

Meeting Report

Obstetric Fistula Prevention as a Catalyst for Safe Motherhood: Successes and Opportunities

March 9-10, 2010
The Carter Center
Atlanta, Georgia

COMPASSION COLLABORATION treatment
surveillance TRANSPORTATION HOPE
DEDICATION EDUCATION training DIGNITY
PREVENTION access DONORS
FUNCTIONING HEALTHCARE SYSTEMS
HEALTH CARE WORKERS caesarean sections
RESTORING safe motherhood



OBSTETRIC FISTULA PREVENTION AS A CATALYST FOR SAFE MOTHERHOOD:
successes and opportunities



Sponsored by HDI (Health & Development International)

PURPOSE OF THIS REPORT

We have written this report to document the proceedings of the meeting on obstetric fistula prevention as a catalyst for safe motherhood, to provide a resource for any person wishing to discover or refer back to information presented at this meeting and to document some of the recent steps in the global effort to eliminate obstetric fistula, which we hope will one day be as successful as smallpox and Guinea Worm eradication.

INQUIRIES regarding this report, the meeting or related topics can be addressed to:

Dr. Anders Seim, Executive Director of HDI: anders@hdi.no

Dr. Rachel Bronzan: rbronzan@msn.com

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A special thank you to Dr. Bill Foege, for a captivating and inspiring keynote speech that renewed the spirit and energy which we all aspire to bring to our work on a daily basis.

Thanks to The Carter Center for providing a warm and welcoming venue, a superb team of people to work with and interesting diversions for the evenings, but we especially thank The Carter Center people for their continued support of work to improve the health and lives of underserved or marginalized people around the world. A particular thanks to Dr. Donald R. Hopkins, Carter Center vice president for health programs and a trustee of HDI, for his thoughtful contributions to the meeting from the time he suggested it onward.

Thanks also to those who did so much behind the scenes to make this meeting such a success. In no particular order, we thank Lisa Wiley, Molly Howard, and their many colleagues at the Carter Center for more than we can recount; Tara Zeravsky and her team at Meeting Expectations for all kinds of organizing assistance; Renee Brown-Bryant of CDC, Ann Clayton and Isa Mhohtaj who together created and printed the meeting's striking poster; Dr. Eve Lackritz and her colleagues at CDC's Maternal and Infant Health branch for contributing staff time on important organizational issues prior to the meeting; to Tony Pietro and everyone we met from the cleaning staff upward at Hotel Indigo Atlanta Midtown for kind hospitality and excellent, efficient, amazingly flexible collaboration before and during our stay; Carrie Barnes and the others at Elise Communications for bringing the meeting out to a much wider audience through many channels; Natasha Cobos for simultaneous translation of the meeting into French for our French-speaking participants; Alexander Fuss and Billy Konkel at Lighting and Production Equipment Inc for their expertise, generous, enthusiastic help, and superb new sound and projection system. The delicious, varied, and beautifully presented food that Jane Quillen and her many chefs and other colleagues at Proof of the Pudding put together for this meeting from breakfast through a gorgeous evening reception was clearly appreciated, and not just by the organizers! Also, Dr. Rachel Bronzan did a huge job as rapporteur both during and after the meeting, pulling together all of the materials into this report and the accompanying CD.

Because this report and these acknowledgements contain statements from several points of view, the organizers would like to thank each and every one of the presenters and participants from three continents for their generous contributions of time, intellectual effort and enthusiasm that made this meeting into the success that it became. We hope and believe that you have thereby contributed importantly to bring the field forward, for the benefit of the women whose lives and dignity we are all striving to protect.

Last and most of all, thanks to Dr. Anders Seim and HDI with its board of trustees for suggesting, organizing and leading the conference. Their vision has linked women's advocates from many places who are working to prevent and treat obstetric fistula, strengthening the international obstetric fistula network through cross-pollination of ideas and efforts.

LIST OF ABBREVIATIONS

BEOC	Basic essential obstetric care
CDC	Centers for Disease Control and Prevention (United States)
CEOC	Comprehensive essential (or emergency) obstetric care
DALY	Disability adjusted life-year
DFID	Department for International Development (United Kingdom)
EmONC	Emergency Obstetric and Neonatal Care
EOC	Emergency obstetric care
HDI	Health and Development International
IOFWG	International Obstetric Fistula Working Group
ISOFS	International Society of Obstetric Fistula Surgeons
LF	Lymphatic filariasis
LSS-EOC	Life saving skills emergency obstetric care
LSTM	Liverpool School of Tropical Medicine
MNCH	Maternal, neonatal and child health
MNH	Maternal and neonatal health
MSF	Médecins Sans Frontières (Doctors Without Borders)
NC	Neonatal care
NGO	Non-governmental organization
PDF	Portable Document Format (Adobe)
TBA	Traditional birth attendant
UN	United Nations
UNFPA	United Nations Population Fund
USAID	United States Agency for International Development
USD	United States dollars
WHO	World Health Organization

EXECUTIVE SUMMARY

Nearly 50 people from Africa, Europe and the United States convened at The Carter Center in Atlanta, Georgia, on March 9 and 10, 2010, to share their work and experiences preventing birth-related mortality and preventing and treating obstetric fistula. National and international agencies, private foundations, NGOs, representatives of Ministries of Health from affected countries and a representative from US congresswoman Rosa DeLauro's office were present. This meeting was held, in part, as follow-up to the October 2005 meeting at which reproductive health experts from four continents outlined practical recommendations for countries affected by obstetric fistula to follow, to help them prevent and treat obstetric fistula while more broadly advancing the cause of safe motherhood.

Dr. Bill Foege (Bill & Melinda Gates Foundation and Emory University) started the presentations with a Keynote Address (presented verbatim in the annex) in which he drew on experiences and lessons from smallpox eradication and challenged listeners to creatively apply those lessons to the expanding effort to prevent obstetric fistula.

Some participants presented ongoing projects and work to prevent and treat obstetric fistula. Others presented updates of the latest estimates of the prevalence of obstructed labor and obstetric fistula, the current worldwide capacity to repair fistulas, the economic impact of obstetric fistula and trends in donor funding and their implication for obstetric fistula.

Dr. Don Hopkins (The Carter Center) closed the presentations with his observations, drawing insightful and useful parallels between Guinea worm eradication and obstetric fistula (this talk is also presented verbatim in the annex). Finally, a plenary discussion was led by Professor Herbert (Bert) Peterson (University of North Carolina).

CONCLUSIONS from the meeting:

1. There is enough science and practical experience now to scale up promising interventions. **Obstructed labor is the low-hanging fruit of maternal mortality**, and we must act now to reduce maternal morbidity and maternal and infant mortality from obstructed labor.
2. **Prevention** of obstetric fistula is highly **cost effective**.
3. **We need more data on the economic impact of obstetric fistula**; this information may be a valuable tool for generating political will for prevention and treatment.
4. There is a need for **standardized indicators / a common language** for those working on obstetric fistula.

NEXT STEPS:

1. **Scale up and continue investigating promising interventions.** Such interventions include:
 - a. Community mobilization within a "catalyst approach" system (as piloted in Niger)
 - b. Maternity waiting areas/homes (as in Ethiopia)
 - c. Facility-based audits, as a means of improving care within facilities
 - d. Rights-based initiative approach to empower individuals and communities

2. Agree on and start using a few **core indicators**.
3. When implementing programs, be sure to collect data that **advance the policy discussion**
4. **Keep a rapid, results-oriented (catalyst) approach.** Develop and maintain the identity of the group of people and organizations who attended this meeting, a group which is different from many others in that its members focus their efforts on rapid, results-oriented interventions to prevent and treat obstetric fistula, whatever the specific methodology used. The group will aim to meet regularly to share experiences, exchange ideas and maintain momentum while making every effort to connect with, and improve connections within, the greater global obstetric fistula community.

BACKGROUND

Three key elements provide the backdrop for this meeting:

The number of women dying in childbirth has remained essentially unchanged since the late 1960s with an estimated 500,000 – 600,000 women dying each and every year.¹ That some poor countries and most “northern” countries have dramatically lowered maternal deaths underscores glaring inequity, and the fact that most of these women are dying each year from preventable causes. Prevention has until recently focused on laudable, essential, long-term solutions like having a midwife at every birth, having functioning and upgraded hospital services available to all, education for all girls, etc.

The question arises; must the international community be absolutely hamstrung and unavoidably tied to helpless watching, as another 14 million or more women are killed over the next 40 years while the world waits for such approaches to have effect? Or can relatively modest investment in additional approaches save lives and protect women’s dignity by rapidly preventing obstetric fistula and the obstructed labor mortality that lies behind it? Could interventions to prevent obstetric fistula and obstructed labor deaths also speed prevention of post partum hemorrhage and eclampsia?

Several diseases have been or are being eliminated or even eradicated using a fairly uniform set of organizational public health tools combined with very different technologies including vaccines, helicopters to spray rivers, annual administration of medications to populations, safe or filtered water, etc. At a global reproductive health policy retreat in 2005, WHO, UNFPA, Ministry of Health professionals from nine severely afflicted countries in Asia and different parts of Africa, reproductive health academicians from four continents, three leading bilateral development assistance agencies, US Centers for Disease Control and Prevention (CDC), and NGOs agreed on a number of recommendations. Delegates agreed that obstetric fistula can be used to catalyze maternal health. Among other things, delegates agreed that it is appropriate to use organizational tools from successful disease eradication efforts to explore rapid prevention of maternal deaths and obstetric fistula.

Varied approaches to rapid prevention of maternal mortality have in recent years been producing promising results. Different initiatives have been introduced independently of one another. It was considered reasonable to examine results so far, to consider whether it is time to scale up one or more of these initiatives.

¹ Subsequent to the meeting, as the report was being finalized, Hogan et al. published an article in Lancet estimating global maternal deaths in 2008 at 342,900 (uncertainty interval 302,100 – 394,300); (www.thelancet.com; Published online April 12, 2010; DOI:10.1016/S0140-6736(10)60518-1). That number too is packed with huge numbers of preventable deaths.

OBJECTIVES OF THIS MEETING

The objectives of this meeting were to:

- Convene individuals and institutions from Africa, Europe, and North America who are working on different initiatives to prevent and treat obstetric fistula
- Share and compare experiences
- Consider whether results currently being achieved by various initiatives are ready to be scaled up
- Discuss ways to move this work forward for those initiatives that seem to warrant scaling-up

KEYNOTE ADDRESS – DR. BILL FOEGE (GATES FOUNDATION, EMORY UNIVERSITY)

In his address Dr. Foegen draws on lessons learned from smallpox eradication to illustrate what will be needed for success in eliminating obstetric fistula, and he challenges and inspires listeners to maintain perspective, to draw others to look the problem of obstetric fistula “in the eye”, and to be tenacious and optimistic in their efforts to eliminate obstetric fistula. To do justice to Dr. Foegen’s eloquent and inspiring speech, the audio recording is included on the meeting CD. A transcript of the address is included in Annex 2.

SUMMARY OF PRESENTATIONS

OPENING REMARKS – SARAH DASH, HEALTH POLICY ADVISOR AND LEGISLATIVE AIDE TO CONGRESSWOMAN ROSA DELAURO

Sarah Dash is a health policy advisor and legislative aide to U.S. Congresswoman Rosa DeLauro. Monday, March 8, 2010 was International Women’s Day. The week before, in recognition of International Women’s Day, many US congresswomen gave statements which were included in the congressional record. In her opening comments, Sarah Dash read Congresswoman Rosa DeLauro’s statement, which was inspired by and drawn from Nicholas Kristof’s book “Half the Sky”. The statement reads:

Madam speaker, I rise to draw our attention to a worldwide problem we could do much more to resolve: obstetric fistulas. Imagine you are 13 years old. You are married against your will to a much older man and become pregnant. When the baby is due you have no medical care, your body is too small, the baby gets stuck. You nearly die. But instead, you wake up to learn that it is your baby who has died, and you now have a fistula, a hole caused by the days of prolonged labor and resulting rotting-away of internal tissue. You are incontinent and cannot walk. You are shunned by your husband and your village. It is hard to imagine being so alone. But this is the real story of Mahabouba, a young girl in Ethiopia, and an estimated 2 million women like her suffer from obstetric fistulas, though we need much better data on this problem. They have suffered in this unspeakable way because they lacked maternity care or were married too young or even because their husbands would not let them go to the hospital. As we mark this day let us raise our voices for these women, let us commit our power and our compassion to providing lifesaving maternity care and preventing these tragedies. Let us help them to stand up and bring new hope for their future. Thank you.

RATIONALE FOR THIS MEETING AND THE CATALYST APPROACH TO PUBLIC HEALTH – DR. ANDERS SEIM, HDI

First, what is the rationale for this meeting? This meeting is based on the idea that demonstrably effective public health tools can perhaps be applied to good effect, to rapidly prevent birth-related deaths and obstetric fistulas.

When the Guinea worm eradication effort began applying the “Catalyst Approach to Public Health”², 3.5 million people worldwide had Guinea worm. In 2009, only 3,210 people in the world had the disease. This is not a disease of the rich or of developed countries with high-functioning health systems and no corruption, yet it is being eradicated. In Nigeria, more than 653,000 people had Guinea worm the first year they counted; in 2008, only 38 individuals had Guinea worm. In 2009, there were 0 (zero) cases of Guinea worm in Nigeria.

Similarly, lymphatic filariasis (LF) is being eliminated. Populations are treated yearly with medication. Scaling up, in 2008, 496 million people worldwide received medication to prevent LF transmission. LF transmission has been stopped in Togo without any high-powered financial support, but with a little help from their friends (CDC and HDI).

Can we do the same with a biologically non-eradicable disease? Can we organize our work in analogous ways to save women’s lives in childbirth and to prevent obstetric fistula? A variety of recent initiatives have had local success, several of which are presented at this meeting. Are any of these approaches ready to be scaled up?

500,000-600,000 women die in childbirth every year. Obstructed labor and hemorrhage are major causes. But these are the same figure as in the 1960s. 2 million women are believed to have fistula. 50,000-100,000 women get obstetric fistula every year. Only 3,500 repairs are done each year [2007 estimate, probably closer to 10,000 repairs per year now, see Dr. Arrowsmith’s talk]. We will never control this problem through treatment alone.

Good people have worked on prevention, but to date prevention has consisted primarily of educating girls, promoting women’s rights, having midwives for every delivery and prenatal care for every pregnant woman, updating hospitals everywhere, stopping early marriage. These goals are all good and appropriate, but they take time. Must we sit on our hands for the next 30 years with nothing happening as another 14 million women die in childbirth? Or can we do something on the side with relatively modest amounts of money as we continue with these longer-term efforts?

Every woman who gives birth is at risk of obstetric fistula, and every woman and child is at risk of death during childbirth. Women can die within a hundred yards of a hospital that would have done a C-section for free. In Sierra Leone, one woman died of obstructed labor at home even though one wall in her house was also a wall of the hospital next door.

