

A Full-Spectrum Approach to Eliminating Obstetric Fistula: How the United States Can Make Its Best Contribution

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Yale Global Health Justice Partnership

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Executive Summary

Obstetric fistula is a maternal health problem that newly affects between 50,000 and 100,000 women per year, particularly in sub-Saharan Africa and Asia. It is caused by prolonged obstructed labor and renders women incontinent, causing them to leak urine and/or feces. It is associated with a lack of access to emergency obstetric care, poor health systems, and the low status of women. Treatment requires surgical repair. Approximately two million women are estimated to be living with obstetric fistula; however, the exact number is unknown.

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Groups including government aid agencies, non-governmental organizations, and inter-governmental entities, such as the United States Agency for International Development (USAID), EngenderHealth, and the United Nations Population Fund (UNFPA), have prioritized eliminating obstetric fistula. Moreover, since 2003, members of the US Congress have introduced bills to raise awareness and provide medical treatment to women suffering from fistula. We applaud the leadership of the US government in championing this important issue. However, ten years after the first US bill on obstetric fistula was introduced, we are at a critical moment to reevaluate and refocus our approaches to addressing obstetric fistula and maternal health more broadly.

This brief asks US policymakers to modify the language of existing legislation being considered for reintroduction or to sponsor new legislation that adopts a full-spectrum approach to eliminating obstetric fistula. The brief is divided into two parts. **In Part I, we offer background on obstetric fistula and on existing public and private efforts to eliminate the condition. We then articulate the components of a successful approach to fistula, which should guide US legislation. In Part II, we evaluate the likely efficacy of bills that have been proposed in Congress and make recommendations for how they or future legislation can be strengthened.** With the changes we propose, US legislation would not only be more likely to aid in the elimination of obstetric fistula; it would also synergistically help address a wide range of maternal-health issues.

Based on extensive research and interviews, we suggest that legislators build on the commitment reflected in prior bills, specifically by undertaking the following:

1. Providing the appropriate level of funding to *prevent and treat fistula*.
2. Expanding the availability and improving the quality of *emergency obstetric care* by focusing fistula prevention efforts on integrated rather than vertical programs.

3. Creating *sustainable programs* to combat fistula by building the capacity of local health workers and capitalizing on existing efforts and expertise.
4. Promoting *community health education* on fistula.
5. Providing social, economic, and psychological support for the *reintegration of women* post-surgery.

These recommendations would help fulfill the aims of the US Global Health Initiative, which commits the United States to meeting the comprehensive health needs of women and girls around the world. They would also contribute to Goal 5 of the Millennium Development Goals, which embodies an international commitment to improve maternal health. Finally, they would advance the US government's goal of partnering with foreign governments and institutions to achieve common development objectives.

This is an opportune moment to enhance support in Congress for the elimination of obstetric fistula and to refine relevant legislation to achieve the best possible health outcomes. In adopting a full-spectrum approach to obstetric fistula, US policymakers will help strengthen health systems and improve the quality of life for women and girls around the world.

PART I: A Full-Spectrum Approach to Eliminating Obstetric Fistula

Background: Obstetric Fistula – Preventable & Treatable

Obstetric fistulas are holes or tears in the tissue wall between the vagina and the bladder and/or the vagina and the rectum.¹ **Approximately 2 million women suffer from obstetric fistula, and each year, 50,000-100,000 new cases occur.**² These figures, however, may be gross underestimates because the neglect and ostracization that comes with obstetric fistulas makes identifying them difficult.³

Prolonged obstructed labor and lack of quality and accessible maternal health care cause 90 percent of obstetric fistulas.⁴ The condition thus differs from traumatic fistula, which is the result of rape or sexual violence and are prevalent in conflict and post-conflict settings.⁵ Obstructed labor also causes 8 percent of all maternal deaths, and 90 percent of cases of obstructed labor result in fetal mortality.⁶ The physiological cause for obstructed labor is a “mismatch” between fetal size and the mother’s pelvis, which is often small as a result of young age or malnutrition.^{7,8} The risk of fistula is increased by social and structural factors, which include the following:

- **Lack of access to antenatal care**, which provides opportunities for early detection of complications.
- **Lack of skilled attendants at birth**, who can provide professional assistance and identify complications that require more advanced care.
- **Lack of emergency obstetric care**, including caesarian sections and other interventions, to handle complications such as obstructed labor.
- **Lack of health education**, which can teach women and their families when to seek health care and to recognize danger signs during pregnancy.

¹ Rebecca J. Cook, Bernard M. Dickens, & S. Syed, *Obstetric Fistula: The Challenge To Human Rights*, 87 INT’L JOURNAL OF GYNAECOLOGY AND OBSTETRICS, 72, 72-77 (2004).

² World Health Organization (WHO), *10 Facts on Obstetric Fistula*, FACT FILE (March 2010), http://www.who.int/features/factfiles/obstetric_fistula/en/.

³ S. Ahmed, R. Genadry, C. Stanton, & A. B. Lalonde, *Dead Women Walking: Neglected Millions with Obstetric Fistula*, 99 INT’L JOURNAL OF GYNAECOLOGY AND OBSTETRICS, S1 (2007).

⁴ *Id.*

⁵ EngenderHealth/The Acquire Project, *Traumatic Gynecologic Fistula: A consequence of Sexual Violence in Conflict Settings*. ACQUIRE REPORT, (May 2006) <http://www.engenderhealth.org/files/pubs/maternal-health/tf-report-english.pdf>.

⁶ Lewis L. Wall, *Obstetric Fistula Is a “Neglected Tropical Disease,”* 6 PLOS NEGLECTED TROPICAL DISEASES e1769 (2012).

⁷ J. P. Neilson, T. Lavender, S. Quenby, & S. Wray, *Obstructed Labor Reducing Maternal Death And Disability During Pregnancy*, 67 BRITISH MEDICAL BULLETIN, 191, 191-204 (2003).

⁸ Cook, *supra* note 2.

- **Lack of access to voluntary family planning**, which enables a woman to choose to delay her first birth, to have healthy spacing between pregnancies, and to limit child bearing if she chooses.
- **Low status of women and gender inequality**, which limit a woman's ability to make decisions about her body and to seek health care when needed.
- **Child marriage**, which leads to pregnancies before a girl's pelvis is developed enough to withstand delivery.
- **Distance and lack of affordable transport**, which may make needed health services physically inaccessible from where a woman resides.
- **Lack of funds** to cover the costs of transportation and/or health care.

