diffusion to shape the emergence of fistula as a political priority.
- We must not forget that fistula is a gender issue. The right policies may be in place but they are not implemented, enforced or prioritized because women are devalued in society.

**Dr. Anders Seim of HDI** advocated the “Community-Based Catalyst Approach to Public Health” for selected situations. This approach focuses heavily on prevention at the community level, for example through community-based volunteers. Dr. Seim discussed the usefulness of having multiple strategies for tackling complex problems. He posits that the community-based catalyst approach could be a bridge between strengthening systems and focus on a specific disease. This approach focuses on observable results and suggests that the tools of disease eradication can be applied effectively to selected non-eradicable diseases/conditions such as obstetric fistula. Dr. Seim shared five criteria for the effective use of community volunteers: 1) Diagnosis by the volunteer must be as accurate as that by a physician; 2) Correct action by the volunteer must positively affect the clinical outcome; 3) The event must not be too rare nor too frequent; 4) A functioning system must provide annual retraining, regular supervision, monthly data collection and analysis, and re-supply of materials; 5) The issue must be important to the community.

Seim also listed ten elements, essential to a community-based catalyst approach: 1) A few people who really care, 2) national program and data managers, 3) an organization with experience in epidemiology to collect and analyze data monthly, 4) resident technical advisors in each country, 5) international meetings twice a year, 6) annual program reviews in each country, 7) annual training and re-training of community volunteers, 8) a network of supervisors, 9) transportation, and 10) course-correction mechanisms.

During discussion it was noted that

- It will be important to have good-quality emergency obstetric care in place before raising communities’ awareness about the importance of using health facilities when they experience obstetric complications.
- Monthly reporting of fistula and tracking and comparing across countries could get the campaign’s momentum going.
- Routine data collection and results of their analysis will direct actions.

The three presentations of Day One by Dr. Ruth Levine, Prof. Jeremy Shiffman and Dr. Anders Seim, provided insight on various elements needed for a successful elimination campaign. The three presenters came from three very different perspectives, but there was a great deal of overlap in the key elements that each presented.

**Dr. Donald Hopkins of The Carter Center** and **Dr. Yankum Dadzie of the Global Alliance for Lymphatic Filariasis Elimination** provided examples of successful programs/campaigns using the Catalyst Approach talked about by Dr. Seim. Dr. Hopkins highlighted the Guinea Worm Eradication Program and Dr. Dadzie highlighted the Onchocerciasis Control Program and the Lymphatic Filariasis (LF) Elimination Program. Most notable was the fact that all of the presented success stories, Guinea Worm, LF and Oncho, contained elements described by all three of the previous presenters, not just those presented by Dr. Seim.

## **Presentations Day Two and Three**

The objective of Day Two was to address the question, “**Is a new paradigm useful for obstructed labor and fistula?**” It began with morning presentations by Dr. Janet Collins, a Center Director at the Centers for Disease Control and Prevention (CDC) and by Dr. Kidza Mugerwa of Makerere University, Uganda, who presented on behalf of WHO headquarters. The third day was devoted to examination of **Regional and National Contexts for Catalyst Efforts**, and Dr. Luc de Bernis of WHO-Geneva made a plenary presentation at the start of the third day. After the opening plenary presentations described below, most of Day Two and Three were spent in working groups and discussion of working group presentations.

**Dr. Janet Collins of CDC**, noted that obstetric fistula is an extremely important issue and that we must succeed in its elimination. She characterized fistula as one of the most shocking indicators in the world of a failed health system, and said the meeting's approach to obstetric fistula as a catalyst and teaming with specialists from maternal health, disease eradication, and country expertise can yield powerful outcomes. She went on to clarify that involvement of different groups coming from different perspectives provides an opportunity for solutions with different partnerships to address both prevention and treatment, financial and cultural problems. Dr. Collins then explained CDC's potential role in the elimination of obstetric fistula. She stated that one of CDC's goals is the improvement of maternal health worldwide, and that obstetric fistula is an important part of this goal; therefore, CDC stands behind the Campaign to End Fistula.

**Dr. Kidza Mugerwa of WHO and Makerere University**, Uganda, presented the *WHO Global Survey on Maternal and Perinatal Health*. Dr. Kidza shared the preliminary results of the WHO Global Survey, which studied the relationship between mode of delivery, intrapartum care, and maternal and perinatal health outcomes in 54 countries. The study provides some interesting facility-based data on obstetric fistula. The research, data collection and analysis are ongoing.