Availability is not enough, this needs a system.

There was a reproductive health policy meeting hosted by UNFPA, CDC, and HDI at Emory in 2005 to get policy agreement from UN agencies, bilateral development assistance agencies and universities, to see whether this kind of approach made sense. One of the conclusions of that meeting was that it does make sense.

² Seim AR. Time for an additional paradigm? The community-based catalyst approach to public health. Bull World Health Organ. 2005 May;83(5):392-4.

Second, what is the catalyst approach to public health? This has come out of CDC, and the guinea worm program is one example of its successful implementation. There are eleven elements that are arguably essential in a community-based catalyst approach to public health.

1. An organization (one or two people) somewhere in the world, who will keep track of numbers.
2. Five or ten people who really care
3. Data manager and program manager in each country
4. Resident technical advisor in each country
5. International meeting twice a year – drives the effort with huge efficiency
6. National program review every year
7. Annual retraining for village volunteers
8. A network of supervisors to visit them every month
9. Transportation
10. Course correction mechanisms (science)
11. Mobilization of political support

Criteria for when village volunteers can be used effectively are presented by A. Seim in the May 2005 WHO Bulletin article (see footnote, previous page), while the eleventh element above was accidentally omitted in that article.

How much would it cost to do for obstetric fistula what has been done for Guinea worm? It might arguably cost about 5 million USD a year for the catalyst aspects (not for C-sections and ambulances) – twice the cost of the Guinea worm program to cover 12 African countries. In Niger the cost has been “guesstimated” to be 22 cents per year per person in the population, \$10 per catastrophe avoided. The cost, the economic loss to the family, is provisionally estimated to be \$2 per day, \$720 per year for 10 years or however long the woman lives. Should that be sustainable? If so, who should pay for it? We have the needed technology, and we know what to do. It’s time to stop this river of suffering.

COUNTRY PRESENTATIONS

The following are brief summaries of presentations on specific projects aiming to prevent and treat obstetric fistula, prevent birth-related maternal deaths, and improve maternal and neonatal health more generally. PDF files of the slides from most of the presentations are available on the conference CD.

NIGER’S MATERNAL DEATH AND OBSTETRIC FISTULA PREVENTION PROJECT – DR. ZEIDOU ALASSOUM, HDI-NIGER

Niger’s Maternal Death and Obstetric Fistula Prevention Project began on February 1, 2008 in two rural cantons of Niger, covering an estimated population of 100,000. This project extends the health system beyond rural health centers by using an innovative community-based approach with villagers as the main actors. The project uses training, monthly supervision, local FM radio stations and other means to

encourage the population to participate in life-saving activities including prompt emergency evacuation
- **The sun must NEVER rise twice over a woman giving birth!**

Almost 600 village volunteers (a woman and a man in each village) were recruited in about 300 localities. They were trained and equipped with educational support materials including a cotton flip-chart, reporting forms that do not require literacy and a register for monthly supervisory remarks. Village volunteers report monthly data on new pregnancies, prenatal consultations, deliveries, maternal deaths and fistula incidence, etc. The aim was to reduce obstructed labor deaths by 75% and obstetric fistula incidence by 50% within two years, aims that were severely criticized for being overly ambitious.

Results

After 23 months of implementation, the project has achieved the following:

- Obstructed labor mortality was reduced from 11 deaths in 2007 to two deaths in 2008 (one in April, one in May 2008); no woman has died of obstructed labor since May 2008, i.e. 20 months so far
- For obstetric fistula there were between 4 and 7 cases in 2007 (uncertainty is based on historical data collection), 5 cases in 2008 and 3 cases in 2009
- Each month, on average, 93% of villages reported monthly data (Range: 85% -100%)
- Prenatal consultations increased (3205 women in '07, 4272 in '08 and 5392 in '09)
- Deliveries assisted by a health professional increased (666 in '07, 880 in '08 and 1196 in '09)
- Postnatal consultations also increased (617 in '07, 1121 in '08, 1409 in '09)
- There is additional, qualitative evidence that the population understands and supports the project
- Post partum hemorrhage deaths have remained stable and high, reinforcing the need for expansion to also include this cause of death. The project has secured national ethics-committee support for a proposed approach and is awaiting final government approval to also address hemorrhage deaths.

Based on these results, the project is being expanded, aiming to cover 263,000 people in 2010.

DISCUSSION: It was noted that the community chooses the village volunteers, selecting individuals who are respected by, and who in turn respect, the community. The volunteers must also be permanently resident in the community and must not travel frequently. Also, 2007 figures, collected retrospectively through interviews by a physician, are probably not very accurate. In the ongoing system, a physician conducts a verbal autopsy for every maternal death. Don Hopkins underscored the importance and success of encouraging villagers to engage in what are fundamentally their own problems – the approach was highly successful in projects with Guinea worm and trachoma – and the impressive result that communities move from being unwilling to let their women go to hospital if her husband is away and cannot give his permission, to actively planning and arranging transportation ahead of time.

STRATEGIES TO REDUCE MATERNAL MORTALITY IN NIGERIA, INDIA AND MEXICO – JUDITH HELZNER, JOHN D. AND CATHERINE T. MACARTHUR FOUNDATION

Maternal mortality has been relatively stable over the last 20 years at about 500,000 deaths per year. However, there are now evidence-based interventions that, if scaled up appropriately, could represent a major breakthrough in terms of reducing maternal deaths in the years ahead.

Starting in 2001, the MacArthur Foundation expanded its focus to include maternal health. The Foundation provides support to agents of change (NGOs, researchers) and explicitly focuses on scaling up these agents' efforts to influence government policies and systems. Examples include cause-of-death interventions, personnel changes and targeted advocacy.

Worldwide, about 25% of maternal deaths are attributable to postpartum hemorrhage. Postpartum hemorrhage can be reduced through 1) prevention, including (a) offering uterotonic drugs such as oral misoprostol after delivery in low resource settings, or oxytocin in facilities and (b) active management of the third stage of labor during deliveries; and 2) management of postpartum hemorrhage when it occurs – for example, the AntiShock Garment stabilizes patient and provides time for transfer to an appropriate facility and can prevent up to 60% of deaths from postpartum hemorrhage. Together these interventions are capable of reducing overall maternal mortality by up to 80%.

About 12% of maternal deaths globally are due to eclampsia – more in Northern Nigeria where a pilot project by Population Council trained ten hospitals in the use of magnesium sulfate to prevent eclampsia and showed a dramatic decrease in deaths. The Ministry of Health is now scaling up drug distribution and training to all states.

Task-shifting to the lowest skilled cadre capable of conducting the task helps allocate scarce human resources appropriately. In India, the OB-GYN professional society supports training of general MDs in emergency obstetric care, and the non-profit grantee Action Research and Training for Health (ARTH) is helping the state of Rajasthan transfer maternal care from MDs to skilled nurse-midwives. This helps overcome the insufficient number and uneven geographic distribution of OB-GYNs and general MDs, respectively.

In Mexico (not presented at the time of the talk, but mentioned during discussion in one of the sessions), budget analysis by Fundar³ showed inequity/inadequacy of maternal health federal-level investments by state in Mexico. Use of that analysis by advocacy NGOs led to \$48 million increase in federal allocation with better distribution to high mortality states, followed by a 300% increase in the rate of decline of maternal mortality in Mexico. The first regional training on maternal health budget analysis is being carried out in Africa now.

³ Fundar is an independent and non-partisan non-governmental organization based in Mexico dedicated to promoting substantive democracy by monitoring public policies and institutions through applied research and critical thinking.

WOMEN’S DIGNITY – CHRISTINE MULINDWA-MATOVU, EXECUTIVE DIRECTOR, WOMEN’S DIGNITY PROJECT, TANZANIA

Women’s Dignity Project, founded in 2002 develops and implements innovative and credible approaches to use research findings as evidence, to generate public debate and to build strategic partnerships. Women’s Dignity has conducted several major research studies concerning fistula; the first one, the Tanzania Fistula Survey in 2001, officially brought the issue of fistula into the limelight in Tanzania. The research is used to create awareness in the community of the link between maternal mortality and equity in health, to mobilize the community to utilize services and generate solutions, and to hold policy makers and service providers accountable. The research is also used for advocacy – to make policy makers aware that 1) fistula exists and can be prevented and treated, 2) fistula, maternal deaths and equity in provision of health services are linked and 3) quality service provision is linked to uptake of services. The community is reached and educated through drama, music, dance, TV, radio, mobile ads on taxis and other means. Policy makers, stakeholders, journalists and the general public are also reached through photo exhibits, seminars, workshops and meetings.

Women’s Dignity is part of various strategic partnerships, is a member of the National Fistula Program (NFP), is a participant in the UNFPA Campaign to end Fistula, is part of the White Ribbon Alliance Tanzania and plays a coordinating role for Health Equity Group, which promotes equity in health through advocacy and empowering communities with information.

Future work will include a greater focus on monitoring and evaluation to measure the impact of Women’s Dignity’s work, creation of a data-bank including a fistula database, and regional expansion of the programme to other countries, starting with Uganda.

BARBARA MAY FOUNDATION IN THE AMHARA AND AFAR REGIONS, ETHIOPIA – DR. ANDREW BROWNING

The maternal mortality rate in Ethiopia is 673 deaths per 100,000 live births according to the 2005 Demographic and Health Survey, but a survey of traditional birth attendants in the Afar region places the rate at 7500 per 100,000 live births. The Amhara and Afar regions differ significantly in their geography, but both areas have severe shortages of health care workers, great barriers to transportation to reach the limited health care and limited public faith in the health system that does exist. The ‘big five’ causes of maternal death (hemorrhage, obstructed labour, infection, eclampsia, and abortion complications) can be addressed by preventing the ‘three delays’ that lead to these complications and death: delay in deciding to get care, delay in reaching care, delay in instituting care.

To solve these problems a three-tiered health network is being established, using traditional structures to enhance basic obstetric care and improve the three delays and adding emergency obstetric care to prevent complications from the big five (such as obstetric fistula).

Layer 1: 650 traditional birth attendants in nomadic villages were trained and equipped to identify and refer high risk pregnant women.

Layer 2: 'Waiting areas' are being built along the road and next to existing government health centers where 'high risk' women can go prior to delivery. These are manned by midwives or health workers who are able to deliver basic obstetric care and refer to the third layer as needed.

Layer 3: Emergency obstetric care service (EmOC) is being established next to government health centers and overseen by volunteer obstetricians and midwives (typically from outside Ethiopia) who will provide the service and train local health workers in EmOC. Patients are retrieved by ambulance after a referral call is made by radio from the waiting areas.

Difficulties encountered but being addressed include non-acceptance of waiting areas, family difficulties with the mother being away for an extended period, difficulties identifying 'high risk' women, TBAs not using the system appropriately, the maternity centre being asked to do more than deliveries and reliance on volunteer obstetricians in the initial phase.

DISCUSSION: It was noted that this is a very powerful approach using a model that is simple and highly effective. It was also noted that although short and nulliparous women are potentially at higher risk of complications, identifying 'high risk' women has only modest power to predict exactly who will experience obstructed labor. There was discussion of the utility of utilizing waiting areas for a majority of women.

TOPICAL PRESENTATIONS

The following are summaries of topical presentations made during the meeting. PDF files of the slides from most presentations are available on the conference CD.

A GLOBAL OVERVIEW: THE EPIDEMIOLOGY OF OBSTRUCTED LABOR MORTALITY – DR. LINDA BARTLETT, JOHNS HOPKINS UNIVERSITY

Obstructed labor is the failure of labor to progress due to mechanical causes (mother, baby, or both = cephalopelvic disproportion (CPD)) and is more prevalent with young maternal age, small or stunted pelvis from early age at first birth and obesity. Obstructed labor causes substantial morbidity and mortality. In nulliparous women obstructed labor tends to lead to decreased uterine activity which in turn can lead to obstetric fistula whereas multiparous women are more likely to go on to uterine rupture. Obstructed labor mortality is 98 – 100% preventable when risk factors and health system issues are addressed.

Data are available on the prevalence of obstructed labor and its associated mortality. WHO conducted a systematic review of the literature to obtain prevalence and incidence data on maternal morbidity and mortality. There was quite a lot of variability between studies/countries – obstructed labor occurred in 1.1% of labors in developed countries and 5.8% of deliveries in moderately developed countries, with the lowest prevalence in the least developed countries. This may be due in part to the fact that a greater proportion of women deliver in facilities in developed countries and obstructed labor may therefore be more likely to be diagnosed there. The prevalence of obstructed labor was significantly different

between community based studies (3%) and facility based studies (5%). There was a significant difference between the countries with the highest and lowest prevalence of obstructed labor, but there was no significant difference between rural and urban settings. In the 2006 WHO systematic review of causes of maternal death published in the Lancet, obstructed labor caused 0% of maternal deaths in developed countries and 4.1% of maternal deaths in Africa (it was the 4th leading cause of maternal death after hemorrhage, sepsis and hypertension). In Asia, obstructed labor was the third leading cause of maternal death after hemorrhage and sepsis, and in Latin American it was the third leading cause of maternal death, resulting in 13.4% of maternal deaths.

There are limited data on the case fatality rate for obstructed labor. In Ethiopia, 9% of those with obstructed labor die and perinatal mortality is very high (62%). Overall there is a 2-10% prevalence of obstructed labor among deliveries, it is the 3rd to 4th leading cause of maternal mortality. Globally, obstructed labor accounts for about 7-8% of maternal deaths with significant regional differences (ranging from 4-13% of maternal deaths). These figures are beginning to show signs of declining.

There are many challenges to measuring obstructed labor. It is a clinical diagnosis defined by poor progress of fetal descent with adequate uterine labor along with objective signs, e.g. molding. Length of labor is often a proxy indicator of obstructed labor in many studies. It is often hard to determine onset of labor and to distinguish false labor from cervical dilation, and the rate of spontaneous labor progress can be slow and still be normal. Medical interventions can affect labor duration. Non-facility-based data are subject to recall bias.

In the studies in the WHO systematic review there was lack of uniformity in reporting criteria (12 to 18 to 24 hours of labor). Future studies will benefit from more uniform criteria/definitions (and the WHO is working on this). Prevention strategies to reduce complications include: primary prevention – address risk factors such as undernutrition and young age at marriage and first birth, secondary prevention – through detection of long labor, use of partograph, not letting the sun set twice on a woman in labor, with appropriate referral, and tertiary prevention – to prevent mortality once obstructed labor has occurred, primarily through C-section.

A GLOBAL OVERVIEW: THE EPIDEMIOLOGY OF OBSTETRIC FISTULA – KATIE GIFFORD, UNFPA AND FLORINA SERBANESCU, CENTERS FOR DISEASE CONTROL AND PREVENTION

(Florina Serbanescu): Obstructed labor is the fourth most common major obstetric complication worldwide, and the fourth most common cause of maternal death in childbirth, causing an estimated 34,000 maternal deaths annually. The primary complication in the woman who survives is obstetric fistula. 80-100% of obstetric fistula cases are caused by obstructed labor; other causes of fistula include symphysiotomy, destructive operative deliveries, operative vaginal deliveries, C-sections and some traditional practices, such as gishiri cuts. About 4 million women a year suffer from obstructed labor and, when neglected, this leads to obstetric fistula in about 2.15% of cases – approximately 50,000 new cases per year.