Women who suffer from obstetric fistula tend to be uneducated, poor, and from a rural area in sub-Saharan Africa or South Asia, and they tend to have been married at a young age.^{9,10} Women typically suffer fistula during a delivery that takes place outside of a health-care facility and without skilled birth attendants.¹¹ Although there appears to be an increased risk of obstructed labor among young women due to their physical immaturity,¹² fistulas occur among women of all ages and with varying histories of child bearing.¹³

The consequences of obstetric fistula are both physical and social. Women with fistula suffer from incontinence, which means they cannot control their urine and/or feces without a surgical procedure. Their ability to have children in the future may also be jeopardized. Twenty percent of women with fistula experience partial paralysis due to nerve damage.¹⁴ Women with fistula are often socially marginalized, which can compound poor treatment that women in general already experience. Women with fistula may be divorced by their husbands and ostracized from their communities, and their socioeconomic status often worsens.¹⁵

Obstetric fistulas are both preventable and treatable. They have been virtually eliminated in the developed world with increased economic and social opportunities for women and the provision of comprehensive obstetric care.¹⁶ However, in the developing world, the number of cases continues to grow, and not nearly enough women receive treatment.

⁹ Suellen Miller, Felicia Lester, Monique Webster, & Beth Cowan, *Obstetric Fistula: A Preventable Tragedy*, 50 JOURNAL OF MIDWIFERY & WOMEN'S HEALTH 286, 286-294 (2005).

¹⁰ Tebeu, *supra* note 8.

¹¹ Tebeu, *supra* note 8.

¹² UNFPA and EngenderHealth. *Obstetric Fistula. Needs Assessment Report: Findings from Nine African Countries*. 2003. <http://www.unfpa.org/fistula/docs/fistula-needs-assessment.pdf> (April 29, 2013)

¹³ Women's Dignity Project and Engenderhealth. *Risk and Resilience: Obstetric Fistula in Tanzania*, 2006. <http://www.fistulacare.org/pages/pdf/resources/RiskandResilienceFistulareport.pdf> (May 21, 2013)

¹⁴ *Id.*

¹⁵ Pierre Marie Tebeu, Joseph Nelson Fomulu, Sinan Khaddaj, Luc de Bernis, Thérèse Delvaux, & Charles Henry Rochat, *Risk Factors For Obstetric Fistula: A Clinical Review*, 23 INT'L UROGYNECOLOGY JOURNAL 387, 387-394 (2012).

¹⁶ Cook, *supra* note 2.

Furthermore, cases most frequently occur among women who are already vulnerable to poor health outcomes. The occurrence of obstetric fistula reveals the inadequacy of maternal health care systems and the lack of attention given to women's health in general. Indeed, suffering endured by women with fistulas is a consequence of widespread neglect and injustice.¹⁷

The political will to address obstetric fistula, coupled with the knowledge of how to prevent it, present an opportunity for the US government to make significant strides against the occurrence of the condition. By adopting a full-spectrum approach to eliminating obstetric fistula, the US government can have a positive impact on this public health problem, as well as a broad range of interrelated women's-health and maternal-health issues. These include a lack of access to health education, voluntary family planning, and quality antenatal and obstetric care.

Background: Building on Current Efforts & Expertise

In many countries where fistula is a concern, there is already a wealth of knowledge about the condition and a strong commitment to eliminating it. **Local capacity thus presents a platform for the US government to expand its efforts to help eliminate fistula, and it also provides models for how to do so.** US assistance should bolster existing local programs and expertise.

According to the Global Fistula Map, there are approximately 238 fistula care facilities across 42 countries, mostly in sub-Saharan Africa and South Asia.¹⁸ These facilities range from periodic or mobile services without an on-site fistula surgeon to permanent facilities with three or more surgeons.¹⁹ Forty-two percent are public/government facilities, while 47.9 percent are owned and run privately/by NGOs.²⁰

¹⁷ According to the WHO, 99 percent of maternal deaths occur in developing countries. Eight hundred women die each day from preventable causes pertaining to pregnancy and child birth, including heavy bleeding, infections, and unsafe abortions. This "reflects inequities in access to health services, and highlights the gap between rich and poor." WHO, "Maternal Mortality," Fact Sheet No. 348, (May 2012), <http://www.who.int/mediacentre/factsheets/fs348/en/>.

¹⁸ Direct Relief, *The Inconvenient Truth Facing Millions Who Suffer from Obstetric Fistula*, (April 15, 2013) <http://www.directrelief.org/2013/04/the-inconvenient-truth-facing-millions-who-suffer-from-obstetric-fistula/>.

¹⁹ Different models of service delivery include: 1) stand-alone fistula centers (e.g., the Fistula Hospital, Addis Ababa, Ethiopia, and Babbar Ruga Fistula Hospital, Katsina, Nigeria); 2) Fistula centers within existing general hospitals or maternity units (as in Nigeria, Niger, Benin, and Tanzania); 3) Urology or obstetric departments of general hospitals offering fistula repair (as in Tanzania, Mali, Senegal, and Kenya); 4) Satellite fistula repair units linked to a fistula center (as in northern Nigeria and planned for Ethiopia); 5) Multilevel/multi-tiered national systems for fistula care, which involves smaller, local units performing basic fistula repairs, while more complex fistulas are treated by visiting surgeons (as in Kenya, Uganda, and the United Republic of Tanzania) or referred to a national or subnational center; and 6) Fistula repair camps managed by national mobile teams (as in Pakistan, Somalia, and the United Republic of Tanzania); See L. de Bernis, *Obstetric Fistula: Guiding Principles for Clinical Management and Programme Development, A New WHO Guideline*, 99 INT'L JOURNAL OF GYNECOLOGY & OBSTETRICS, S117-S121 (Nov. 2007).

²⁰ Direct Relief, *Global Fistula Map*, (2013) <http://www.globalfistulamap.org/>.

Among the oldest and most notable facilities specializing in obstetric fistula is the Hamlin Hospital, Addis Ababa, which opened in 1974. It provides holistic prevention, treatment, rehabilitation, and long-term care to women.²¹ Its work emphasizes raising awareness about fistula; building local capacity by training health-extension workers, midwives, and doctors; and collaborating with local health authorities. Each year, the hospital conducts approximately 2,500 surgical repairs. Its efforts have expanded through the creation of mini-hospitals in existing government facilities, which are located strategically to be most accessible to women with fistula.