**Dr Luc de Bernis of WHO** shared the draft of WHO's new *Manual on Obstetric Fistula: Guiding Principles for Clinical Management and Program Development*. The manual is divided into two sections, the first focusing on development of national strategies and programs in the context of maternal health. The second section is on treatment, including surgical, nursing, pre- and post-operative care, as well as rehabilitation care. The Manual is intended for policy makers, health managers and providers. It is a collection of information that provides guidance based on the current state of knowledge, while recognizing that there is a lack of evidence in many areas discussed in the guidelines. WHO hopes the manual will be revised in the near future as the evidence base grows in areas such as surgical and clinical care, training, rehabilitation techniques and elimination programs. Copies of the manual will be mailed to all meeting participants in PDF format and hard copy once they are available for distribution.

**Ruth Kennedy from the Addis Ababa Fistula Hospital (AAFH)** gave a closing plenary presentation at the end of Day 3. She provided a detailed overview of the conference, highlighting gains at the meeting and major points of consensus.

Miss Kennedy pointed out that obstetric fistula provides a “visible picture of where we have failed” to provide essential health services for women, and she emphasized that efforts to prevent and treat obstetric fistula can advance the cause of improving maternal health.

She noted that the group had come far in reaching the objectives of the meeting, and she was convinced that the actions recommended by the meeting will help to move the cause forward. While timeframes had not been decided, she acknowledged that we will likely need more than five years to reach our goals. She specified that the key was to reduce the stigma around women with fistula, to make women suffering from fistula tangible—women to be touched and not averted. Miss Kennedy went on to advocate a more holistic approach to dealing with fistulas that focuses on prevention, treatment and post-treatment. She also noted the progress of the AAFH over the last 30 years as inspiration for others to continue their efforts and closed with the story of a young Chadian woman named Halime who had suffered from obstetric fistula, and how working in partnership her life had been turned around to the point where Halime is now helping others with fistulas in Chad.

Finally, Miss Kennedy stated that fistula is already serving as a catalyst because we “are not just patching up bodies; we're giving their lives back to young girls and allowing them to lead productive lives.”

## IV. Working Groups

**On Day 2** meeting participants broke into three topical groups. The working groups were mixed and participants self-selected the group they wanted to work in. The three topics were: 1) Policy and Advocacy, 2) Strengthening Services and the Role of the Community and 3) Monitoring and Evaluation/Data Collection.

The three groups were given the task of deciding whether or not the key elements identified by the presenters on Day One were or could be applicable to the obstetric fistula elimination campaign from a policy, service/community, and monitoring and evaluation perspective. Group participants also identified what modifications were needed to the listed elements and whether elements were missing that had not been identified by the presenters.

There was agreement that all key elements identified would be useful to the obstetric fistula initiatives in some form or another. While groups added some key elements, none of the elements identified by the presenters of Day 1 were discarded.

The table below is a synthesis of the conclusions of the working groups on Day 2.

### Synthesis of Key Elements for strengthening national fistula elimination initiatives

Policy and Advocacy
<ul style="list-style-type: none"><li>▪ <b>Political leadership/champions</b> are needed at global and national level. Champions need to be visible, have moral authority, and have technical expertise and knowledge.</li><li>▪ <b>Organize focusing events</b>, e.g. based on data concerning the local situation.</li><li>▪ <b>Frame clear messages</b> for obstetric fistula in a way that is most effective to motivate political change, with potential variations by context and by country.</li><li>▪ <b>Ensure predictable and adequate funding.</b> Fistula prevention requires functioning health systems that give priority to women, which will require the considerable funding that is also needed to reduce maternal mortality in accordance with the Millennium Development Goals. Specific, costed plans are needed to determine the amounts.</li><li>▪ <b>Build technical consensus</b> about approach, and present <b>clear policy alternatives</b> that can be expected to successfully address the issue. The expert community needs to agree upon a clear set of interventions and determine how much they cost and ensure unity of message to gain progress.</li><li>▪ <b>Select clear indicators</b>, and incidence indicators are recommended because they provide public health impact data that is vital for advocacy with governments. Economic impact data would also provide powerful arguments.</li><li>▪ <b>Use data effectively</b> for advocacy and to influence policy decisions at the local, national, and international levels.</li><li>▪ <b>Determine how the global policy partnership can function best</b> – loosely, or with centralized leadership, or with a “tight core in a broad alliance”.</li><li>▪ <b>Capitalize on local wisdom.</b> This is crucial for success. We should also consider the wisdom and voice of the women that suffer from obstetric fistula and how we can ensure their voices are heard.</li><li>▪ <b>Stimulate horizontal diffusion of policy, and competition</b> - Both of these approaches can be effective ways to make fistula and its prevention a political priority.</li><li>▪ <b>Encourage civil society pressure</b> from human rights groups as well as professional associations.</li></ul>