Risk factors for obstetric fistula include:

- Reproductive factors
 - Cephalo-pelvic disproportion
 - Large fetus compared to the pelvis
 - Malrotation or malpresentation
 - Narrow pelvis, short stature
 - Young maternal age at birth
- Socioeconomic factors
 - Poverty
 - Low or no education
 - Rural residence
 - Early marriage
 - Low women's status
- Health-system related factors
 - Poor infrastructure
 - Lack of skilled personnel
 - Limited hours of operation
 - Fees
 - Poor quality of care

Africa is the region where the percentage of deliveries attended by a skilled caregiver has increased most slowly over the past two decades.

Accurate measures of incidence and prevalence of obstetric fistula are lacking; many of the studies to date are hospital-based studies, yet population-based surveys often result in overestimates (reporting of urinary incontinence that may be due to other causes) and questions are not validated. There is an acute need to develop and disseminate tools for surveys, surveillance and research.

(Katie Gifford): Expanding on the presentation by Florina, Katie discussed global estimates of obstetric fistula prevalence, the obstetric fistula needs assessments conducted to date and what is being done now to address the data gaps.

According to the World Health Organization's Global Burden of Disease Estimates (2004), worldwide there are approximately 4 million cases of obstructed labor annually, with 75% of obstructed labor occurring in South-East Asia and Africa. Many of the global prevalence estimates of fistula are based upon the number of women who seek care, and these are likely underestimates. The prevalence is difficult to assess because women who suffer with obstetric fistula are usually difficult to find unless they self identify or present for care. Women often face multiple barriers in seeking care, including lack of awareness of treatment availability, cost, absence of decision-making ability and social stigma, all of which affect the number of women seen in a facility and therefore the accuracy of fistula prevalence data. Available data may not be reliable or generalizable because they are often based on small scale studies, facility-based data collection, or population-based studies with low specificity. Urinary

incontinence not related to fistula is a likely source of overreporting. Estimates of fistula prevalence range from 654,000 to 3.5 million with an estimated 50,000 to 80,000 new cases annually.

In 2003, EngenderHealth and UNFPA conducted the first ever large scale mapping of obstetric fistula in nine African countries. To date, a total of 41 countries have mapped the condition, with variations in approach and depth of analysis. Individual country assessments provide important information on the contextual situation: the capacity of the country to provide fistula prevention, treatment and rehabilitation, perspectives of women, communities and providers. But most data are not nationally representative and are not comparable across countries.

Some of the key findings that emerged frequently in the country assessments were limited access to emergency obstetric care, low C-section rates, high number of deliveries at home or with a traditional birth attendant, low use of antenatal care and family planning, low awareness of the importance of skilled birth attendance and of the risks of pregnancy and childbirth, poor transport, bad roads and lack of funds for transport and care.

To address the data gap, UNFPA has worked with partners to support the development of a set of fistula questions within the revised emergency obstetric care facility-based assessment tools. Additionally, partners including UNFPA developed a standard fistula module for the Demographic and Health Survey, though to date this has not been validated through clinical examination. The Data, Indicators and Research Working Committee of the international Obstetric Fistula Working Group has developed a shortlist of obstetric fistula indicators including impact, policy and social environment, prevention, treatment and reintegration. Additionally, it is recommended that countries integrate obstetric fistula into national reproductive health policies and plans. Obstetric fistula indicators should be included in the Health Management Information System (HMIS) and the national register of maternal mortality. The Geneva Foundation for Medical Education and Research data collection database is being reviewed to ensure agreement between its data points and the indicators included in the shortlist. This database should be employed for collecting data on obstetric fistula.

UNFPA recognizes the data limitations and gaps that exist in the work to address obstetric fistula. It is essential to have more robust and comparable data for effective program approaches, increased advocacy and policy level attention.

DISCUSSION: Dr. Don Hopkins stressed that it is best to identify 6 or 7 core indicators that should be collected, out of the 50-odd proposed. This is in fact being done, and countries or researchers can select from the other indicators to collect data as needed for specific settings or purposes.

OBSTETRIC FISTULA TREATMENT CAPACITY: GLOBAL STATUS – DR. STEVE ARROWSMITH, WORLDWIDE FISTULA FUND

Limited data are available on the worldwide capacity for treatment of obstetric fistula. The prevalence is essentially unknown (perhaps 4 million women living with obstetric fistula); incidence data suggest about 130,000 new cases of obstetric fistula occur every year. It is difficult to assess global capacity for

treatment of fistula – individual treatment sites may have multiple sources of funding and may be counted twice, and there is probably a significant amount of surgery occurring at non-affiliated facilities that is not recorded. Eighty surgeons participated in a recent survey of obstetric fistula repair, Pakistan reports 35 obstetric fistula surgeons, and there were 50 participants at the first meeting of the International Society of Obstetric Fistula Surgeons (ISOFS); 300 participants at the most recent ISOFS meeting. A reasonable estimate is that about 10,000 to 11,000 repairs are performed annually, worldwide. USAID and UNFPA have funded approximately 29,000 repairs since the beginning of their programs (~2004). There is clearly more capacity than there used to be, but have 520,000 fistulas occurred in the past years while only 30,000 were repaired?

Dr. Arrowsmith emphasized that prevention and treatment are partnered, and people in both areas must work together. He highlighted the similarities between the two in terms of the need for data, accountability, resources and capacity, and declared that there is a **moral imperative** for the global community to invest in and improve both.

DISCUSSION: The discussion focused both on the burden of disease (attendees discussed the idea that the incidence of obstetric fistula is likely closer to 130,000 new cases per year rather than 50,000, though data are lacking) and on key aspects of training for obstetric fistula repair. It was emphasized that it is important to pick trainees who are interested and provide close follow-up and ongoing support; training is a lifelong process not a discrete event. There is hope to develop accreditation guidelines. ISOFS is about to implement a fistula repair guideline that could be used for accreditation.

CAN OBSTETRIC FISTULA PREVENTION WORK IN UNSTABLE SITUATIONS? – GILLIAN SLINGER, DOCTORS WITHOUT BORDERS (MSF)

MSF began obstetric fistula repair activities in 2006, in two sites, and has since expanded to nine sites in five countries. MSF also refers fistula patients for repair to partners (MoH and others) in these countries. Seven of the projects are fistula camps or campaigns, the other two are on-going fistula projects that also provide comprehensive emergency obstetric and neonatal care (Abéché, Chad and Jahun, Nigeria). Four of the nine projects are in stable contexts, five of the nine are in unstable contexts. Obstetric fistula prevention in unstable situations occurs at four levels, all in concert with partners:

- Level 1 – Prevent the first fistula by providing emergency obstetric and neonatal care (EmONC) services with skilled attendants through technical support, equipment, training, and lobbying the MoH; also establish functioning referral and communication system
- Level 2 – Sensitize communities, women, men, mothers in law, TBAs, leaders
- Level 3 – Employ foley catheter treatment for at risk and fresh fistula cases (many fistulas will heal themselves with foley catheter treatment); where foley catheter treatment is not successful or for a vesico-vaginal fistula that is not fresh, use fistula registers to record patient contact details and contact them when surgical fistula repair is available
- Level 4 – Prevent subsequent fistulas post repair through sensitization, follow-up, focal points, and maternity waiting homes.

In 2009, EmONC activities in MSF contributed to prevention of obstetric fistula in stable and unstable contexts through 51 basic emergency obstetric and neonatal care centres, 54 comprehensive emergency obstetric and neonatal care centres, skilled attendants at more than 100,000 deliveries and more than 12,000 C-sections.

Challenges include access to skilled attendants, safety of staff and patients, staff retention, likely disruption of activities if very unstable and maintaining an effective working partnership. But, YES! It is challenging but POSSIBLE to prevent obstetric fistula in unstable situations.

DISCUSSION: Dr. Andrew Browning noted that in Ethiopia they have a waiting area for all women who have had previous OF, and the outcomes for these women, after C-section, are dramatically better than for those women whose husbands prevented their going to the waiting area. As a means of feedback to the community on these statistics, the team sometimes calls on postpartum women who had C-section to report to antenatal women in the hospital that they are there with a healthy baby because of the C-section.

BUILDING CAPACITY FOR ESSENTIAL OBSTETRIC CARE – DR. NYNKE VAN DEN BROEK, LIVERPOOL SCHOOL OF TROPICAL MEDICINE

Dr. van den Broek presented two approaches to improving maternal and neonatal health in developing countries. First, baseline surveys in sub-Saharan African countries (including Malawi, Kenya, Sierra Leone and Nigeria) demonstrated a paucity of both basic and comprehensive essential (emergency) obstetric care (BEOC and CEOC). Issues identified included de-motivated staff who lacked knowledge and skills to effectively diagnose and manage obstetric and newborn complications and who were also not 'empowered', poor working environment, lack of supportive supervision, and lack of leadership and team work.

A new life saving skills emergency obstetric care and neonatal care training package (LSS-EOC and NC) was developed by WHO, LSTM and the Royal College of Obstetricians and Gynecologists and is being delivered and evaluated in 5 African and 3 Asian countries. The package is a 3-4 day competency based training utilizing adult education techniques and focusing on the nine signal functions of EOC, 5 main causes of maternal mortality (including obstructed labour), and complications of C-section. Evaluation of the training, with pre- and post- training assessments, revealed: participants found it enjoyable and useful, knowledge and skills of participants were significantly improved, behaviors and practices in providing care were improved and there were measurable improvements in health outcomes (e.g. increased use of the partograph with earlier detection of obstructed labor, decreased maternal morbidity and reduced fresh still births).

A second approach to improving MNH used audit techniques to improve the third delay: delay in receiving care after getting to the health care facility. The audit cycle: 1) select standards to audit, 2) measure current practice, 3) feed back and identify necessary changes, 4) implement changes, 5) re-evaluate practice, and then back to #1. This approach was applied to standards for management of prolonged and obstructed labour in Kenya and Malawi. There were impressive improvements in the use

and quality of partographs, and in time to C-section for obstructed labour. The approach is particularly effective because caregivers themselves become aware of the shortcomings of the care provided in their system, work to make the improvements, can measure and experience the positive change over a relatively short period and are ultimately motivated to continue the approach and improve service delivery and health outcomes in their institutions.

ONGOING RESEARCH AND RECENT FINDINGS ON PREVENTING MATERNAL MORTALITY – DR. MARIO MERIALDI, WHO AND PROF. BERT PETERSON, UNIVERSITY OF NORTH CAROLINA

Dr. Merialdi: There is an ongoing collaborative effort in maternal health to develop a systematic approach to address needs that arise in the field. This movement started as a discussion group (with support from the Maternal Health Task Force), and hopefully others will join. There is a common denominator to many of the presentations from the first day of this meeting: the need to address compelling needs from the field. The critical issue is to establish a strong link between knowledge and action. We heard about research gaps, either in terms of lack of data, or lack of clinical or biomedical information, but also a lack of information and knowledge on *how* to implement, in the most effective way, interventions that we know are effective. The other challenges that we face are the barriers that prevent the translation of knowledge into action, which often produce implementation bottlenecks. All these conditions end up creating health system deficiencies. How do we respond to these problems in a successful way?

Peter Piot, previous director of UNAIDS, told a story of how the HIV/AIDS community evolved, how they became so successful and were able to generate so much awareness and create so much attention to mobilize resources effectively. The tipping point was when the community agreed on critical issues, came to consensus on concrete action. They agreed to treat as many people as possible around the world. Consensus was not 100%, more like 60-70%, but was enough to present the community as a unified structure with a common framework and a common objective. This gave the opportunity for people to join and find their niche in the framework. For example, the Clinton Foundation decided their role would be doing research to decrease the cost of treatment as much as possible. This was part of the general framework of making treatment available to as many people as possible. This story is similar to what we heard in the keynote address yesterday. Coalition, alliances, ultimate objectives – these are critical and these are exactly what Peter Piot and the HIV community did.

When this group focused on maternal health formed, and we started to think how we could embark on some sort of road map to do something similar for maternal health, several principles arose.

1. Priorities – they should not be set on the basis of the ideas of individuals or institutions. They should be set on the basis of what is needed in terms of developing guidelines for action at the field level – how to implement, how to finance – not just biomedical guidance.
2. Once priorities are set, if the knowledge is not there it should be generated through research. To be effective, the research effort should be as collaborative as possible – researchers, funding

agencies, and implementers. This will enable research efforts that will optimize the use of resources and avoid duplication. The traditional paradigm of one agency funding one group to answer one research question still has value. But imagine the potential of a community formed by the best scientists, the most powerful funding agencies who could pool their resources, and the implementers and policy makers who could direct the research process so it is directly pointed at implementation. This group is what is here today, as I look around, it is what I see. Anders brought us here and gave us the opportunity to do something like this.

3. The results of this research should immediately be taken to feed back into guidelines. Wouldn't it be nice if we had a system that immediately brought the results of research into guidelines, and if that system would be recognized and accepted by everyone because it is owned by everyone?

These concepts appear to form a cycle. Bert is the person who has to be credited for figuring out this life cycle linking knowledge with implementation.

Prof. Bert Peterson: Credit goes to lots of folks at WHO and others who are here today. It really is a concept whose time has come.

The single overriding objective, as Dr. Meriardi has said, is to make sure we tackle these challenges with the best available science. We have to make certain that the science base is continually translated to action. That translation is where we need to focus additional effort. We have to create a group of us, not just researchers, but also those in the field who are going to implement this science base, the donors who are going to help fund it, and the institutions that are going to take it on as their core mission.

A key lesson, mentioned yesterday, from smallpox and mentioned again with respect to HIV is the idea of building a real, core coalition to make this happen. We need to embrace this for maternal health including obstructed labor and fistula prevention.

So we're going to get this core family in place, and guidance is going to be created by us together, looking at how we're going to make things happen – for policies and programs and practices. And we need that guidance to be built on the best available science, so we need a process to make that happen.

We did this for birth control for women with HIV. There was a huge gap in knowledge about what birth control was safe and effective for HIV positive women. These gaps, that critical interface between what we know and what we need to know, those are the areas that need to be research priorities. Identify the gaps to generate the science base.

The medical eligibility criteria for contraception were published in 1996. A few months later, work by WHO identified an increased risk of myocardial infarction and stroke in women with hypertension who took oral contraceptives. But it took four years for those risks to be reflected in the second edition of the WHO medical eligibility criteria. We decided we had a responsibility that went way beyond that. We established continuous identification of research evidence for updating guidance in a timely fashion. So

that's really this cycle that we're beginning to create together for maternal health including obstructed labor.