At the country level, some national governments have also made significant efforts to create a supportive environment for the elimination of fistula. For example, in Uganda the Fistula Technical Working Group (FTWG) has integrated fistula services into the health system, established standards and guidelines for services, and built an information base to inform practice.²² For the first time, in 2013, the Nigerian president included funding for a public response to obstetric fistula in the country's budget proposal.²³

In addition to local and national efforts upon which US assistance can build, several international organizations, development agencies, and NGOs have proven track records of technical assistance and funding for the elimination of fistula. Their work provides further platforms and lessons for US support. In 2003, UNFPA launched the Global Campaign to End Fistula in order to improve maternal health and reduce the occurrence of fistula. UNFPA also serves as the secretariat for the International Obstetric Fistula Working Group, a global coalition of institutions and practitioners, including USAID, which coordinates and advances efforts to eliminate fistula.²⁴ In 2011, UNFPA supported more than 7,000 fistula repairs, fostered local capacity through a Competency-Based Fistula Training Manual for surgeons and a Midwifery Program, and began a study to examine post-operative prognosis and rehabilitation

²¹ Hamlin Fistula International, *Our Activities*, (2009) <http://www.hamlinfistula.org/our-activities.html>.

²² USAID and Fistula Care, *Creating an Enabling Environment for Fistula Prevention and Treatment in Uganda*, (March 28, 2013) http://www.fistulacare.org/pages/pdf/technical-briefs/Uganda_TWG_TB_FINAL_3_28_13.pdf.

²³ On October 10, 2012, President Goodluck Jonathan presented the 2013 budget entitled "Fiscal Consolidation with Inclusive Growth," to a Joint Session of the National Assembly. Under the theme of Gender Empowerment, the budget states: *The Ministry of Health, in addition to scaling up its ongoing "Save a Million Lives" initiative, plans to give back health and hope to one-third of the pool of young girls and women who have been waiting a long time for V.V.F repairs through surgery and economic rehabilitation.*

²⁴ Campaign to End Fistula, *Tracking progress in the Campaign to End Fistula*, INTERNATIONAL OBSTETRIC FISTULA WORKING GROUP (November 2010) http://www.endfistula.org/webdav/site/endpointfistula/shared/documents/invisible%20links/dispatch/november%202010%20english/UNPFA_DispatchPDF_WorkingGroup.pdf.

of fistula patients. UNFPA's 2011 operating budget for the Maternal Health Thematic Fund, which encompasses the Campaign to End Fistula, was \$33.3 million.²⁵

Current work by USAID also presents an opportunity to expand the US response to fistula. In 2007, in addition to its wider efforts to address maternal and reproductive health, USAID implemented the Fistula Care project, which increases access to services in order to prevent and treat obstetric fistula, to support training of providers, and to conduct research.²⁶ From 2005-2012, USAID supported over 30,000 fistula repairs and trained more than 5,000 people in the prevention and treatment of the condition. To monitor and assess the quality of programs, USAID has collected data on each case treated and health-care professional trained and conducted research to enhance its evidence base. It is currently conducting a randomized controlled trial that could lead to improvements in the quality of care and reduce the length of hospital stays for women with fistula.²⁷ The program also currently funds more than 35 treatment sites and 44 prevention-only sites.²⁸ By building upon USAID's partnerships, efforts, and expertise, the US government could further strengthen its efforts to eliminate obstetric fistula.

The Three Pillars of a Full-Spectrum Approach

Despite the high level of international commitment and progress made toward eliminating obstetric fistula, there is room for improvement. The number of repairs being conducted pales in comparison to the number of new cases that occur each year. However, even if massively scaled up, treatment alone cannot fully address fistula. This is because very severe fistulas are difficult to treat, and because a treatment-based model still leaves women vulnerable to physical and social harms—both those caused specifically by fistula and those caused by weak health care systems and the low status of women. **An effective program to eliminate obstetric fistula must therefore prevent future occurrences as well as provide treatment and reintegration support to survivors.** Indeed, comprehensiveness is a key principle against which US governmental support for ending fistula should be evaluated. Programs for prevention, treatment, and reintegration must complement each other to

²⁵ UNFPA, Maternal Health Thematic Fund, Annual Report 2011.

http://www.endfistula.org/webdav/site/endpointfistula/shared/documents/reports/MHTF%202011%20annual%20report%2008_2_2012.pdf

²⁶ USAID, Fistula Care, and EngenderHealth, *Our Vision*, (2013) <http://www.fistulacare.org/pages/about-us/>.

²⁷ USAID, Fistula Care, and EngenderHealth, "FISTULA CARE, Associate Cooperative Agreement GHS-A-00-07-00021-00 Annual Report October 2011 to September 2012," (Nov. 2012),

http://www.fistulacare.org/pages/pdf/Annual_Reports/FC_Annual_Report_FY11-12_exec_summary.pdf (April 29, 2013)

²⁸ USAID, Fistula Care, & EngenderHealth, *Program Background*, (2013) <http://www.fistulacare.org/pages/about-us/program-background.php>.

decrease the backlog of women awaiting treatment, restore their dignity, and prevent others from enduring this unnecessary hardship.

Prevention

Prevention is a critical component of obstetric fistula programs. Social and structural problems, including poverty, gender discrimination, insufficient investments in maternal and reproductive health, and poor infrastructure, are inextricably linked to the occurrence of fistula. Eliminating fistula thus requires attention to the various circumstances that cause women to suffer the condition, as well as broader health injustices.

The ability to prevent fistulas before they have occurred must be fostered by improving maternal health care in developing countries. Goals should include:

- Guaranteeing access to delivery with a skilled attendant.
- Strengthening referrals to emergency obstetric care, including cesarean sections, to address complications in birth.
- Providing voluntary family planning, health education, and other core reproductive health services that enable women to determine when and how many children to have.

In the long term, public and private reform efforts involving both women and men should address the low status of women by:

- Improving the education of girls.
- Providing economic and social opportunities for women.
- Ending child marriage.

Treatment

Approximately 90 percent of fistulas can be repaired.²⁹ However, about **85 percent of women with fistula do not seek treatment due to shame, financial costs, and a lack of knowledge about its availability.**³⁰ The cost of surgical treatment is estimated to be approximately \$350-450, varying within and across different countries and providers.