## Strengthening Services and the Role of the Community

### Underlying requirement: availability of emergency obstetric care

- **Ensure good overall management and case management**
  - Overall management is needed at government, facility and community levels: requires government priority and assignment of focal points at national and sub-national levels as well as ensuring adequate human resources, equipment and materials and financial resources.
  - Case management: need to geographically distribute capacity to treat fistula, delegate responsibilities to appropriate cadres, bring care as close to people as possible, create criteria for referral, improve facilities and infrastructure as well as skills of staff, manage referral systems to ensure that they are functioning.
- **Use data effectively**, which requires effective management to determine what to collect, how to collect it, and ensure it is being collected. Even without a fully functioning system, available knowledge can be used to target interventions.
- **Create a website for technical matters**, which can be used by all organizations to post tools, approaches and success stories.
- **Consider technical and public health innovations** such as using other cadres of staff, innovative transportation schemes, community-based health workers/volunteers, birth preparedness planning and voucher schemes.
- **Subsidize fistula prevention and treatment** so that it is affordable for those who need it.
- **Capitalize on local wisdom** to address the cultural context by working with opinion leaders and key members of the community such as religious leaders, grandmothers, village leaders, district counselors, women's groups, and men.
- **Establish continuing structured training** of technical/clinical staff, and annual training for community volunteers.
  - Technical staff: all need training and retraining, as well as supportive supervision (linked to program monitoring and evaluation) and standardized supervision checklists.
  - Community volunteers: should be trained in maternal health more broadly with a component on fistula, to counsel and refer women that are currently pregnant, do case detection as appropriate, and do community mobilization and education, which will also require an adequate supportive supervision system.
- **Other elements to consider:** broader transportation issues and transportation for supervisors, having a dedicated program manager and technical advisors in each country, effective communication strategy, reintegration/ rehabilitation/counseling, family planning knowledge and services, behavioral change communications (BCC) strategies.

### Monitoring and Evaluation/Data Collection

- **Measure the extent of the problem** through well-designed prevalence surveys in several countries (2 African and 1 Asian), potentially through the Demographic and Health Surveys (DHS), and use modeling to generalize to similar settings.
- **Build consensus on clear indicators for prevention and treatment** - Proposed indicators, which all convey information on degree of successful prevention though some were considered under the heading of treatment (and which will all benefit from further discussion) include:
  - **Met need for obstetric services**: number of operative deliveries / live births or the number of deliveries in the population;
  - **incidence** : number of new fistula cases / number of reproductive-age women in the population;
  - **fistula ratio** : fistula cases / number of deliveries;
  - **prevalence** : number of fistula cases / number of reproductive-age women in the population.

- **Work with national and regional institutions** to build expertise in reproductive health epidemiology in order to facilitate regular data collection and analysis; dedicated national data managers will generally be needed; consider using Geographic Information Systems (GIS) and existing data bases on community locations and infrastructure status.
- **Use the data** to improve policy, service-provision and outcomes, locally, nationally, and internationally.
- **Implement a pilot study** in a carefully selected area with high prevalence and a defined catchment area to track numbers of cases, monitor and record the delays in the community and facility levels, and conduct criterion-based mortality and near-miss audits for complications of pregnancy and childbirth.

**On Day 3** meeting participants broke into three new working groups, two of them based on geographic region: Africa and Asia. The two regional groups were asked to review the key elements listed above in their national, regional and global context and then determine which were missing in their country, and to suggest what action was needed. The reports from Africa and Asia showed notable similarity.

The third working group was established for Global Partners. This group was also asked to review the elements above and note those applicable to the international context. Among those, the group was asked to determine which are missing and actions needed to put them in place. This third group was also given the task of considering and providing greater clarity on some of the specific issues that arose in the previous day's plenary session including: partnership, integration of obstetric fistula in reproductive health, fundraising and advocacy, and research issues.

Results from the three working groups and discussion of their reports to the plenary led to the recommendations listed at the beginning of the document.

Some detailed information on suggestions from all three working groups is included in the Day 3 Working Group Notes located in Annex B, pages 19-20.