What do we need to do from this point on? Getting the best available science into practice – how do we do that? What's the action part of that look like? How do we know what we need to know to do the right thing? Once we've got the information, how do we ensure that we get it into action, into practice? We may want to create a conceptual framework along these. We don't stop at having the science. Yesterday we talked about it's not enough to know what to do, we need to know how to do it. That is implementation research. We need to create a life cycle for action in maternal health.

THE BILL & MELINDA GATES FOUNDATION AND MATERNAL HEALTH – DR. FRANCE DONNAY, SENIOR PROGRAM OFFICER, MATERNAL HEALTH

The current global momentum presents a unique opportunity for Maternal, Neonatal and Child Health (MNCH). The overarching themes of the MNCH strategy at the Bill & Melinda Gates Foundation are 1) focus on critical conditions causing neonatal and maternal mortality, 2) focus on delivery of existing interventions at home, in the community and at first-level clinics, 3) develop appropriate new technologies for use at all different levels, 4) enhance interactions between frontline workers and families/communities (MORE and BETTER interactions with EFFICIENT solutions and EQUITABLE reach) and 5) implement and evaluate a model of impact comprised of 4 initiatives in several key geographic locations.

For effective implementation, the Foundation believes the following is needed: develop and introduce new or adapted interventions, shape demand in the community and improve health practices, enhance frontline worker capabilities and performance, and advocate for a supportive policy and program environment. Examples of intervention packages for mother and baby were given, with a specific example for obstetric fistula. Most practically, kits (supplies for individuals' use) and checklists (tools that help ensure essential care practices are performed) can be used throughout the continuum of care to improve care delivery. Evaluations of these birth kits have demonstrated reductions in neonatal infection and mortality rates, however it should be noted that these evaluations cannot disentangle the benefits of kits from those of co-interventions.

PREVENTING OBSTRUCTED LABOR MORTALITY BY INTEGRATION WITH HUMAN RIGHTS PROGRAMMING – DR. BEN SCHWARTZ, CARE

Dr. Schwartz began by noting that when he started preparing his talk he questioned whether a rights-based approach could actually be effective in preventing obstetric fistula or obstructed labor deaths. While studying the question and preparing the talk he became convinced that, in fact, a rights-based approach does have considerable power, even in preventing obstetric fistulas and obstructed labor deaths.

International covenants and treaties and national laws declare a right to health for all people, but the disparity between the requirements of law and the limited enforcement through the courts defines a critical gap in the effectiveness of health rights in improving health outcomes. CARE takes a rights-based approach to health, to realize the powerful effect of local action on national policies and practice. This approach transforms the relationship between the community and the healthcare system; healthcare providers shift from being those who hold the power based on their education and position to “duty bearers” and community members shift from supplicants to “rights holders”. CARE works to change attitudes and beliefs of individuals and communities to empower them as right holders.

In Peru, a triad of interactions between citizens, government, and healthcare providers improved health system accountability and, consequently, health care delivery; 1) citizens and coalitions (“rights-holders”) were able to make their political voice heard through ForoSalud, a civil society network with members elected to regional and national councils that demands participation in social and health policy design, 2) women trained on health rights, institutional responsibilities and legal framework would observe services and monitor acceptability, reporting to ombudsmen and 3) local committees that included healthcare providers and community representatives engaged in oversight and management of first level facilities. Similarly, CARE organized rights-based oversight of health facilities in Nepal engaging women in Dabi (pressure) groups to increase awareness of rights, identify and analyze problems, conduct advocacy, and participate in health facility oversight. CARE facilitated establishment of 25 Dabi groups, but in 43 other communities such groups developed from within the community.

International movements must be linked with national and local action, and education and support to change the relationship of women and communities with health systems is critical. While experience in Peru and Nepal suggest that communities will probably not focus on obstructed labor specifically, they will work to improve maternal health and the accessibility, acceptability and quality of care which will reduce obstructed labor morbidity and mortality.

THE ECONOMICS OF OBSTETRIC FISTULA AND CURRENT RESEARCH – PROF. DEBORAH MCFARLAND, ROLLINS SCHOOL OF PUBLIC HEALTH OF EMORY UNIVERSITY

Dr. McFarland discussed the role, generally, of economic analysis in public health work and then presented the results of a study of the economic burden of obstetric fistula in Niger. The objectives of the study were 1) to establish the disease burden, in DALYs (disability adjusted life years), of obstructed labor and its sequelae, 2) to estimate costs to the health system of Niger, 3) to assess how many DALYs could be averted through preventive measures and 4) to estimate the cost to the Niger government of implementing these measures. Data were collected through a literature search, meta-analysis of fistula characteristics from selected studies, and informant interviews and informal focus groups in Niger. There were an estimated 111,570 DALYs due to obstructed labor and fistula in Niger. One untreated case of obstructed labor could potentially result in 58.56 DALYs. This analysis was kept quite simple, but the cost of preventing obstetric fistula included the cost of improving and equipping existing health facilities to provide C-sections. If the untreated case of obstructed labor were appropriately treated with a \$65 C-section before adverse consequences occurred, the 58.56 DALYs for that woman could be

averted for only \$1.11 per DALY – a highly cost-effective program. Additionally, infrastructure improvement to prevent and treat obstetric fistula will positively affect the entire health system. Limitations of the analysis include reliance on poor quality secondary data for incidence, prevalence and costing data, societal costs are difficult to measure (social burden of stigma, loss of productivity) and there is inherent simplicity in the modeling approach.

DISCUSSION: Don Hopkins noted that if the analysis were done using an intervention that is simpler and cheaper than C-section that the savings would be even greater. Katie Gifford noted that this does not include the cost of reintegration, which could be a very expensive portion of the economic burden of obstetric fistula. Prevention of obstetric fistula would then be even more cost saving, although currently probably not many countries are spending much on the reintegration of women after fistula repair.

TRENDS IN THE FOUNDATION WORLD AND IMPLICATIONS FOR THIS INITIATIVE – DR. ANDERS SEIM, HDI Information for this presentation was pulled together by Becky Castle at Project Resource Group. The data are from the public domain and the research, funded by the Rockefeller Foundation, looked at the donor landscape for health systems.

Global health spending totals 5-6 trillion USD annually; 1-2% of global health spending comes from donors, ~16.7 billion USD. Of the 16.7 billion USD, bilateral agencies, UN agencies, and multilaterals make up the majority of global health giving. Approximately 1.1 billion come from private nonprofit organizations. Nearly half of all bilateral giving comes from the US, but Western Europe, Nordic countries and Japan are key donors as well. A snapshot of the breakdown of health contributions was shown for Nigeria. Of 390 million USD donated in 2006, 303 million (78%) went to vertical disease control programs; the amount of donor money that went to reproductive health was too small to register on the graph.

Looking at private global health giving, nearly 1.1 billion dollars are donated every year and 84% of this comes from the Bill and Melinda Gates Foundation. The Clinton, Ford, Packard, Hewlett, Buffett and Rockefeller Foundations make up 60% of the remaining 174 million USD of donor funding.

Individual philanthropists contribute 75% of all philanthropic giving in the US (2008) and there is an upward trend in international giving. High-net-worth individuals, family foundations and corporations can play a very important role in start-up. But it takes a large investment of time and money to find and cultivate them systematically. This is too costly to pursue except for large NGOs with considerable fundraising staff and in situations where there is a strong, established donor-base of individuals. Obstetric fistulas may be especially interesting for families and individuals interested in women's empowerment.

There are certain conditions and trends related to donor funding that have important implications for the future of donor funding.

- Health systems:
 - Fragile health systems in low-resource regions often cannot absorb higher levels of funding committed in recent years
 - Donors and policy-makers are seeking ways to strengthen health systems to scale up programs, but a shortage of health workers is a limiting factor, and HIV/AIDS programs often are not integrated with other services, including maternal/child and reproductive health
- Health metrics
 - Formation of the WHO-led Health Metrics Network and the Institute for Health Metrics and Evaluation at University of Washington underscore the movement from assessment of program effectiveness through simple outcomes (numbers reached, etc.) to more complex evaluation of impact (decrease in disease prevalence, etc.)
 - Data are used to drive decision-making and policy development at local, national and global levels, and to show new and potential donors the return on investment.
 - In the current economic climate, measurable results will be even more important to funders.
- Global economy
 - In 2008 and early 2009, a 43% fall in the S&P500 was a harbinger of future giving by individuals and foundations.
 - Falling tax revenues may force governments to decrease available grant dollars
 - Returns on investments in fundraising may be lower and may take more time to secure than has been the case historically.

Foundations and individuals must be encouraged to help us examine whether approaches work (start-up funding). But when we go to the next stage, to scaling up, then it's not reasonable to expect that people raising money in their homes should raise the money to do this. Between individual philanthropists, large foundations and government donors there may be opportunities for obstetric fistula funding.

KEY ISSUES ARISING FROM THE PRESENTATIONS – DR. DONALD R. HOPKINS, THE CARTER CENTER

Please see Annex 3 for a transcript of Dr. Hopkins' insightful reflections on the key issues of the meeting, the parallels between obstetric fistula and Guinea worm eradication and the four stages necessary to create change. The audio recording of his talk is included on the meeting CD.

PLENARY SESSION

PROF. HERBERT PETERSON – CHAIR

This summary of the plenary session aims to capture the main points and ideas of the participants as they were presented by the participants. Many ideas were put forth without general debate by the group, therefore the ideas should be considered part of a brainstorming effort rather than a definitive list of agreed-upon topics to pursue further.

Prof. Bert Peterson led the plenary session and began by asking:

- Where do we want to be this time next year?
- If we are going to move this field forward, what would we do and how would we do it?
- What are the absolute top priorities, the most important things we could and should do right now?

Top priorities suggested by attendees fell into three main categories and an ‘other’ category:

1. A need for **standardized indicators / a common language**
2. A need to **implement effective strategies**; we need to ACT NOW to reduce maternal morbidity and maternal and infant mortality from obstructed labor; put science into action while indices are being developed/tested
3. A need to **define the role of this group and** its position within **the global obstetric fistula family** – will this group continue to meet separately from the existing groups, and, independent of that decision, where/who constitutes the home of the global fistula family
4. Other ideas not included above

The following are summaries of the participants’ thoughts and contributions to each of these topics.

INDICATORS

Participants agreed that there is a need for a common language, standardized indices, through which everyone working on obstetric fistula can communicate. Participants discussed the following:

What exists:

A Campaign to End Fistula working group, led by UNFPA and CDC, has been working to develop indicators. Florina Serbanescu noted that development of indicators has been laborious. June 2010 is the deadline for producing a PDF report of the indicators. The short list is available (59 indicators all categorized). Preference has been given to indicators that are already collected in surveys, so there will be no or little additional burden to surveys. What is still being developed is the complete description of indicators with limitations, strengths and cautions about usage. Feedback will be solicited about the indicators as they are used, to improve them. The indicators will not be put in print, so they can be continually updated. The best 6 indicators to be used as core indicators have not been selected.

Sensitivity and specificity of the questions is not fully determined, so there should be caution initially in using and interpreting the data.

CDC has reviewed survey tools that are in existence and has made recommendations on how to collect data on obstructed labor and fistula at the population level. A lot of the population-based data coming from DHS surveys are believed to be subject to over-reporting (i.e. for urinary incontinence).

What is needed:

- A common language – standardized indicators (as being developed by the Campaign to End Fistula working group) and, specifically, a small group of core indicators for universal use
- Feedback on the indicators from those who begin to use them (the working group can then issue recommendations for modifications to the indicators)
- Of note, there is a call out from DFID to work on measuring maternal mortality at national and sub-national levels in 6 African countries – there may be a good opportunity to link up with that effort
- “Know the truth” (as put forth by Bill Foege in his keynote address) – we need baseline measures of the above-mentioned indices to allow us to demonstrate intervention and program performance in terms of quality, output and resource consumption.⁴
- Active surveillance for maternal mortality, maternal morbidity and obstructed labor/obstetric fistula
- A millennium development goal for maternal health is already defined – perhaps we need a sub-goal defined for obstetric fistula
- Data sources are not currently available for some of the indicators developed by the working group (e.g. awareness of pregnancy complications among women who are pregnant and also policy, treatment and reintegration indicators)
- Define success – what is success, what does it mean, how do we know when we have achieved it?
- Qualitative data: good focused social science research into birth cultures and understanding the cultures/contexts in which the births/complications are occurring

IMPLEMENT EFFECTIVE STRATEGIES

This section includes many suggestions raised in response to the discussion of indicators. While all present seemed to agree that having appropriate indicators and establishing the baseline for those indicators are essential for many aspects of our work, there was also a strong sense that we must act *now*, using tools we know work and testing new tools we think will work, to prevent and treat as much obstetric fistula as possible. There is no excuse for waiting; indeed, we have a moral obligation to move forward to save lives.

⁴ As Bill Foege would agree and as was pointed out at another point in the meeting, none of the successful disease elimination and eradication programs (smallpox, Guinea worm, etc) had decent baseline numbers when they started. And one cannot count women dying for a year or more without intervening, in order to secure decent baseline data in a geographic area.

What we know works:

- Maternal waiting areas/homes probably have enough evidence to start scaling up. A WHO report on maternity waiting areas highlighted dramatic reductions in maternal mortality with their use (presented by Dr. Andrew Browning)
- Audit process (presented by Dr. Nynke van den Broek)
- Niger approach (presented by Dr. Zeidou Alassoum)
- CARE and Women's Dignity Project approach – use communities to build accountability to improve quality
- Toll-free number to call for assistance for a woman in labor (an example from MSF in Chad, presented by Gillian Slinger)

What is needed:

- Scale-up of the above successful approaches
- Implementation research to tell us *how* to put this research into action and how to do this smoothly, quickly and continuously; create a life cycle for action
- A solid review of the evidence base to know the gaps in our understanding.
- Regarding the auditing process – need to think about how to analyze complex interventions and attribute causality of effect to components within a complex intervention, because in obstetric fistula work one will always ethically and morally have to offer more than one thing, so the whole evaluation framework and analysis needs some statistical creative thinking. This could be a research area in itself, using obstetric fistula as a morbidity marker or outcome measure but you still need to develop a methodology for evaluation. Obstetric fistula could be a topic within which to develop a methodology for evaluation.
- A system. As with the Niger approach, more than availability (e.g. of transport or C-section) is needed. One needs a system (and that system automatically introduces accountability) that includes logistics, community support, monitoring, data collection, etc. It is necessary that the personnel, medications, everything is available. The impact is not the impact of *a* technology, but it's the combination of all these things within a system, and the system includes accountability and data collection.
- More information on how to work with communities to make sure that women are identified and transferred; what are the strategies to train workers to identify a woman with obstructed labor, what are the strategies to work with the families themselves to make the idea of going to a facility acceptable, and then actually transferring a woman to a health facility, and then the issues at the health facility (equity, quality and speed of care, etc.) – need to scale up each step that is involved.
- Issue of money for transport (particularly in Africa) – examine the idea of having the hospital have money for transportation so they can reimburse people for bringing women to care
- Capitalize on the availability of mobile phones for communication
- Increased use of the partograph

- Symphysiotomy – Dr. Linda Bartlett presented a review⁵ of symphysiotomy from 2002 that she felt was compelling with regard to how safe symphysiotomy is compared to C-section; there is also no scarred uterus that would confer more risk for the next pregnancy. In fact, after symphysiotomy women end up with a larger pelvis that could be safer for the next birth. Dr. Bartlett felt symphysiotomy could be ready for a randomized controlled trial to assess safety, feasibility, acceptability
- At a local and national level, identify and examine the failures that led 100 women with obstetric fistula to have that pregnancy outcome
- Look at the cost of the interventions
- Examine the economic burden to the community and the nation

MOVING FORWARD: THE GLOBAL OBSTETRIC FISTULA FAMILY AND THE CATALYST MEETING GROUP

There was much discussion regarding the nature and domicile (if any) of the global obstetric fistula family, the role of this meeting group within the global obstetric fistula family, whether and to what degree this meeting group should be folded into existing structures and, to the degree that this meeting group joins formal obstetric fistula family structures, how to incorporate it and how to manage that larger structure/family.