Availability of treatment is increasing; however, so is the backlog of cases. While 17,878 women received treatment in 2012, according to treatment sites responding to a global survey,

²⁹ USAID, Fistula Care, & EngenderHealth, *Surgical Repair & Rehabilitation*, (2013) <http://www.fistulacare.org/pages/what-is-fistula/surgical-repair.php>.

³⁰ United Nations Population Fund & EngenderHealth, *OBSTETRIC FISTULA NEEDS ASSESSMENT REPORT: FINDINGS FROM NINE AFRICAN COUNTRIES* (New York: United Nations Population Fund & EngenderHealth 2003).

as many as 100,000 women experienced new cases of fistula.³¹ **To expand the availability of treatment, goals should include:**

- Strengthening hospital capacity and training local health-care workers to identify and treat fistula.
- Locating treatment in areas accessible to women.
- Providing financial support for transportation and healthcare.

Reintegration

The physical consequences of fistula often lead to the social stigmatization and exclusion of affected women, including by their families. **After treatment, social, economic, and psychological support is needed to facilitate the reintegration of women into their communities.** Programs should prioritize:

- Offering skills training and income-generation schemes.³²
- Providing psychosocial support and health education.³³
- Ensuring long-term care for women whose fistulas are beyond repair.³⁴

For further information on reintegration, please refer to Appendix A.

Setting the Standards for Success

Within the three pillars outlined above, **there are principles recognized globally as core aspects of effective and rights-promoting health care for women.** Core among these principles are ensuring availability, accessibility, acceptability, and good quality of all services and goods in health services.³⁵ Public health practice and research show that efforts and interventions must

³¹ Direct Relief, *Obstetric Fistula Repair and Prevention*, (2013) <http://www.directrelief.org/focus/maternal-and-child-health/obstetric-fistula/>.

³² USAID, Fistula Care, EngenderHealth, and IntraHealth, *Prevention and Recognition of Obstetric Fistula Training Package*, MODULE 9: PRINCIPLES OF POSTOPERATIVE CARE AND REINTEGRATION OF WOMEN WITH OBSTETRIC FISTULA, http://www.fistulacare.org/pages/pdf/Training/Module_9_Postoperative_care_and_reintegration_Fistula_Care.pdf.

³³ Rachel Pope, Maggie Bangser, and Jennifer Harris Requejo, *Restoring Dignity: Social Reintegration After Obstetric Fistula Repair In Ukerewe, Tanzania*, 6 GLOBAL PUBLIC HEALTH 859, 859-873 (2011).

³⁴ Women's Dignity, *Social Reintegration after Repair of Obstetric Fistula in Tanzania*, (2007) <http://www.womensdignity.org/files/Fistula.pdf>.

³⁵ It is now internationally accepted that all health-related facilities, goods, and services must be available, accessible, acceptable, appropriate, and of good quality (called the "AAAQ standard"). For more information on the development of the AAAQ framework and the importance of participation in rights-based health work, see: Helen Potts, "Participation and the Right to the Highest Attainable Standard of Health," University of Essex Human Rights Centre, (2007), <http://www.essex.ac.uk/hrc/research/projects/rth/docs/Participation.pdf>. See also: WHO Millennium Development Goals,

be locally driven and built on existing health-care infrastructure. Programs must ensure that every woman, regardless of her socioeconomic status or location, can access appropriate and effective health care. Programs must also be accountable for their work and involve women in decision making. Addressing obstetric fistula through these and other, related principles, discussed more fully below, will increase the impact of US legislative efforts to help eliminate fistula and improve maternal health systems.

Promote Sustainability & Local Capacity

Programs must be designed to ensure long-term functionality. Prevention, treatment, and reintegration strategies must take into account local capacity and resource limitations in order to be cost-efficient and sustainable.

- Additional efforts proposed by the US government should collaborate with existing successful programs, such as USAID and EngenderHealth’s Fistula Care program and UNFPA’s Campaign to End Fistula.
- To use resources efficiently, programs must utilize local health and social welfare infrastructures responsible for and capable of addressing obstetric fistula.³⁶
- Competency-based training and learning exchanges for local health workers must be promoted to increase capacity to treat obstetric fistula independently in countries where it is prevalent.³⁷

Ensure Availability & Accessibility

Programs must be available in sufficient quantity and be financially and geographically accessible.

- Women need adequate health services, including antenatal care and emergency obstetric care.
- Communities should have access to health education that focuses on readiness for pregnancy, recognition of complications, and preparation of emergency plans.³⁸

“MDG 5: improve maternal health,” (2000), http://www.who.int/topics/millennium_development_goals/maternal_health/en/; and US Global Health Initiative, “Principles,” (2009), <http://www.ghi.gov/about/principles/index.htm>.

³⁶ See P. Hawe, M. Noort, L. King, & C. Jordens, *Multiplying Health Gains: The Critical Role Of Capacity-Building Within Health Promotion Programs*, 39 HEALTH POLICY, 29, 29-42 (Jan. 1997); See also Beth R. Crisp, Hal Swerissen, & Stepehn J. Duckett, *Four Approaches to capacity building in health: consequences for measurement and accountability*, 15 HEALTH PROMOTION INTERNATIONAL, 99, 99-107 (2000).

³⁷ P. MacDonald & M. E. Stanton, *USAID Program for the Prevention and Treatment of Vaginal Fistula*, 99 INT’L JOURNAL OF GYNECOLOGY & OBSTETRICS, S112-S116 (Nov. 2007).

- Access to services outlined above should be facilitated by financial assistance for care and transportation to health facilities.

Facilitate Acceptability

All programs must be non-discriminatory³⁹ and respectful of medical ethics as well as the culture of individuals and communities where they are implemented.

- Health-care facilities and health workers must obtain informed consent and respect patient confidentiality.
- Health-care professionals must be trained to treat obstetric fistula patients with dignity.

Meet Core Standards of Quality

Programs must be scientifically and medically appropriate.

- High quality of health-care requires continuous training and supervision of health-care professionals.
- Research should be conducted to improve existing surgical techniques and develop international and national standards for obstetric fistula care.⁴⁰

Ensure Accountability

Obstetric fistula programs must include transparent accountability mechanisms to monitor efforts and provide means of redress in cases of failure or harm.⁴¹

- Monitoring and evaluation should be based on quantitative and qualitative indicators that assess the process and the outcomes of programs.