## ANNEX A

### Agenda

#### Obstetric Fistula as a Catalyst: Exploring Approaches for Safe Motherhood

Day 1 – Monday, 3 October 2005

Atlanta, Georgia - USA

#### Morning Session: Obstructed Labor and Obstetric Fistula

Chair: Dr. Francisco Songane, Mozambique

Time	Topic	Presenter
8:15 – 8:45	Registration	
8:45 – 8:50	Welcoming Remarks	Dr. Jay McAuliffe/Coordinating Office of Global Health - CDC
8:50 – 9:15	Meeting Objectives and Introductions	Dr. Anders Seim/HDI
9:15 – 9:30	Current Knowledge on obstructed labor and obstetric fistula	Dr. Colin Bullough/University of Aberdeen
9:30 – 9:40	Discussion and Clarification	
9:40 – 10:00	Campaign to end Fistula	
10:00 – 10:15	Discussion and Clarification	Dr. France Donnay/UNFPA
10:15 – 10:45	Coffee/Tea Break	
10:45 – 11:00	Fistula as a Catalyst: Policy Issues	Mary Ellen Stanton/USAID
11:00 – 11:15	Discussion and Clarification	
11:15 – 12:15	Discussion Session: Ongoing Initiatives and Country Environments for Obstetric Fistula Elimination	Various Presenters
12:15 – 13:15	Lunch	

#### Afternoon Session: What Works as seen through other eyes

Chair: Dr. Berit Austveg, Norwegian Board of Health

Time	Topic	Presenter
13:15 – 13:35	What Works: Lessons from Global Health Successes	Dr. Ruth Levine/Center for Global Development
13:35 – 14:00	Discussion	
14:00 – 14:20	Generating Political Priority for Safe Motherhood	Prof. Jeremy Shiffman/Syracuse University
14:20 – 14:45	Discussion	
14:45 – 15:00	When can we use a community-based catalyst approach?	Dr. Anders Seim/HDI
15:00 – 15:15	Coffee/Tea Break	
15:15 – 15:30	Tools that Successful Disease Eradication Programs have in Common	Dr. Anders Seim/HDI
15:30 – 16:00	Guinea Worm Eradication, a successful example of the catalyst approach	Dr. Donald Hopkins/The Carter Center
16:00 – 16:25	Discussion	
16:25 – 16:55	Oncho Control and Global Lymphatic Filariasis (LF) Elimination from an Organizational perspective – Two catalyst approach examples	Dr. Yankum Dadzie/Global Alliance for LF Elimination

16:55 – 17: 20	Discussion	
17:20 – 17:30	Brief Introduction to Day 2 Plan of Work	
18:00	Reception	Hosted by UNFPA

## Day 2 – Tuesday, 4 October 2005

### Morning Session: Is a new paradigm useful for obstructed labor and fistula?

Chair: Dr. Salwa Al-Eryani, UNFPA Yemen

<b>Time</b>	<b>Topic</b>	<b>Presenter</b>
9:00 – 9:10	Fistula from the CDC Perspective	Dr. Janet Collins/Chronic Disease Center - CDC
9:10 – 9:30	WHO Global Survey on Maternal and Perinatal Health (2004-2005)	Dr. Kidza Mugerwa/Makerere University
9:30 – 9: 40	Discussion/Clarification	
9:40 – 10:00	Synthesis of Key Elements for Successful Interventions from Day 1	Kate Ramsey/UNFPA
10:00 – 10:30	Coffee/tea Break	
10:30 – 11:30	Ongoing Initiatives/Country Presentations	Various Presenters
11:30 – 13: 00	Working Groups	
13:00 – 14:15	Lunch	

## Day 2 – Tuesday, 4 October 2005

### Afternoon Session: Is a new paradigm useful for obstructed labor and fistula? continued

Chair: Mary Ellen Stanton, USAID

<b>Time</b>	<b>Topic</b>	<b>Presenter</b>
14:15 – 15: 30	Group Presentations	
15:30 – 16:00	Coffee/Tea Break	
16:00 – 17:00	Discussion and Debate	
17:00 – 17:30	Video presentations: “A Walk to Beautiful” and BBC Video - “Dead Mums Don’t Cry”	

### **Day 3 – Wednesday, 5 October 2005**

#### **Morning Session: Regional/National Contexts for Catalyst Efforts**

Chair: Prof. Oladosu Ojengbede, Univ. of Ibadan, Nigeria

<b>Time</b>	<b>Topic</b>	<b>Presenter</b>
9:00 – 9:20	Guiding Principles for Clinical Management and program Development	Dr. Luc de Bernis/WHO
9:20 – 9:30	Discussion/Clarification	
9:30 – 11:00	Working Groups	
11:00 – 11:30	Tea/Coffee Break	
11:30 – 12:30	Asia and Africa Group Presentations	
12:30 – 14:00	Lunch	