Regarding the global obstetric fistula family:

- UNFPA has done a great job of being the convener of the family.
- The family has been a fluid entity. People have joined and worked on things that interest them.
- There is no requirement for membership.
- UNFPA has an obstetric fistula website to provide a central location for resources.
- The objective of the International Obstetric Fistula Working Group (IOFWG) has been to achieve many of the ends that Mario Marialdi suggested in his talk. There are groups on advocacy, training, reintegration, etc. The group has also identified a research agenda – it would be helpful to build on that existing mechanism.
- The Campaign to End Fistula has really helped the community to move forward and it would be good to know what each of the subgroups has been working on.

And with regard to **this meeting group**:

- A redundant or competitive structure would not be good.
- Expanding the obstetric fistula community or building on it would mean building on a group that has already done a lot of work.
- It would be helpful to know what each of the subgroups in the Campaign to End Fistula has been working on.
- What could this group do to be most helpful at this point?

⁵ Björklund K. Minimally invasive surgery for obstructed labour: a review of symphysiotomy during the twentieth century (including 5000 cases). BJOG. 2002 Mar;109(3):236-48. Review

- What would be the most important things we could do to contribute to and comprise a family?
- Does a family home need to be created beyond the role that UNFPA has played as convener of the family?
- Does the work need to be enhanced somehow?
- What is the comparative advantage of this group meeting separately versus joining existing groups?

Dr. Judith Helzner raised this last point with the following questions and comments regarding this meeting group. Who are we and how do we relate to these other groups? In the American Journal of Public Health Jeremy Shiffman applied political science methodology to determine why there was or was not political will to reduce maternal mortality in selected countries around the world (see paper included on meeting CD)⁶. He came up with a number of factors that explain in political science terms why some countries would have greater attention to and funding for maternal mortality reduction. Some of the factors identified apply to the 'sub'-topic of obstetric fistula. There needs to be clarity on what is the resonating frame (that is, what is the overarching framework within which the issue rests e.g. poverty reduction or empowerment of women). You need a champion of the cause at various levels (global level, inside a ministry of health, etc.) to fight for it. There need to be indicators and solutions that will improve those indicators (so that a politician would be willing to put their reputation on the line to fight for that topic). There is a need for an institutional home for maternal health – so far there is not one (like UNICEF for children's health). What would be the comparative advantage of this group forming itself as a community compared to the other mechanisms? There are many strikes against us; we have no home, no champion, multiple resonating frames, indicators not yet in place, not sure we know how to get the data we need to show improvement. So what *is* the comparative advantage of this group meeting versus the other existing groups?

Participants contributed the following examples of unique or important attributes of this meeting group that might warrant having this group maintain its own identity while engaging with the rest of the global obstetric fistula family.

- Christine Mulindwa-Matovu – I think the uniqueness of this group is that each one of us is making a different kind of intervention. We can borrow from each others' experiences and apply them in different settings. We could pick and choose from successful endeavors. I feel the uniqueness is different from the UNFPA working group – they work toward the broader context of reducing maternal deaths. I believe that within this group we have that potential to learn from each other and compliment what we are already doing on the ground (she gave the example of the Niger project providing helpful ideas for her work)
- Linda Bartlett – We're here because Anders proposed the catalyst idea – I don't want to lose that because clearly it has worked, so, if we can, let's learn how it worked and then expand that.
- Isabella Danel made a plea to take on obstructed labor and obstetric fistula work beyond the big picture of maternal health (see below under Other Thoughts and Ideas: Political Will)

⁶ Shiffman J. Generating political priority for maternal mortality reduction in 5 developing countries. Am J Public Health. 2007 May;97(5):796-803.

OTHER THOUGHTS AND IDEAS

Some other more general points were made regarding what is needed to move forward effectively with rapid obstetric fistula prevention:

- Seth Cochran – There is a need to put all the things that these organizations have done onto one ‘table’ so that people working at the grass roots level can draw on those resources.
 - Gillian Slinger of MSF is the point person for creating the global map of individuals and organizations engaged in fistula prevention, treatment and rehabilitation/reintegration activities.
 - The question was raised, could/will this global map be interactive, and allow individuals to post their own activities there?
 - UNFPA fistula website is a central location for many (but certainly not all) activities
- Political will needs to be generated, as noted in Judith Helzner’s discussion of the political science framework of Jeffrey Shiffman.
 - Reina Turcios-Ruiz noted that there has been success with gaining political will for rotavirus vaccine in Africa because a dramatic measurable impact can be demonstrated in just one year, and that to package aspects of OF as a low-hanging and accessible fruit would make it enticing and would help gain political will.
 - Isabella Danel emphasized that obstructed labor *is* the low hanging fruit of maternal mortality and she believes it is a special area in maternal health that we need to tackle, it is a leading cause of mortality and it results in fistula, which has a lot of emotional impact, and she therefore entered a plea to take this on in a special way, beyond the big picture of maternal health.
- Development and adoption of a strategy for rapid prevention of obstetric fistula, similar to the SAFE strategy for trachoma⁷
- Sharing of experiences and lessons learned on the ground, so that those working in the field can learn from one another – how, tangibly, do we improve hospitals and train medical providers at all levels
- Throughout, make certain that communities are involved in all of these processes, rather than formulating a plan from afar and then imposing it

⁷ Subsequent to the meeting, Rachel Bronzan suggested “**AWARE24**” as an acronym to summarize rapid obstructed labor mortality and fistula prevention: Agitate the Community making them **Aware** and **Alert** to the issue, utilize **Waiting** homes/areas, promote **Attended** deliveries, and **Refer** for **Emergency** obstetric care **within 24 hours**.

CONCLUSIONS

Although the meeting touched on a wide range of topics related to obstetric fistula, there are four main conclusions from this meeting.

1. There is enough science and practical experience now to scale up promising interventions. **Obstructed labor is the low-hanging fruit of maternal mortality**, and we must act now to reduce maternal morbidity and maternal and infant mortality from obstructed labor.
2. **Prevention** of obstetric fistula is highly **cost effective**.
3. **We need more data on the economic impact of obstetric fistula and of its prevention**; this information may be a valuable tool for generating political will for prevention and treatment.
4. There is a need for **standardized indicators / a common language** for those working on obstetric fistula.

NEXT STEPS

1. **Scale up and continue investigating promising interventions.** Such interventions include:
 - a. **Community mobilization within a “catalyst approach” system**, as piloted in Niger – mobilize communities to address and prevent birth-related deaths and obstetric fistula themselves, using simple and available resources
 - b. **Maternity waiting areas/homes**, as being implemented in Ethiopia – these should be expanded and explored in different contexts
 - c. **Facility-based audits**, as presented by Dr. van den Broeke – audits can improve care within facilities and help address the ‘third delay’, delay in instituting care
 - d. **A rights-based initiative approach**, as implemented by CARE and Women’s Dignity Project, to change attitudes and beliefs of individuals and communities, to empower them as rights holders in appropriate and conducive settings
2. Agree on and start using a few **core indicators**.
3. When implementing programs, be sure to collect data that **advance the policy discussion**.
4. **Keep a rapid, results-oriented (catalyst) approach.** Develop and maintain the identity of the group of people and organizations who attended this meeting, a group which is different from many others in that its members endeavor to implement rapid and effective interventions to prevent and treat obstetric fistula, though applying a variety of specific approaches to do so. The group will aim to meet regularly to share experiences, exchange ideas and maintain momentum while making every effort to connect with, and improve connections within, the greater global obstetric fistula community.

ANNEX 1 – MEETING AGENDA

<p style="text-align: center;">Day 1 – MORNING Chair: Ambassador Barbro Kirkpatrick</p>
<p style="text-align: center;">8:15 – 8:55 Registration of participants & light buffet breakfast</p>
<p style="text-align: center;">8:55 – 09:30 Welcoming remarks HDI – Ambassador B. Kirkpatrick Sarah Dash from Congresswoman Rosa DeLauro’s office WHO – Dr. Mario Meriardi UNFPA – Katie Gifford</p>
<p style="text-align: center;">9:30 – 10:00 Rationale for this Meeting and the Catalyst Approach to Public Health Dr. Anders Seim, HDI</p>
<p style="text-align: center;">10:00 – 10:30 Keynote Presentation Dr. Bill Foege, Gates Foundation and Emory University</p>
<p style="text-align: center;">10:30 – 11:00 Coffee Break and Group photo</p>
<p style="text-align: center;">COUNTRY PRESENTATIONS</p>
<p style="text-align: center;">11:00 – 12:00 Niger Dr. Zeidou Alassoum, HDI-Niger</p>
<p style="text-align: center;">12:00 – 12:30 Nigeria, India and Mexico Dr. Judith Helzner, MacArthur Foundation</p>
<p style="text-align: center;">12:30 – 1:30 Lunch</p>

<p>Day 1 – AFTERNOON</p> <p>Chair: Ambassador Barbro Kirkpatrick</p>
<p>1:30 – 2:00</p> <p>Tanzania, Women’s Dignity Project Christine Mulindwa-Matovu, Women’s Dignity Project</p>
<p>2:00 – 2:45</p> <p>Ethiopia, Barbara May Foundation Dr. Andrew Browning</p>
<p>TOPICAL PRESENTATIONS</p>
<p>2:45 – 3:00</p> <p>A global overview: Epidemiology of obstructed labor mortality Dr. Linda Bartlett, Johns Hopkins University</p>
<p>3:00 – 3:15</p> <p>Coffee Break</p>
<p>3:15 – 4:00</p> <p>A global overview: Epidemiology of obstetric fistula Florina Serbanescu, Centers for Disease Control and Prevention Katie Gifford, UNFPA</p>
<p>4:00 – 4:30</p> <p>Obstetric fistula treatment capacity: global status Dr. Steve Arrowsmith, Worldwide Fistula Fund</p>
<p>4:30 – 5:00</p> <p>Can obstetric fistula prevention work in unstable situations? Gillian Slinger, Médecins Sans Frontières</p>
<p>5:00 – 5:30</p> <p>Building Capacity for Essential Obstetric Care Dr. Nynke van den Broeke Liverpool School of Tropical Medicine/Royal College of Obstetricians and Gynaecologists</p>
<p>Day 2</p>

Chair: Ambassador Barbro Kirkpatrick
<p>8:30 – 9:10 Ongoing research and recent findings on preventing maternal mortality Dr. Mario Meriardi, WHO and Prof. Bert Peterson, University of North Carolina</p>
<p>9:10 – 9:35 The Bill & Melinda Gates Foundation and Maternal Health Dr. France Donnay</p>
<p>9:35 – 10:20 Preventing Obstructed labor Mortality by Integration with Human Rights Programming Dr. Ben Schwartz, CARE</p>
<p>10:20 – 10:40 Coffee Break</p>
<p>10:40 – 11:40 The Economics of Obstetric Fistula and Current Research Prof. Deborah McFarland</p>
<p>11:40 – 12:00 Trends in the Foundation World and Implications for this Initiative Dr. Anders Seim</p>
<p>12:00 – 1:00 Lunch</p>
<p>1:00 – 1:30 Observations on the Presentations Dr. Don Hopkins</p>
<p>1:30 – 3:30 Plenary Session Prof. Herbert Peterson, Chair</p>
Closing Remarks – Amb. Barbro Kirkpatrick and Dr. Anders Seim

ANNEX 2 – TRANSCRIPT OF DR. BILL FOEGE’S KEYNOTE ADDRESS

Some time back I fell, had shoulder surgery, and our four year old granddaughter sent me a get well card. I phoned her and told her how much I liked the flowers she had made and the colors that she had put on them.

And there was silence and then she said, “But what else?”

And I said, “Well I liked everything. I liked the words, I liked the other things you drew.”

“What else?”

I am glad you’re at this meeting and I hope you leave the meeting asking the question, “What else?”, because you are at the beginning of a long journey.

And I often tell students the story of the American civil war battle at Chancellorsville. And at Chancellorsville, Stonewall Jackson, the southern general, did a very clever thing and outflanked the federal troops and the confederates won that battle. But there was a man from Wisconsin by the name of Colonel Thomas Allen who inspired his troops with words that the survivors remembered for the rest of their lives. He said, “When you hear the signal, go at double quick towards the end and don’t stop until you hear the order to halt.” And he paused and he said, “And you will never hear the order to halt.” And so you’re going to leave this meeting knowing that you won’t hear the order to halt.

At age 12 I had a paper route and one person on the route was a very slow reader, and so he got the newspaper only on Tuesday and Friday. And I learned that on the other days I now had an extra paper. If I would go into the tavern the bar tender was so anxious to get rid of me that he would buy the paper. Well I’ve lost half my sight now and I have a new appreciation for that man who could only read two newspapers a week. And I say that because while our individual vision may change, the vision of public health just keeps enlarging. There are some things that don’t change at all, that is, the basis of public health, which is to eliminate premature mortality - not all deaths, premature mortality. It is trying to eliminate unnecessary suffering and it’s trying to improve the quality of life.

The other thing that doesn’t change is the basic philosophy behind public health is social justice. Trying to provide everything we know for everyone. Social justice.

But what is changing? What we’re involved in. So when I started in public health 52 years ago we were basically concerned with infectious diseases. And then at my time at CDC we saw this gradually change and so we became involved in chronic diseases and nutrition and occupational health and environmental health and injury control. And in the ‘60s I ended up working in the relief action during the Nigerian civil war, and when I came back I presented on what we had done. We developed surveillance systems so that we knew where the refugees were, and the numbers. We had surveillance systems on the infectious diseases that they had and we confined ourselves to things we could do something about. We didn’t just collect information to be collecting information; we had information on

the numbers of refugees, how much food was coming in, how much food was being distributed, and so forth.