³⁸ P. MacDonald, *supra* note 37.**

³⁹ The International Covenant on Economic, Social and Cultural Rights (ICESCR) disallows discrimination in access to health care on the grounds of race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status, sexual orientation, and civil, political, social, or other status, which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health. See: ICESCR, Article 2, <http://www.un-documents.net/icescr.htm>. See also: WHO, "Health and Freedom from Discrimination: WHO's Contribution to the World Conference Against Racism, Racial Discrimination, Xenophobia, and Related Intolerance," Health & Human Rights Publication Series, Issue No. 2, (Aug. 2001), http://www.who.int/hhr/activities/q_and_a/en/Health_and_Freedom_from_Discrimination_English_699KB.pdf; USAID Health Policy Initiative, "Performance Monitoring Plan: Task Order 1," (Sept. 3, 2006), http://ghiqc.usaid.gov/hpi/docs/hpi_pmp.pdf.

⁴⁰ *Id.*

⁴¹ See also Rene Loewenson, *Participation and Accountability In Health Systems: The Missing Factor In Equity?* EQUINET: NETWORK FOR EQUITY IN HEALTH IN SOUTHERN AFRICA (2010).

- Results should be used to build an evidence base of successful programs and best practices.

Promote Participation

Women suffering from obstetric fistula must be included in the decision-making process for programming through effective community participation.

- Feedback from women who have experienced obstetric fistula should be used in assessing priorities and evaluating strategies for fistula programs.
- Women who have received treatment for fistula may be trained to become advocates for prevention, treatment, and reintegration in their communities.

PART II: How the United States Can Make Its Best Contribution

US Legislation – A Part of the Solution

Various branches of the US government are actively seeking to improve women's health through the elimination of obstetric fistula. USAID, as noted in Part I, launched its Fistula Care program in 2007. The Obama administration's Global Health Initiative has also prioritized a focus on women, girls, and gender equality, including a reduction of maternal mortality around the world.⁴²

Moreover, **since early 2000, obstetric fistula bills have been introduced in Congress to raise awareness about the condition and to secure funds for US assistance in its elimination.**

Legislation addressing factors that influence the occurrence of obstetric fistula, such as women's rights and child marriage, have also been proposed in both the House of Representatives and the Senate.⁴³ The bills specific to obstetric fistula are briefly described below:

- **2003 “Recognizing the horrific effects of obstetric fistulas” (H. R. 447)** Introduced by Representative Edolphus Towns (D-NY) to establish and enhance US collaborations with foreign agencies and organizations to promote maternal health care. Co-sponsored by 22 Democrats.
- **2004 “Repairing Young Women’s Lives around the World Act” (H.R. 3810)** Introduced by Representative Carolyn Maloney (D-NY) to ensure contributions by the US government to UNFPA for the prevention, remedy, and repair of obstetric fistula. Co-sponsored by 39 Democrats. Reintroduced in 2005 (H.R. 2811) and in 2007 (H.R. 2114).
- **2004 “Obstetric Fistula Surgical Repair, Assistance, and Prevention Act” (H.R. 4848)** Introduced by Representative Chris Smith (R-NJ) to amend the Foreign Assistance Act of 1961 in order to provide funding for the establishment of centers for the treatment of obstetric fistula in developing countries. Co-sponsored by 1 Democrat and 3 Republicans. Reintroduced in 2005 (H.R. 2957).

⁴² <http://www.ghi.gov/about/principles/index.htm>

⁴³ See, e.g., Representative Berman (D-CA)'s Global Partnerships Act of 2012 (H.R. 6644); Representative McCollum (D-MN)'s Child Marriage Violates the Human Rights of Girls Act of 2011 (H.R. 3357); Representative Clarke (D-NY)'s Global Sexual And Reproductive Health Act of 2010 (H.R. 5121); Representative McCollum (D-MN)'s International Protecting Girls By Preventing Child Marriage Act of 2007 (H.R. 3175); Senator Reid (D-NV)'s United Nations Population Fund Restoration Act of 2008 (S. 2682); Senator Biden (D-DE)'s International Violence Against Women Act of 2007 (S. 2279); Senator Durbin (D-IL)'s International Child Marriage Prevention and Assistance Act of 2006 (S. 3651).

- 2010 “Obstetric Fistula Prevention, Treatment, Hope, and Dignity Restoration Act of 2010” (H.R. 5441)** Introduced by Representative Carolyn Maloney (D-NY) to authorize the US president to deliver assistance for the prevention and treatment of obstetric fistula. Co-sponsored by 17 Democrats and 2 Republicans. Reintroduced in 2011 (H.R. 949).
- 2012 “United States Leadership to Eradicate Obstetric Fistula Act” (H.R. 5748)** Introduced by Representative Rosa DeLauro (D-CT) to enact a ten-year strategy for US programming and assistance to eliminate obstetric fistula in sub-Saharan Africa. Co-sponsored by four Democrats.

Comparison & Evaluation of Three Bills on Obstetric Fistula

Below is a table comparing the three main obstetric fistula bills outlined above: Representative Smith’s 2004 Bill (H.R. 4848), Representative Maloney’s 2010 Bill (H.R. 5441) and Representative DeLauro’s 2012 Bill (H.R. 5748). The bills are evaluated within the framework of the three pillars and sub-principles of a full-spectrum approach to obstetric fistula, as articulated in Part I of this brief. The table is followed by a discussion of the bills strengths and weaknesses and recommendations for strengthening US legislation regarding obstetric fistula.