### **Day 3 – Wednesday, 5 October 2005**

#### **Afternoon Session: Regional/National Contexts for Catalyst Efforts continued**

Chair: Samantha Lobis, AMDD, Columbia Univ., USA

<b>Time</b>	<b>Topic</b>	<b>Presenter</b>
14:00 – 14:30	Global Partners Group Presentation	
14:30 – 16:00	Summary and Closing Remarks	Ruth Kennedy/Addis Ababa Fistula Hospital

## ANNEX B

### Working Group Notes

	Element Missing/Issue	Action Needed
<b>Africa and Asia Regions</b>	Good management lacking at the district and sub-district levels, including awareness and involvement of communities (case management)	<ul style="list-style-type: none"> <li>▪ Strengthen Behavioral Change Communication (BCC) strategy and communication for effective referral</li> <li>▪ Empower fistula survivors to advocate, educate, and counsel</li> <li>▪ Use existing data to activate local, community and religious leaders to provide oversight for community activities</li> <li>▪ Resource flows to districts and sub-districts</li> </ul>
	System not functioning to provide maternal health and treatment care due to lack of adequate human resources (distribution, training, retention, supervision), equipment and finances	<ul style="list-style-type: none"> <li>▪ Utilize fistula to advocate for improvements in the system and mobilize resources</li> <li>▪ Policy interventions to increase resource allocation for training of skilled attendants, health facility services, and strengthening referrals</li> <li>▪ Public and private partnerships</li> <li>▪ Innovation, including possibility for delegation to other cadres to perform repairs</li> <li>▪ Use regularly collected data to inform decisions and change policy on rural staffing</li> </ul>
	Lack of clear indicators for Monitoring and Evaluation (M&E), particularly measurement of prevalence	<ul style="list-style-type: none"> <li>▪ Use available data</li> <li>▪ Conduct well-organized structured studies to guide planning and implementation and to allow for evaluation of impact (prevention-study)</li> </ul>
	Lack of effective use of data	<ul style="list-style-type: none"> <li>▪ Establish comprehensive data collection systems at national level</li> <li>▪ Include obstetric fistula data in health information systems</li> </ul>
	Accountability missing where services are present	<ul style="list-style-type: none"> <li>▪ Monitoring and Evaluation (M&amp;E) at all levels, including feedback and supervision</li> </ul>
	Almost none of the elements are in place in countries in conflict	<ul style="list-style-type: none"> <li>▪ Regional responsibility (use organisations such as AMREF)</li> <li>▪ Determine a special strategy for these situations</li> </ul>

<b>Global Partners</b>	Partnership/Leadership	<ul style="list-style-type: none"> <li>▪ Tighten the existing alliance, with a “tight nucleus” and a large coalition</li> <li>▪ Establish working groups to look at the following issues: <ul style="list-style-type: none"> <li>- Partnership evolution</li> <li>- Costing and Economic issues</li> <li>- Data, Indicators and Research</li> <li>- Clinical and Training issues</li> </ul> </li> </ul> <p>(UNFPA to move these forward)</p>
	Integration of obstetric fistula in reproductive health	<ul style="list-style-type: none"> <li>▪ Mapping of service delivery points for treatment, training centres, emergency obstetric care and family planning services</li> <li>▪ Review issues regarding support to health systems, human resource strategies, utilizing expatriate volunteers (use existing agencies with experience for the needed screening process), sustainable supply of equipment and supplies</li> <li>▪ Pre-service education, in-service training, and Training of Trainers (TOT)/training centres</li> </ul>
	Fundraising and Advocacy	<p>Partnership working group to look at:</p> <ul style="list-style-type: none"> <li>▪ Available advocacy materials</li> <li>▪ Clear messages regarding obstetric fistula and linkages to Emergency Obstetric Care (EmOC) and Maternal and Newborn Health activities</li> <li>▪ Sources, use and focus of funding</li> <li>▪ Donor coordination</li> </ul>
	Data, indicators <sup>4</sup> and research	<p>Above Monitoring &amp; Evaluation working group to consider the following:</p> <ul style="list-style-type: none"> <li>▪ Pull together available economic and epidemiologic data</li> <li>▪ Begin counting: # of fistulae encountered and # of fistulae surgeries in Ethiopia + at least 1 African + Asian country (use Demographic Health Survey (DHS), prevalence studies and then do modeling): requires development of a case definition which was then proposed and discussed (see Recommendation 1) b. ii.)</li> <li>▪ Clinical data and care studies: develop a common reporting form and a central database</li> </ul>

<sup>4</sup> NOTE: The meeting’s working group on M&E suggested using “Fistula Ratio” as an indicator: # of fistulas / # of deliveries. Further discussion will clarify various aspects concerning the application of this indicator, initially proposed in July 2005 by C. Stanton et al.

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