I presented this at an EIS conference. And the man who started the Epidemic Intelligence Service, Alex Langmuir, got up after my talk, and anyone that had ever worked at CDC during those days hated that picture of Alex Langmuir standing up after you had given a talk because he would go right to the heart of something you had forgotten. And so he stood up and this time he said something different. He said, "I was opposed to you going to Nigeria to work on the relief action. I didn't think this was something CDC epidemiologists should be doing." But he said, "When I see what you have done with surveillance systems in the relief action I have changed my mind, and this is only the second time in my life that I have changed my mind in the course of a talk."

Well now, public health keeps increasing so that we are now talking about mental health, we are talking about how to come up with a metric to measure health outcomes, to improve what happens with health care delivery in this country. So it expands.

And I think of a Nigerian classmate of mine when I was in the school of public health, Yemi Ademola, who died shortly thereafter during the war in Nigeria. But he wrote in the yearbook, "Nothing is beyond the interest of public health people," because we are global, not only in the geographic sense, but in our vision of life and health and the relationships of everything. So we're involved in public health, in redefining what is unacceptable and trying to do something about it, to try to put this in priority order, to have some perspective.

Now after my shoulder surgery they kept asking me how much pain do you have on a scale of one to ten. There were some days I might have put that number up fairly high. And then I would think about Haitians under rubble for days with injuries and I would think, "This is nothing." Perspective.

And I think back to Saturday, August 8, 1998, 3 pm. I was very frustrated. It was a Saturday. I had my list of things to do and things were going well and now one of the things I had to do was to pressure clean the car port. Then I realized that I had loaned out the pressure cleaner, the nozzle was clogged and I simply couldn't get it open. And so I had to buy a new nozzle. Six stores, three hours later I'm ready to start, I'm back home and there's a message from Walt Dowdle. And the message tells me that one of our employees, Louise Martin was among the missing people in the Nairobi embassy bomb blast.

Suddenly you get perspective. You're not having a bad day at all.

Why do I say all of this? Because of the suffering of a woman with a fistula, as you've been hearing: shunned by her family and society, doomed to a friendless existence, unable to find work that provides for a future, discarded by her husband, required to accept a smell that will not improve, knowing that there are not better days ahead. *This* is a ten on the scale of suffering and none of us will know what that really means.

My second point, with expansion of public health we keep using the experiences and the skills and the tools that we have learned with previous things so none of this is lost, we just keep expanding what we do. Some of us address fistulas periodically; I admire those who have taken this on as a vocation.

I advise students NOT to draw up a life plan, because they can't possibly know the opportunities that will present in their lives. Few of us knew anything about fistulas when we went through our training. But the people in this room were open to figuring out what were the problems of the world and how we can use our skills. And now you end up frustrated by how hard it is to tell this story to other people, frustrated by the inability to get resources, frustrated by the inability to comprehend what it means not only for an individual woman, but then to multiply that by the thousands. Why is it so hard to get the attention of these problems?

Well, a few years ago we had a tsunami; recently we had an earthquake in Haiti. In both of those cases we lost someplace in the neighborhood of 200,000 people, and the world responded the way you would hope it would respond. It was on the news every night. In each case two ex-presidents from the United States were sent out to look at this. Money came flowing in. This is the way the world should respond.

How long does it take to lose 200,000 children in this world, from preventable problems? One week.

Think of that. So this week we lose as many children as we lost in the tsunami, or in Haiti, but that happened last week also, and it will happen next week and it will happen every week this year.

Why is it so hard to get attention on these things?

I tell students about grizzly bears, who are very lone animals, except during the salmon run. And during the salmon run you see these pictures of many grizzly bears along the river.

And the question is how do they get along? And the animal behavioral people tell us they get along by never looking each other in the eye. Isn't that interesting?

If they look each other in the eye there has to be a confrontation. They have sufficient peripheral vision that they know where the other bears are but they never look them in the eye. And I tell students of public health, "That's your job. Figure out how to get people to look at these problems because if they do, there has to be a confrontation. You can no longer ignore it."

Those of you who are in attendance at this meeting have been doing that. You have been learning how to get the world to make eye contact. And there are things that can be done, both for repair and for prevention.

Third, and last point: Are there lessons to apply from previous global public health programs?

I once took a class on creativity, and the instructor gave us one word, asked us to write it down at the top of the page and then said, "Now think of what's the next word that comes to your mind, and keep doing that until you have 50 words on this page." So everyone did this. Then the instructor said, "Think of some problem you're having at work that you've not been able to solve, and quite deliberately write

down that problem and apply it to each one of those words.” And the instructor said, “I’ll guarantee you that you will come up with some new ideas that you’ve never thought of before.” And sure enough after 50 words I had three new ideas that I’d never thought of before.

Why? Because creativity isn’t really thinking outside the box, it’s putting together two pieces of information you already know in a new way. So in a very real sense you’re thinking inside of two boxes. It’s the same process with humor. Things are funny because two pieces of information come together. And you have to know both of the pieces of information; if you have to explain a joke it’s not funny, it’s never funny. But two pieces of information come together in a way that you weren’t thinking of before, and that’s funny.

And so when Henny Youngman says, “My grandmother is 80 years old and she still doesn’t use glasses,” you get a mental picture. And then he adds, “...she drinks right out of the bottle”. And now you get a different picture, and it’s the putting those two together that is funny.

Or if any of you listen to Garrison Keillor, he had the joke program this last weekend. And he said, “What’s a transistor? A priest who wears nun’s clothes.” Now, it takes you a minute but see it’s... no one has to give you new information. That’s what creativity is about. So ask yourself what you could do that is really creative. I think some of the new technologies, the fact that you have cell phones all over Africa now, just has to change how you approach this problem.

In Africa, I’ll give you an example, in Africa it’s said that a third of the drugs are adulterated, but you don’t know which third. Two students from Ghana came up with an idea. If you play Lotto here in Georgia, you pay money and you get a ticket and you scratch off an area that gives you a number. And now you know whether you’ve won or not. These students said why couldn’t you do that on every vial of medicine? And when you buy it you scratch off this part, you come up with a number and with a cell phone you call a particular number, enter those numbers, and now you learn whether that is an authentic drug or an adulterated drug. Now this is so simple. And they figure, 1.3 cents per vial the manufacturers could apply it. Well it’s to everyone’s benefit to do this. So it’s using new technology but in a creative fashion. And there are many ways you could use cell phones when it comes to fistulas.

One other example. I was involved in a discussion of an area where they were trying to figure out how to get women in during their labor, into the hospital. And so they were talking about having an ambulance service and by the time they figured out what it would cost to have three or four ambulances, drivers, an infrastructure to make this work, it’s very expensive.

An alternative is to have at the hospital a fund; you pay any driver that brings in a woman in labor an amount of money that makes it worth their while and suddenly every vehicle in that catchment area of the pregnant woman becomes eligible to be “a taxi”. And you know even if you make this \$25, a pretty large sum, or \$50, it turns out to be so much cheaper than trying to get an ambulance service. If you paid \$50 to a driver, for \$25,000 a year you could handle 500 women in labor.

So, back to creativity. What I’m going to do is mention some of the lessons that we learned in smallpox eradication. They’re not all applicable, but what I would like you to do is think in terms of, when you

hear one of those, what would you do if you put fistula against that, and does it bring any new idea at all. And it doesn't have to be right now. If you write it down and it comes to you in three days that's great.

Here are some of the lessons from smallpox eradication.

1. Know the truth. That is why we have surveillance systems. We didn't have to wait with smallpox to have a perfect surveillance system to begin working. You work with whatever you have. But we improved it until the efficiency of surveillance in smallpox literally became 100% at the end, that we knew about every case. So what does that mean with fistulas? How best to find patients, respond to their needs, mobilize the resources and monitor results? And ask how could you use surveillance systems to monitor prevention? How to get women in labor seen? What is working to reduce the toll? That is the reason for surveillance, to know the truth, and once the truth is known it helps you figure out what to do next.
2. Clear-eyed management. And we heard Anders say that, yes, science is important; we have to have science in order to know what to do. But the basic skill needed in public health is management. You have to have people that can see the big picture, the parts, and figure out how to solve a solution for each of those parts.
3. Choose ultimate objectives. In prevention that of course requires surveillance to demonstrate a reduction in cases. What will that take and how do you implement it? And you're going to start out with a very primitive system and you're going to gradually improve it. I like the approach that you're taking here, where people have now had some experience in different countries and you're getting together to pool your knowledge and figure out what could you put together to improve what each one of you will be doing in the future. And when you're looking at objectives, choose ultimate objectives. Choose the last mile objectives because that's the way you know what the first mile should look like. If you're leaving Atlanta for San Francisco, it makes a great difference if you know that the last mile is San Francisco. Otherwise you go in any direction.
4. Choose strategies and tactics that will most effectively achieve those objectives. And we're so fortunate that we're going to be hearing over the next two days early experiences that you have had with testing these different strategies and tactics. Avoid certainty. Richard Feynman the great physicist, in a talk in 1963, said, "The Achilles heel of science is certainty," to be certain you know what you're talking about. He said, "Even in physics, where our facts seem to be much better than in other areas," he said, "every fact is certain only within some margin of error. Nothing is absolutely certain." And he said, "We spend our lives trying to disprove some of these rules in physics." But then he went on to talk about you know certainty is the Achilles heel also for religion and for politics and for everything. So avoid certainty. Proceed in this process as the learning, not the learned.

5. Coalitions. You can't do anything in this world alone. And Gandhi once said that in terms of, he said to seek interdependence with the same zeal that you seek self reliance. And then he went on to say, "Because there is no alternative." You simply have to do things as a coalition.

Gary Wills wrote a book about the Gettysburg address and he reduces the Gettysburg address to one lesson. He said, "These two hundred seventy-two words..." and, by the way, we almost didn't hear the Gettysburg address because Lincoln was sick that day. By the time he got on the train to go back to Washington he was so sick that he couldn't do anything. He was put to bed when he got back to Washington and we don't hear about him for two weeks. Do you know why? Lincoln had smallpox. And Don Hopkins can tell us about that because it's in his book. So he was in the early prodrome of smallpox. What if he had this 24 hours earlier, we may not have heard the Gettysburg address.

But Gary Wills... what we learn about the Gettysburg address is "those 272 words changed the United States from a plural noun to a singular noun." Now that sends chills up my spine. That's what coalitions are. They bring people together into a singular approach – many different tactics, but a singular approach. You're not fighting each other. You're trying to figure out what's the best way to do this. You're combining [*inaudible*] your talents and your experiences. And the first need is for that clear vision of that last mile. You will need to learn to suppress individual egos. And I think this is one of the greatest lessons of smallpox eradication, that to get a coalition that worked you had to suppress egos so that people were all getting their satisfaction out of an outcome, and that's what made them excited and happy, it was not a turf battle. And I think back to our experiences with smallpox in India, and we lost our national and corporate identities. We became really a unit aimed at the eradication of smallpox.

6. Next point. Continuous quality improvement needs to be built in right from the beginning. Not something that you wait for a year or two to add. And think of this early and think of it often. And in India what we did, in every endemic state we actually had a meeting of the field staff once a month, that's how fast we were getting feedback. And you talked about having a meeting every six months. Figure out what it really takes in order to get continuous quality improvement. It may not take a meeting. It may take a reporting system that's back and forth with such speed that you can improve between meetings.
7. Choose allies. From where? Well, government obviously is the single biggest ally that you can get. That's where the resources are, that's where you can get differences. And Anders mentioned Guinea worm in Nigeria, and Don Hopkins will remember, I think Nigeria may have been reporting less than 10,000 cases of Guinea worm a year. Until Don and others organized a look, house by house, and at one point in time what did they find? 700,000 people with Guinea worm. This got the attention of the Nigerian government, and if I recall this correctly the Nigerian government put up \$1,000,000 in order [comment from audience not heard]... \$2,000,000, okay, \$2,000,000 because now they're part of the coalition, they see the size of this problem. They know the truth. So, bring truth to power.

But also look at corporations. I don't know if you read the New York Times article on Witty the head of GlaxoSmithKline. *That's* the kind of person you need. He is so passionate about improving health in Africa, this is the kind of person you need to be part of your coalition. And I might say that actually Merck and GlaxoSmithKline and Pfizer and other corporations, they're becoming the latest chapter in global health, changing everything. And it used to be people wanted to stay away from them because of their profit motive. I tell you these people have something to offer.

In Botswana we've had a coalition with the Gates Foundation, Merck, Harvard, the government of Botswana. Ten years ago you could not mention AIDS in Botswana. And when I was there people said, "It's a radio disease." I said, "What does that mean?" They said, "We talk about it on the radio but we never talk about it between ourselves." And sure enough if you went to a funeral no one said, "This person died of AIDS." And I once made rounds in Botswana at a hospital where 90% of the patients were AIDS patients. The word was never used. We heard that this person had tuberculosis, this person had this or that chronic diseases; no one ever said anything about AIDS. We later went to a room off the ward, and I asked the medical officer in charge, "How do you come to work every morning? What are you doing for your own mental health?" And I immediately regretted the question, because he sat there and stared. And he didn't say anything. And there's his staff, and I'm embarrassed now, what I've done. And suddenly tears start flowing down his face. And then he said, "I've never told anyone this before. I'm one of four sons. My three brothers have died of AIDS. I don't have a choice." And in Botswana where they wouldn't talk about AIDS ten years ago, the rate of HIV positivity in newborn children has gone from 40% to 4% in this decade. Think of that, from 40% to 4%. Because of a coalition that actually works.

And people now can go to testing stations and get their HIV status. And when I was there a few years ago I went to a testing station and there was a couple from the university, and I asked them why they were there. And it turns out they were there because of a soap opera on the radio that was so powerful in telling people what to do about AIDS, and the storyline was so powerful, that the majority of people in Botswana were listening to this every week. And because of that, they came in for testing. And they told me they had never had sex, but they had agreed that they would get tested before they did. Now, the difference in ten years. So, it's powerful to get these coalitions and to get corporations and governments as part of the coalition.

Church groups. At the beginning of the AIDS epidemic it was difficult to get church groups. It's not difficult any more. You can get church groups very much involved.

There's an organization that started out in Senegal called Tostan. And Tostan, someone mentioned Nicholas Kristof, and I told Nicholas Kristof about Tostan and he included a whole chapter in his book on Tostan because it's one of the great demonstrations of the power of

empowerment. It started in one village in Senegal where a woman was simply trying to talk to women about how they could have more power if they organized with other women in the village. She didn't even try to guide them on what they should be doing with that power, but they said they did not want to have genital cutting for their daughters the way they had had it. And they went to the chief and he said, "Well, we can't stop that or our young women will not be marriageable to surrounding villages." These women would not give up. And finally the chief agreed to get, I don't know, seven other chiefs together. And the women persuaded these seven chiefs for all villages to stop, the seven villages to stop genital cutting. Now that's pretty powerful in itself, except this has now moved like an infectious disease from woman to woman and village to village and includes millions of people in Africa. There must be half a dozen countries that are now involved in this. And I'm willing to predict that the problem of genital cutting in the world is being solved and that we've already passed a tipping point, not because of a Cairo declaration or anything else UN agencies or other groups have done, but because of women getting some power in one village and having this spread out. Get hold of that group and see what they could do to help to reduce the obstetrical problems.