	Standards for Evaluation	Representative Smith’s 2004 Bill (H.R. 4848)	Representative Maloney’s 2010 Bill (H.R. 5441)	Representative DeLauro’s 2012 Bill (H.R. 5748)
<i>Comprehensiveness</i>	<i>Prevention</i>	Promotes dissemination of educational materials (pamphlets, brochures, posters) and appropriate seminars in developing countries	Authorizes the president to address social and health issues leading to obstetric fistula	Includes health education on child birth, risk associated with child marriage, and female genital mutilation Promotes prompt detection of prolonged labor and necessary action through village “labor monitors”
	<i>Treatment</i>	Creates no fewer than 12 Centers of Excellence for	Authorizes the president to support the treatment of	Creates 8 Centers of Clinical Excellence for treatment of obstetric

	treatment	obstetric fistula	fistula
<i>Reintegration</i>	Not mentioned	Supports reintegration and training programs	Promotes public health and health-care delivery system research on rehabilitation
<i>Sustainability & Local Capacity</i>	Not mentioned	Seeks to build local capacity and improve national health systems Provides tools for countries to address fistula Builds on coordination facilitated by the International Obstetric Fistula Working Group	Expands health system capacity and training opportunities
<i>Availability & Accessibility</i>	Provides transportation, temporary shelter, food assistance and surgery for those who do not have resources to pay	Increases access to sexual and reproductive health services	Distributes programs based on the size and demographics of the population suffering from obstetric fistula Promotes referral systems for prenatal and obstetric care and transportation for women to health facilities
<i>Acceptability</i>	Not mentioned	Not mentioned	Incorporates culturally appropriate child-birth education, preparation, and planning, to be provided through Centers of Clinical Excellence Develops localized prevention programs that are culturally appropriate, including

			evidence-based systems of care and instruction in the identification of prolonged labor
<i>Quality</i>	Not mentioned	Not mentioned	<p>Establishes in the United States an International Obstetric Fistula Institute for Sub-Saharan Africa to facilitate data collection and research</p> <p>Promotes use of standard clinical protocols</p> <p>Creates an advisory panel for surgical outcomes and quality, comprised of no fewer than 15 senior practicing surgeons from the United States and other countries</p>
<i>Accountability</i>	Requires reporting by the president on implementation of programs	<p>Requires reporting by the president on implementation of programs</p> <p>Develops and implements evidence-based programs and research to measure effectiveness and efficiency of programs and annual reporting</p>	<p>Requires reporting by the president on implementation of programs</p> <p>Enforces clinical standards and accountability through the US-based Obstetric Fistula Institute</p>
<i>Participation</i>	Not mentioned	Not mentioned	Designs flexible strategies that remain responsive to needs of women afflicted by or who stand at risk of

The table above shows that Representative Smith’s bill, which was referred to committee in 2005, focuses solely on treatment, failing to recognize that obstetric fistula cannot be eliminated if we do not prevent new cases. Representative Maloney’s bill addresses the need to treat obstetric fistula and to address the health and social causes of fistula. It also emphasizes the utilization and development of local capacity, thus contributing to sustainability. However, important principles like acceptability, quality, and participation are not addressed.

Representative DeLauro’s bill addresses fistula through three main initiatives: (1) the establishment in the United States of an International Obstetric Fistula Institute for Sub-Saharan Africa, (2) the creation of eight Centers of Clinical Excellence for the treatment of fistula, and (3) the creation of a US medical corps. The bill, which has been referred to committee, begins to address prevention, treatment, and reintegration. However, through its focus on US-led training and clinical structures, it ignores the reality that the US medical establishment, in general, is not experienced in treating fistula.⁴⁴ The bill does not ensure that information and capacity are localized and sustained. Moreover, its design focuses on accountability to actors in the United States, rather than to the persons most affected on the ground, and it does not incorporate all necessary components of prevention. It also is not designed in the most efficient manner. As a result, the bill does not yet meet several of the standards outlined in Part I of this brief.

Rather than building upon existing efforts and expertise on obstetric fistula, the bill’s initiatives are dependent upon the success of new, US-created institutions. The bill ignores the wealth of knowledge and experience that already exists in the global South and fails to support the important development goals of health-system strengthening and country-level ownership. Moreover, it creates separate, stand-alone fistula treatment centers, which contributes to the lack of integration in reproductive health and maternal-health services. In addition, while it introduces education on child birth, it does not specifically mention voluntary family planning or the importance of locally trained and skilled birth attendants, all crucial components in the prevention of fistula.

⁴⁴ See: distribution of surgeons on the Global Fistula Map (<http://www.globalfistulamap.org>); See also: CE Foust-Wright, SA Shobeiri, CL Curry, LH Quiroz, and MA Nihira, “Medical student knowledge of global health problems: obstetric fistulas in developing countries,” *JOURNAL OF REPRODUCTIVE HEALTH*, 57(9-10), 427-30 (Sept. 2012).

Representative DeLauro's bill has undoubtedly revived US attention for obstetric fistula and its impact on women's lives globally. Its long-term scope and sought-after financial contribution are commendable. Nevertheless, the bill could be even stronger if improved in two key ways:

- **Build on Existing Efforts and Expertise**
 - a. Rather than create stand-alone institutions, US support should work to develop local capacity in accessible and acceptable health facilities. It can do this in part by building upon the existing work of USAID, UNFPA, EngenderHealth, and other international and national organizations.
 - b. Furthermore, the United States should focus on the training and capacity-building of local health professionals to ensure that programs have continued success. A temporary medical corps composed of US doctors will not ensure consistent and long-term care.⁴⁵ Furthermore, US doctors typically are not trained to conduct fistula repair nor do they often have experience with fistula patients. They are therefore not the best the pool of applicants from which fistula surgeons or trainers for health personnel could be sourced. South-to-South training should be encouraged, and investment in obstetric fistula treatment research may be better directed toward communities where the condition is prevalent.

- **Ensure Comprehensiveness of Globally Recognized Principles of Health Interventions**
 - c. The United States must create a comprehensive effort that seeks to prevent future occurrences of fistula and provide treatment and reintegration support to existing sufferers.
 - d. While Representative DeLauro's bill incorporates both prevention and treatment, most of the prevention efforts would be led by US-guided Centers of Clinical Excellence, which indicates a prioritization of treatment and success that would hinge on the creation of new institutions.
 - e. Voluntary family planning should be incorporated into the bill.
 - f. The bill should also emphasize improving the availability and accessibility of emergency obstetric services. This would entail increasing the number of skilled birth attendants as well as a commitment to training and quality control.

⁴⁵ Luwam Semere & Nawal M. Nour, *Obstetric Fistula: Living With Incontinence and Shame*, REVIEWS IN OBSTETRICS & GYNECOLOGY, 193, 193-197 (2008).

- g. The bill should include social and economic support in the form of skills training and counseling that are needed to facilitate the reintegration of women into their communities after fistula treatment.