And then I would think of the global health groups. You know a decade ago global health was still not a place where people had much confidence. And when I started out in global health and wanted to go overseas people advised me not to do that, they said, "You'll ruin your career", that you cannot come back and get back into the main stream of a career." There wasn't really a track for global health at that time. Everybody that got into global health did it on their own in different ways. You certainly could not have thought of global health research. And now everything has changed, in ten years, and I think this is mainly because of Bill and Melinda Gates. Everything has changed and now there are research projects in global health, there are career tracks in global health. And if you go to the school of public health here in Atlanta, the Rollins School of Public Health, it started with a global health track and the other tracks, epidemiology and statistics and so forth, were not very pleased. They said that's soft science and we deal in hard science. Global health is now the biggest recruiter of students in the entire school of public health. And so the students come in for global health. You'll find the same thing if you go to medical schools, students want to go into global health. Everything has changed. You can now get allies in global health that you could not have had ten years ago. But we have to learn how to tell the stories. And we heard such a powerful demonstration this morning. What are some other lessons?

1. First, smallpox eradication did not happen by accident. Stephen Hawking in his book *A Short History of Time* says the whole history of science is the gradual realization that things do not happen in an arbitrary fashion, that this is a cause and effect world. Fistulas will not disappear by accident.
2. Number two, every public health decision ultimately requires a political decision. And the lesson that follows is, learn how to get the right information to politicians at the right time that they make good decisions. It took me a long time to learn this. I used to get so frustrated with

political decisions. And one day my deputy, Bill Watson, at CDC said, “You know you’re being very arrogant. If the politicians made a bad decision it’s because you did not get the right information to them at the right time for them to make a good decision.” So that was the second step in my understanding the political process. The third and most important is to realize how labor intensive that really is. You have to get information to them but they keep turning over. And so I don’t miss an opportunity now when I talk to students without saying some of them should think about going into politics. It’s a much shorter cut to get these people who are trained in public health into politics rather than to keep training politicians.

And I told a group yesterday of public health people meeting in Atlanta for sexually transmitted diseases, 1200 of them, and I was saying to think about going into politics. And I said that the idea that power corrupts and absolute power corrupts absolutely is something we credit to Lord Acton. Lord Acton plagiarized that from Isocrates who 2000 years ago said exactly that. But it’s in our lifetime that that statement was improved by a man by the name of Paul Warnke, who said, “That may all be true, but the most corrupting of all is the fear of loss of power.” And isn’t that what we’re seeing in congress right now? On the one hand, people who are willing to sell this country out because they fear losing the next election. And on the other hand people who say, “We’re not going to run again because we don’t like working in a cesspool.” And so that’s the place we’ve gotten ourselves into. The political impact, though, is so important, you have to figure out how to make the case and when you get your allies, corporations and universities and so forth, get allies that know how to use their political impact.

And the smallpox program was marked by a tenacity that was very spectacular. And that’s what you need to do. You have to inspire people to tenacity that they don’t in fact lose heart when this takes a year, five years and ten years, that they’re preparing something for the future. When I talk about tenacity I often quote Mae West who described one of her suitors as being so tenacious she said, “He’s the kind of man you have to marry to get rid of.”

Not only tenacity, but optimism. People often say if you’re an optimist it’s because you don’t understand what’s going on. Well the fact is that you can know the truth and it can be very discouraging and you have to be an optimist. And I tell students when you are hiring people, sure there’s a time when you need cynicism, and there is a time when you need reality, and whenever you need that contract out for it, but don’t get those cynics on your staff because they ruin the environment of your office. And so, get positive people who are working on this. It’s hard for me to imagine that people who are not positive would work on fistulas, so I think you have a head start on that. And while the objective in smallpox eradication was global, the work was always local. And that’s the way it will be with fistulas. You have to know the culture and you have to understand what’s happening here in order to make the difference.

3. Finally, evaluation was the key to finding the deficiencies. And we used to use the mantra of the American Management Association, and we repeated this hundreds of times. You get what you inspect, not what you expect. Know the truth.

Finally let me quote from a book by Gregory Burns, it's called Satisfaction: The Science of Finding True Fulfillment. And he says, "Happiness and pleasure are passive emotions that come from things that happen to you. Our notion of happiness is by and large due to genetics and luck. But satisfaction is a positive emotion you experience because of things you make happen yourself." This group is going to feel a lot of satisfaction in the future.

So while the lessons are many, what's the greatest gift of smallpox eradication? Well you have to go back to the very first lesson, and that is it's a cause and effect world. And it's the demonstration, once again, that the coordinated action of dedicated people can plan a rational future. This does not have to be a world of plagues and disastrous governments and conflict and fistulas and uncontrolled health risk. It's possible to plan a rational future and we should settle for nothing less. We should settle for nothing less.

Thank you.

ANNEX 3 – TRANSCRIPT OF DR. DON HOPKINS’ “KEY ISSUES ARISING FROM THE PRESENTATIONS”

Good afternoon. You can hear me okay, I think. I’m here now not because you need to see me but I’d like to be able to see you and this is easier for me to read my notes from here than when I’m sitting down. I have really enjoyed this conference and I’ve been thinking to myself going through this very special experience how much like the early days of some programs, including smallpox and Guinea worm in my experience, this has been. And I certainly hope after the Guinea worm program is over to be able to write up that story to describe the various things we went through and if I had done that already I would have been able to save myself a lot of time here. I’m going to make some observations very much in the spirit of somebody who is standing, sitting outside of this subject area looking in. And you can tell, as you may have earlier today when I completely misinterpreted one of Deb McFarland’s slides, that this isn’t my area. But there are certain things that are in common. Sociologists say that in order to create change, such as we are trying to do, that there are three or four stages. The first stage is to describe the problem. The second stage is to show that there is a solution to the problem. Third stage, show that the solution to the problem can work in the field. And in the fourth stage, add leadership. I’m going to walk through those very briefly in the context of this.

In terms of the problem, we’ve heard of obstetric fistula, a terrible clinical problem, huge disparity between northern countries more or less and southern countries in that respect, perhaps the largest such disparity of any disease problem or condition. About 2 million people affected in an uncertain number of countries, numbering in the dozens, so not just a terrible problem but a big problem. And thirdly, we’ve heard in the course of the discussions yesterday and today that however big the problem is now, however bad it is now, it’s getting worse because we’re falling behind. The capacity to mend people with obstetric fistulas is much less than the incidence of new people coming on board with obstetric fistulas. And the range I picked up was somewhere between about 2 million people estimated per year already, prevalence, with between 50,000/100,000 new cases per year, capacity for perhaps 10,000 surgeries per year on people. So, big problem, terrible problem, the world is falling further behind in regard to that problem.

In terms of solutions we’ve seen some examples here, clearly not exhaustive, but some examples that several effective solutions exist to the problem and have been demonstrated, and the one I’m most familiar with is the one of HDI that we’ve heard about in Bankilare, Niger. In a population of about 100,000 people, an 89% reduction of obstetric fistula over two years, 100% reduction in [obstructed-] birth-related deaths over two years. With those kinds of numbers if we think of, instead of the kind of intervention that was applied in Bankilare, if that were a vaccine people would be very, very excited about it, a vaccine with that kind of effect. I’m especially pleased personally, as well, that many of the village based health workers working in this are people who earlier worked in the Guinea worm eradication program.

But in addition to the existence of effective solutions that we’ve seen illustrated here, we’ve seen also manifest and testimony given to the broad impact of the solutions, especially the prevention interventions. And just to mention three: reduction in maternal mortality, increase in provision of

reproductive health services, reduction in fetal and infant deaths. So we focus on obstetric fistula but have this much broader impact in the process of going after that single condition.

But in addition to effective solutions [and] broad impact, there's also serious economic impact. Some of it we heard reflected by Deb McFarland earlier today. And I put together most of these notes last night and I would still say that to me, looking at the, for example, as we heard yesterday, relative costs of treating people with obstetric fistulas as compared to costs of preventing people from getting obstetric fistulas in the first place, to me that's the wrong comparison. And that among several things that Deb talked about this morning, I think one of the most powerful things economically to talk about, to push people on, is to think about, challenge people in regard to; it's of course important how much it costs to mount this intervention but get people to realize that it's also costing something NOT to mount the intervention. In other words it's costing a lot not to do prevention or treatment for obstetric fistula in this case. And that one of the comparisons, one of the economic hammers we want to acquire as soon as we can is to be able to, with some authoritativeness, allow people to compare what is it costing to continue neglecting this problem as compared to what it would cost us to deal with it.

So that we have a solution, and we've shown to a degree solutions, several solutions work in the field. What about the leadership component? And here's where I want to spend the rest of these few minutes. I have just thought about some aspects of leadership or elements of this approach where I think leadership is very important.

One is the need to define the overall goal. And these are more or less in chronological order, not necessarily in order of importance. You need all of these. I wouldn't suggest leaving any of them out. But, defining the overall goal in the global context, to the best of our knowledge, how many countries, in how many countries can obstetric fistula be said to be a significant problem? What's that global context? Bill Foege spoke yesterday about establishing ultimate objectives. What's the desired outcome? Surely it is to reduce, whatever the size of the problem is now, it's to reduce it significantly, maybe to reduce it to zero. And in establishing that global context, remember the Millennium Development Goal #5 as part of that context.

Secondly, apart from defining the overall goal, articulate certain strategies. And we heard yesterday I thought very cogently and very powerfully, the idea that this problem demands, the solution to this problem demands an approach that incorporates prevention *and* treatment. It's not either/or, it should be both. We also heard the importance of increasing partnerships, starting with Bill Foege yesterday morning, increasing collaboration. We heard that the Campaign to End Obstetric Fistula is already engaged [with] about 25 partners in 47 countries. I thought when I was getting tired last night of how this Campaign to End Obstetric Fistula might in English be called End Obstetric Fistula, in which case the acronym could be EnOF or Enough! But that was a product of when I was tired.

We also heard in terms of strategies the importance of engaging women who are survivors of obstetric fistula as counselors. And we heard this morning again the importance of local rights, mobilizing local people to understand what their governments and others should be providing them, to understand what they can do for themselves better, to understand that they don't need to tolerate at least some of

this misery, that it's possible to get rid of some of this burden. And one of the advantages of this, in one sense, of the obstetric fistula problem, is sort of like the tag line that's used in some advertisements for dentistry: that you don't need to floss all of your teeth, just the ones you want to keep. In terms of obstetric fistula, everybody has a mother, many people have a sisters, a lot of people have aunts, nieces, cousins who are female, etcetera. This problem, in certain countries, affects everybody including legislators and people who might be inclined to neglect other problems, but this is something that affects everybody. And once you begin mobilizing, and starting, if necessary, with the women, it's easier to mobilize around it.

Still on strategies: I underscore indices. And in my personal experience this is just a very powerful tool that you neglect at your peril. And I spoke a little about this yesterday. Dupont Corporation has the motto that "What gets measured gets done", which is a powerful motto. It was mentioned yesterday of a number of indices put together and that within that a core number of indices – and I would just say all of my personal and professional experience says go with a few indices, go with indices that are focused and go with indices that are standardized. Each country is free to develop different or complimentary indices in much more detail, you need much more detailed indices to run programs, but in order to judge how the overall initiative is going, to have some sense as to how the overall thrust in a given country is going, you need a handful of indices. And I would assert if you're getting into even nine or ten indices that's already too many. And you have to be ruthless in that regard. There's freedom to develop a number of indices in addition to that, but focus on a few indices that will need to be refined in the course of the initiative, they will need to evolve, but keep them few in number. And have them cover key services, and as you get more sophisticated, perhaps track key times, but few in number, focused and standardized. I also mentioned yesterday, this does at least four things. One of the most important things it does is to focus attention of programs on the areas that are most important, if those indices are well chosen, on the outcomes that are most important to the efficacy of the program. It also serves secondly as a powerful motivator: friendly, constructive competition. You can show progress. You can show lack of progress, to shame those who need to be shamed where there's lack of progress. And in that regard I like to refer to what I call the "Disney principle". Those of you who have been to Disney World or Disney Land, you know, particularly in the summer, the lines can be very long. But people tolerate those lines provided two things are true: one, the line is moving, and secondly, nobody is cutting into the line in front of you. And so in formulating indices, you want indices that will move with effort, that will move faster with greater effort, because that's what you're trying to unlock. And that's a very powerful thing. It will also, I told Bill Foege yesterday after his talk, that my formulation of this business of how do you use data is, that I use in talking to students is, that our job in public health is to use our data, among other things to make the right people uncomfortable. You want to motivate the decision makers and have ministers of finance, for example, to understand that it's not just money down a rat hole going to the ministry of health, it's not just "well, this money can be better used for something else". The framework you want to convey is, "If this money is not spent on this program, *these* are the consequences, and those consequences, you can imagine them, might affect your aunt, your sister," etc. And finally, focused, few standardized indices can be attractive to donors because it also allows them to see movement as a result of their funding.

Next topic is just in terms of the overall issues. Now I've talked about finding a goal, and mostly what I've talked about is different kinds of strategies and things to think about, including indices. Assess the problem. And you remember someone showed yesterday a graphic, I think it was our good doctor from the London school, a table with red spots showing where different services were available in different clinics. The [practical use of these] plots is, where there's space, to fill those spaces, to get those spaces filled. That was one of the most powerful tools we used early in the Guinea worm eradication program as well, so that you could see at a glance where there are holes. And it was mentioned yesterday also of the fistula survey and inventories of services; assess the problem, assess the capacity to deal with the problem. Scaling up is clearly a very important aspect, issue in this initiative as well, and you cannot know how much you need to scale up if you haven't assessed the problem, if you don't have an overall goal as well for where you want to go. And I would just say, somewhat related to this, that I think one consideration might be made to perhaps publishing a summary of this meeting in *Lancet* or something like that, and certainly the global initiative should consider an annual summary, report card of some sort using a few key indices, but also some prose in WHO's *Weekly Epidemiologic Record*, for example, to show year to year what the progression is and provide a forum for encouraging and shaming, as appropriate.

Program reviews, where you get together a few countries to learn from each other, to challenge each other, has also been a very powerful tool. We've used it at The Carter Center in the Guinea worm eradication program, in river blindness program, trachoma program, and we even partnered with WHO year before last in Benin republic to apply it to six countries, their Buruli ulcer programs. And I can tell you in each one of those experiences in the beginning – well, in the beginning with Guinea worm we didn't have Power Point yet, it was overheads, and things like that – but the point is the data are going to be terrible in the beginning. In this instance you're further along already, it's going to be better. But it will get better. And there is nothing so motivating as knowing you're going to have to present again next year, and country Y had a much better presentation than my country did, as a powerful motivator for content, and not just for the nature of the presentation. And I would note, it occurred to me right off the bat here, you've already got significant activity going on in East Africa, in Tanzania, Ethiopia and Uganda on this issue of obstetric fistula. You also have, on seat in Ethiopia right now, a minister of health, very capable, about five years in place now, for whom maternal health is one of his highest priorities. The other one is malaria. And so I can easily imagine getting together at least those three countries in East Africa at least once a year or so to compare notes and learn from each other and stimulate each other.