Action Steps for US Policymakers

This brief asks US policymakers to modify the language of existing legislation or to sponsor new legislation that adopts a full-spectrum approach to eliminating obstetric fistula. Drawing on the principles and critiques offered above, we recommend that legislation should include mechanisms to undertake the following:

1. Deliver appropriate level of funding to *prevent and treat fistula*, as prior bills have done.
2. Expand the *availability* and improve the *quality* of *emergency obstetric care services* to prevent future occurrences of fistula and promote maternal health.
3. Create *sustainable* programs to combat fistula by building the *capacity of local health workers* and capitalizing on existing efforts and expertise.
4. Promote *community health education* on fistula, including on danger signs, prolonged labor, antenatal and obstetric care, the importance of delayed age at marriage and first pregnancy, and voluntary family planning to prevent unintended pregnancies.
5. Provide social and economic support for the *reintegration of women* after their surgeries. *For further information on reintegration, please refer to Appendix A.*

These five action steps will ensure that US assistance provides treatment and reintegration services to fistula patients and helps prevent new cases of fistula. Furthermore, following these steps will ensure that women are better able to access quality health care. In turn, US legislation would help improve the state of maternal health around the world.

Appendix A: Post-Surgical Rehabilitation and Reintegration

Surgery may repair obstetric fistulas, but afterward, women often still experience negative psychosocial and economic consequences, which hinder their ability to restore their lives fully. In the period after surgery, the ability to resume work and access to counseling, health services, and social support are integral to a fistula survivor's rehabilitation and reintegration. Some reintegration services are currently being provided by international health organizations, development agencies, and local agencies. However, the demand for these services is not being met. Moreover, the human and financial resources needed to adequately deliver and assess the quality and effectiveness of rehabilitation and reintegration are insufficient.⁴⁶

Key elements of promising rehabilitation and reintegration programs for women who have received fistula treatment should address the following areas:

- **Ability to Resume Work:** Provide alternate forms of income generation, which do not require physical exertion and meet the varying needs of women.
- **Counseling & Health Services:** Provide psychosocial counseling and access to health services for the future physical and emotional needs of women.
- **Social Support:** Create a supportive social environment by educating communities about fistula.

Ability to Resume Work

In Ukerewe, Tanzania, a peer-reviewed study of women who received surgical repair for fistula focused on their sense of their quality of life, both pre- and post-surgery. Sixty percent of these women described work as most important for helping them restore a sense of normalcy.⁴⁷ However, physical limitations and the fear of experiencing another fistula from bodily exertion often hampered their ability to resume their work.

Such studies show that it is necessary to provide an alternate means of income generation for women during the first year post-surgery, especially for women who lack support from families and partners.⁴⁸ Assistance could include income-generation activities that

⁴⁶ UNFPA. Maternal Health Thematic Fund. Annual Report 2011.

http://www.endfistula.org/webdav/site/endpointfistula/shared/documents/reports/MHTF%202011%20annual%20report%2008_2_2012.pdf

⁴⁷ R. Pope, M. Bangser, & J. H. Requejo, *Restoring Dignity: Social Reintegration After Obstetric Fistula Repair In Ukerewe, Tanzania*. GLOBAL PUBLIC HEALTH. 6(8), 859-873. (2011).

⁴⁸ *Id.*

do not require physical exertion, such as micro-credit, vocational training, and small-business promotion. Women also often require literacy training and even new clothes.⁴⁹

Counseling & Health Services

Following reintegration, some women may still feel and experience isolation.⁵⁰ In a study in West Africa, post-operative counseling was positively associated with women's ability to reintegrate.⁵¹ It resulted in increases in self-esteem scores and indicators for positive behavioral intentions, such as improving health and talking to family members about fistula. It was also associated with an increase in knowledge about fistula and fistula prevention.

Psychosocial counseling can assist women in being comfortable sharing their experiences living with fistula and redeveloping a sense of respect and dignity.⁵² Psychosocial counseling is also important for women as they consider having children and/or remarrying, as these decisions can affect their role and place in society as they reintegrate.⁵³

In addition, following repair, women often have ongoing physical health needs and concerns. Post-operative care should be available and accessible. Ideally, each patient should be connected to a designated health worker who can provide her with post-operative care.⁵⁴ Access to health services should also include discussions on sexual health, future fertility, voluntary family planning, and the importance of access to facilities with the capacity to perform caesarean deliveries.

Social Support

For many women with fistula, familial support is necessary both for accessing treatment and for recovering post-surgery. After treatment, most women are unable to return to work immediately and need economic assistance and physical care. For women without a support network or whose families live a great distance from the treatment centers where initial

⁴⁹ Measure Evaluation RPH. Family Planning And Reproductive Health Indictors Database. Percent Of Obstetric Fistula Treatment Centers That Provide Social Reintegration Services.

http://www.cpc.unc.edu/measure/prh/rh_indicators/specific/of/number-of-fistula-treatment-services-which-include

⁵⁰ J. Molzan Turan, , K. Johnson, & M. Lake Polan, *Experiences Of Women Seeking Medical Care For Obstetric Fistula In Eritrea: Implications For Prevention, Treatment, And Social Reintegration*. GLOBAL PUBLIC HEALTH, 2(1), 64-77. (2007).

⁵¹ K. A. Johnson, J. M Turan, L. Hailemariam, E. Mengsteab, D. Jena, & M. L. Polan, The Role Of Counseling For Obstetric Fistula Patients: Lessons Learned From Eritrea. PATIENT EDUCATION AND COUNSELING, 80(2), 262-265. (2010).

⁵² USAID. Fistula Care, EngenderHealth & IntraHealth, *Prevention and Recognition of Obstetric Fistula Training Package, MODULE 9: PRINCIPLES OF POSTOPERATIVE CARE AND REINTEGRATION OF WOMEN WITH OBSTETRIC FISTULA*, http://www.fistulacare.org/pages/pdf/Training/Module_9_Postoperative_care_and_reintegration_Fistula_Care.pdf.

⁵³ Pope, *supra* note 47.

⁵⁴ Molzan, *supra* note 50.

recovery takes place, temporary accommodations and caregivers are needed.⁵⁵ Funds for transportation may also facilitate the provision of social support.⁵⁶

Studies have noted that community education on fistula and timely surgical repair are important components of rehabilitation and reintegration, as they have a significant impact on perceived quality of life.⁵⁷ For communities to be able to support fistula patients after surgery, they must recognize the cause and the effects of the condition. According to the World Health Organization (WHO), the minimum reintegration service package should include counseling on what fistula is, how the injury is sustained, future risk factors, and how to prevent fistula from occurring again, including through the use of family planning and good obstetric care.⁵⁸

Existing Programs: Platforms & Lessons for US Assistance

From 2010-2011, the number of social rehabilitation centers sponsored by the UNFPA Campaign to End Fistula increased, with 25 new facilities offering social rehabilitation. In addition, 60 percent of countries in which the campaign operates worked to ensure rehabilitation and reintegration services.⁵⁹ In 2011, UNFPA provided social reintegration services to 2,700 people who had received surgical treatment in 19 countries. Services offered counseling, income-generation activities, start-up funding, and business training. UNFPA, in conjunction with the Johns Hopkins University Bloomberg School of Public Health, is also conducting research on post-operative prognosis, improvements in quality of life, social reintegration, and rehabilitation of women who have been treated for fistula.

With assistance from UNFPA, Liberia has become “a pioneer and a role model” in fistula rehabilitation and reintegration.⁶⁰ The Liberia Fistula Project, which involves NGOs and the Ministry of Health and Social Welfare, trains survivors to become fistula advocates and provides them with literacy, business-administration, and design skills. From 2008-2011, 169 women were trained and provided with medical care, a starter kit, skills training, accommodation, and transportation to their homes.⁶¹

Fistula Foundation - Nigeria has provided reintegration services to women who have been successfully treated and those with irreparable fistulas. It is comprised of four

⁵⁵ Pope, *supra* note 47.

⁵⁶ Measure Evaluation RPH, *supra* note 49.

⁵⁷ *Id.*

⁵⁸ Measure Evaluation RPH, *supra* note 49.

⁵⁹ UNFPA, *supra* note 46.

⁶⁰ *Id.*,

⁶¹ John Mulbah, Philderald Pratt and UNFPA. Liberia Fistula Project.

<http://www.endfistula.org/webdav/site/endpointfistula/shared/documents/invisible%20links/IOFWG%202011/Day%202/Liberia%20Presentation.ppt>

departments that provide counseling and outreach, surgical treatment, socioeconomic empowerment, and hostel accommodations. From 2009-2012, with sponsorship by the UNFPA, the Irish government, and the Australian High Commission, the foundation has provided training in various trades and crafts to 3,115 women who were successfully treated for fistula and 411 who did not receive full repairs.^{62,63}

In addition to offering treatment to women suffering from obstetric fistula at the Danja Fistula Center in Niger, the Worldwide Fistula Fund also incorporates social reintegration programs. It provides vocational training, entrepreneurial guidance, and literacy development. These programs last two weeks to eight months based on the needs of the particular patient.⁶⁴

Family Care International works with community-based partner organizations to help women establish a means of earning income through training in modern methods of livestock farming and the provision of \$200 reintegration grants. This helps fistula survivors regain confidence, demonstrate their value to families, and achieve greater status in their communities.⁶⁵ The Hamlin Hospital, Addis Ababa has also developed a technical training program to help post-surgical women become self-reliant and self-sufficient. In addition, the hospital is building a hostel for women who do not have a home to return to after surgery.⁶⁶

Some local NGOs have incorporated social reintegration into their fistula programs. In Tanzania, the Women's Dignity Project, in partnership with EngenderHealth, has called for the institutionalization of reintegration efforts to reduce the "emotional and economic impacts of fistula."⁶⁷ In Mekelle, Ethiopia, The Healing Hands of Joy/ Safe Motherhood Project provides boarding to women prior to their treatment and training in maternal health communications skills and health education. Women also learn literacy and income-generation skills. The Dambata Rehabilitation Centre, supported by the Foundation for Women's Health and Development in Northern Nigeria (FORWARD), offers accommodation for women for up to a

⁶² Fistula Foundation - Nigeria, "Reintegration of Incurable Fistula Survivors," <http://www.endfistula.org/webdav/site/endpointfistula/shared/documents/invisible%20links/IOFWG%202011/Day%201/Reintegration%20of%20Incurable%20Fistula%20Survivors%20II%20-%20Musa%20Ilsa.pptx>.

⁶³ Fistula Foundation - Nigeria, "Social Reintegration of Obstetric Fistula Patients: The Journey so Far," <http://www.endfistula.org/webdav/site/endpointfistula/shared/documents/publications/Social%20Reintegration%20of%20Obstetric%20Fistula%20Patients%20-%20Musa%20Ilsa.ppt>

⁶⁴ Worldwide Fistula Fund, "A Million Eyes on Social Reintegration," <http://worldwidefistulafund.org/1297/a-million-eyes-on-social-reintegration/>

⁶⁵ Family Care International. "New lives for obstetric fistula survivors (continued): more success stories from Burkina Faso," <http://familycareintl.org/blog/2012/04/20/new-lives-for-obstetric-fistula-survivors-continued-more-success-stories-from-burkina-faso/>.

⁶⁶ L. De Bernis, Obstetric Fistula: Guiding Principles For Clinical Management And Programme Development, A New WHO Guideline. INTERNATIONAL JOURNAL OF GYNECOLOGY & OBSTETRICS, 99, S117-S121. (2007).

⁶⁷ Women's Dignity Project and Engenderhealth. "Risk and Resilience: Obstetric Fistula in Tanzania, 2006," (May 21, 2013), <http://www.fistulacare.org/pages/pdf/resources/RiskandResilienceFistulareport.pdf>.

year and provides literacy classes and training in knitting, sewing, and soap-making.⁶⁸ Once trained, women are given money to buy supplies and start their own businesses. During their stays, women also receive psychosocial counseling and are given the opportunity to rediscover normal life by working in the center's vegetable gardens and tending livestock.

In addition to the programs highlighted above, there are numerous community-based and ad hoc programs that serve women in the post-treatment and reintegration period, with the assistance of USAID and EngenderHealth's Fistula Care Project, among other programs.⁶⁹ These various initiatives offer platforms and lessons upon which the US government can build its approach to reintegration as a pillar of eliminating obstetric fistula.

⁶⁸ De Bernis, *supra* note 66.

⁶⁹ USAID, Fistula Care Project, and EngenderHealth, "Social Workers - A Critical Support Group for Rehabilitating and Reintegrating Fistula Clients," <http://isownigeria.org/ISOW%20Presentation.pdf>