Advocacy is clearly another very important issue that I would mention here, and say that in regard to advocacy, success is best. And in that regard, the example we heard, again, of HDI, I mention that because I'm familiar with that one, is a very powerful example for advocacy. But in advocacy, also remember, you need that economic club of some estimation of how much more it's costing country X or the world to neglect this problem compared to how much we estimate it would cost to address this problem.

And my final point in regard to these sorts of issues is the increasing and refining of the evidence. That's been referred to several times here. This has to be refined. We've got some already but it needs to get better. As Bill Foege said yesterday, I think he phrased it in terms of not being satisfied, ever, or feeling

you have all of the answers. And I would only add that in regard to improving the evidence base, such improvements need to be targeted, that was mentioned this morning, and it needs to be timely: the faster the better with due attention to the quality. And in looking at aspects of evidence that could use refining, we referred earlier to economic benefits, but some issues mentioned yesterday that I just flagged as examples here, the issue of targeting all women versus women at high risk, or women thought to be at high risk. And there's a parallel in the malaria area where in many instances priority attention was given to pregnant women and children under five compared to getting long-lasting impregnated bednets to the whole community. The latter, it turns out, is much more effective in that instance. But we need data. We need data also on this problem of subsequent fistulas and the role that they play. The issue of using foley catheters to increase healing in a large percentage of people with relatively smaller fistulas is something else where more data could be useful.

And almost finally I just want to say how pleased I have been to have been a part of this, and the fact that we have had, especially, our colleagues from Niger here, participating in it, not just the experiment in Bankilare, but contributions to the discussions here.

And finally, finally I want to tell you that Bill Foege didn't tell you all of the story about President Abraham Lincoln and smallpox yesterday. The part he left out was that when Lincoln came back to the White House with his smallpox he held cabinet meetings while he was ill with smallpox because there was delay in the proper diagnosis. In fact they had to bring in a professor from Johns Hopkins who made the correct diagnosis, finally, of the president. But at that time the White House was open to the public, and people were milling around, would be milling around seeking jobs, mostly, and Lincoln put up with this but he was clearly perturbed by it, to a degree. So at one point he said to one of his assistants, whose name was Nicholai, he says, "Nicholai, you know there's one good thing about this", this being me having smallpox. "What's that Mr. President?" "I now have something that I can give everybody."

ANNEX 4 – LIST OF PARTICIPANTS

Last Name	First Name	Credentials	Title/Organization	Address	Telephone	Fax	E-Mail
Alassoum	Zeidou	MD, MPH	HDI's Resident Representative in Niger	B.P. 2854; 207 Avenue du Canada, Niamey, Niger	+227-2073 8435 +227-9693 1763		zeidou@hdi.no ; zalassoum@yahoo.fr
Anderman	Carolyn	MPH, PhD	Deputy Director One By One	4041 Roosevelt Way NE Suite C Seattle, WA 98105	(206) 297-1418		carolyn@fightfistula.org
Arrowsmith	Steven	MD	Medical Director Worldwide Fistula Fund	452 Union Ave. SE Grand Rapids, MI 49503 USA	(505) 979-1995		arrow@wfmic.org
Asma	Yaroh	Pediatrician	Niger's Director of Reproductive Health	Ministry of Health, Niamey, Niger	+227-9698 2591		asma_adam@yahoo.fr
Barnes	Carrie		ELISE Communications	215 Church Street, Philadelphia, Pennsylvania 19106	(215) 235-4208	(215) 599-8736	carrie@elisecommunications.com
Bartlett	Linda	MD, MHSC	Scientist Johns Hopkins Bloomberg School of Public Health				lbartlet@jhsph.edu
Beattie	Karen J.	Director	Fistula Care Project EngenderHealth	440 Ninth Avenue New York, NY 10001 USA	(212) 561-8072	(212) 561-8067	kbeattie@engenderhealth.org
Berg	Cynthia J.	M.D., M.P.H.	Maternal Health Scientist Division of Reproductive Health Centers for Disease Control and Prevention (CDC)	4770 Buford Hiway MS K-23 Atlanta, GA 30341 USA	(770) 488-6262	(770) 488-6285	cjb3@cdc.gov
Brann	Alfred W.	M.D.	Professor of Pediatrics, Director, WHO Collaborating Center in Repr. Health Emory University School of Medicine	49 Jesse Hill Jr. Drive Atlanta, GA 30303	404-778-1591 or 1592	404-778-1593	abrann@emory.edu

Breeze-Harris	Heidi		Founder, Executive Director One By One	4041 Roosevelt Way NE Suite C Seattle, WA 98105 USA	(206) 297-1418	(206) 374-3010	heidi@fightfistula.org
Bronzan	Rachel	MD, MPH	Independent Contractor Epidemiologist	248 Fair Haven Road Fair Haven, NJ 07704 USA	(732) 224-1257	(732) 224-1257	rbronzan@msn.com
Browning	Andrew	MD	Founder The Barbara May Foundation Medical Director Barhirdar Hamlin Fistula Centre	c/- SIM PO Box 127 Addis Ababa Ethiopia	+251 (0)582 206042		andrew_browning@hotmail.com
Chowdhury	Sadia	MD	The World Bank, PRHCBP, Reproductive Health Unit	The World Bank, 1818 H Street NW, Washington, DC 20433	202-473-1984		schowdhury3@worldbank.org
Cochran	Seth		Founder & Executive Director OperationOF	OperationOF, Inc. 401 Congress Avenue Suite 1540 Austin, TX 78701	512-687-3479	512-687-3499	seth@operationof.org
Creanga	Andreea A.	ME, PhD	Epidemic Intelligence Service Officer Division of Reproductive Health Centers for Disease Control and Prevention	4405 Reserve Dr. NE Atlanta, GA 30319	(770) 488-6033		acreanga@cdc.gov
Danel	Isabella	MD, MS	Acting Deputy Director for Policy and Communication, Center for Global Health, CDC/Washington Office	2212 Cathedral Ave. NW Washington, DC 20008	(202) 320-1345		ixd1@cdc.gov
Dash	Sarah	MPH	Legislative Assistant, Congresswoman Rosa DeLauro, CT-03	2413 Rayburn House Office Building, Washington, D.C. 20515	(202) 225-3661	(202) 225-4890	Sarah.Dash@mail.house.gov
Diallo	Yacine	PhD	UNFPA Representative /Niger UNFPA, 11 207- Niamey- Niger		+227 2072 29 80 (Office) +227 9090 9794 (Mobile)	+227 2072 3363	ydiallo@unfpa.org

Donnay	France	MD, FRCOG, MPH	Senior Program Officer Maternal Health Family Health Division	Bill & Melinda Gates Foundation 1432 Elliott Avenue West Seattle, WA 98119 USA	(206) 770- 1891	(206) 494- 7040	france.donnay@gatesfoundation.org
Foege	William (Bill)	MD, MPH	Senior Fellow, Global Health Program Bill and Melinda Gates Foundation Presidential Distinguished Professor Emeritus of International Health Rollins School of Public Health, Emory University	P.O. Box 23350 Seattle, WA 98102 USA	(206) 709- 3100	(206) 494- 7040	
Ganda	Oumaroy	MD	Urology Niamey University Faculty of Medicine Minister of Health's personal representative to the meeting				ganda1@caramail.com
Ganges	Frances		Senior Technical Advisor White Ribbon Alliance	1 Thomas Circle, NW Suite 200 Washington DC 20005 USA	(202) 777- 9769		fganges@whiteribbonalliance.org
Genadry	Rene	MD, FRCS©	Johns Hopkins University School of Medicine Johns Hopkins Bloomberg School of Public Health	Johns Hopkins @ Greenspring 10755 Falls Rd, #330 Lutherville, MD 21093 USA	(410) 583- 2991	(410) 583- 2992	rgenadr@jhmi.edu
Gifford	Katherine (Katie)		UNFPA Headquarters	UNFPA, 220 East 42nd Street, New York, New York 10017 USA			gifford@unfpa.org
Hayes	Dyanne M.		Treasurer, HDIFormer Vice President-Programs, Conrad N. Hilton Foundation	1452 Green Ranch RoadReno, NV 898519 USA	(775)622- 1110		dyannehayesreno@aol.com
Helzner	Judith F.		Director, Population and Reproductive Health John D. and Catherine T. MacArthur Foundation	140 South Dearborn Street Chicago, IL 60603 USA	(312) 920- 6233		jhelzner@macfound.org

Hopkins	Don	MD, MPH	Vice President, Health Programs,	The Carter Center, One Copenhill 453 Freedom Parkway, Atlanta, GA 30307	(404) 420-3837	(404) 874-5515	sdsulli@emory.edu
Kiserud	Torvid	MD, PhD	Head of Reproductive Health – Research Cluster Head of Clinical Fetal Physiology Research Group, Dept Clin Med University of Bergen Consultant to Fetal Medicine Unit Department of Obstetrics & Gynecology Haukeland University Hospital	Haukeland University Hospital N-5021 Bergen, Norway	+47 55974200	+47 55974968	torvid.kiserud@helse-bergen.no
Lie	Mons	MD, PhD	Professor University of Oslo Medical School	Ullevaal University Hospital, 0407 Oslo, Norway	+47-2211 9191; Mobile: '+47		Mons.lie@online.no Mons.Lie@ullevaal.no Mons.lie@uus.no
Lozano	Briana		Public Health Graduate Student Emory University	1411 Druid Valley Dr. NE Apt. F Atlanta, GA 30329	(661) 208-9161		ihj0@cdc.gov
McFarland	Deb	PhD, MPH	Professor Emory University School of Public Health	Deborah A. McFarland, PhD, MPH, Associate Professor, Department of Global Health, Rollins School of Public Health of Emory University, 1518 Clifton Road, Atlanta, GA 30322, USA	(404) 727-7849		dmcfarl@emory.edu
Meriardi	Mario		WHO - Geneva, Italian A Senior Person on Research				merialdim@who.int
Meulenberg	Claudia D.		Associate Director, Grants Management – Global Health United Nations Foundation	1800 Massachusetts Ave. NW, 4th Floor Washington, DC 20036 USA	(202) 887-9040	(202) 887-9021	cmeulenberg@unfoundation.org

Muldrow	Margaret (Migs)	MD	Dermatology Presbyterian St. Luke's Medical Center	1601 E. 19th Ave. Suite 4450 Denver, Colorado 80218	(303) 830- 2900	(303) 830- 2901	kkrrhmm@hotmail.com
Mulindwa Matovu	Christine		Executive Director Women's Dignity	P.O.Box 79402 Dar es Salaam	255-22- 2152577/8	255-22- 2152986	cmmatovu@womensdignity.org
Mwangi	Lucy W.		Director Freedom From Fistula Foundation	P. O. Box 44261 - 00100 GPO Langata Road Nairobi	254 - 20 - 603641/3	254 - 20 - 600231	lucy.ipa@gmail.com
Owens- Kirkpatrick	Barbro		Chair of HDI's Board of Trustees	Barbro Owens-Kirkpatrick, 1101 Klish Way, Del Mar, CA 92014-2633	+1-858-245- 2410	+1-858- 764-0604	barbkirkpatrick@mindspring.com
Pascal	Djakounda Mariama	MD-MPH	National Program Officer / Reproductive Health /UNFPA UNFPA, 11 207- Niamey- Niger		+227 2072 29 80 (Office) +227 9090 9803 (Mobile)	+227 2072 3363	mariama@unfpa.org
Peterson	Herbert B. (Bert)	MD	Kenan Distinguished Professor and Chair Department of Maternal & Child Health Director, WHO Collaborating Center for Research Evidence for Sexual and Reproductive Health Gillings School of Global Public Health Professor Department of Obstetrics & Gynecology School of Medicine University of North Carolina	CB #7445, 401 Rosenau Chapel Hill, NC 27599-7445 USA	(919) 966- 5981	(919) 966- 0458	E: herbert_peterson@unc.edu
Schwartz	Benjamin	MD	Senior Director, Health Program, CARE USA		(404) 979- 9204		bschwartz@care.org
Seim	Anders	MD, MPH	Executive Director, HDI	HDI, Svestadvn. 27, 1458 Fjellstrand, Norway; 318 Seth Place, Rockville, MD, 20850	+47-6691 0022 '+1-202-674- 5532	+47-6691 9416	anders@hdi.no

Serbanescu	Florina	MD, MPH	Maternal and Infant Health Branch Division of Reproductive Health Centers for Disease Control and Prevention (CDC)	4770 Buford Hwy, NE Mailstop K-23 Atlanta, GA 30341-3717 USA	(770) 488-6226	(770) 488-6242	fserbanescu@cdc.gov
Slinger	Gillian		Reproductive Health Advisor Médecins sans Frontières Switzerland	MSF-CH 78 Rue de Lausanne 211 Geneva 21 Switzerland	00 41 22 849 89 11 (Direct) 00 44 77 081 799 44 (Mobile)	+41 (0) 22 849 84 88	Gillian.SLINGER@geneva.msf.org
Smith	Tricia A.		Attorney	1745 Rubenstein Drive Cardiff, CA 92007 USA	(760) 753 4726	(760) 753 2796	triciaasmith@cox.net
Steele	Rita	PH.D.	HDI Board Member	3290 Macomber Drive Pebble Beach, CA 93953 USA	(831) 626-0884	(831) 626-0885	ritasteele6093@sbcglobal.net
Turcios-Ruiz	Reina M.	MD	Medical Epidemiologist Centers for Disease Control and Prevention	4770 Buford Hwy MS K-23 Atlanta, GA 30341 USA	(770) 488-6219	(770) 488-6242	rnt0@cdc.gov
van den Broek	Nynke	PhD, FRCOG, DTM&H	Head Maternal and Newborn Health Unit Director LSTM/RCOG International Partnership Liverpool School of Tropical Medicine	Pembroke Place Liverpool, L3 5QA United Kingdom	+44 151 705 3301/3154		vdbroek@liverpool.ac.uk
Wall	L. Lewis	MD, DPhil	President, The Worldwide Fistula Fund Professor of Obstetrics & Gynecology, School of Medicine Professor of Anthropology, College of Arts and Sciences Washington University in St. Louis	Dept. of Obstetrics & Gynecology Campus Box 8064 Washington University School of Medicine 660 South Euclid Avenue St. Louis, MO 63110 USA	(314) 747-1402	(314) 362-3328	WALLL@wustl.edu

ANNEX 5 – CONTENTS OF MEETING CD

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 - a. Dr. Bill Foege's Keynote Speech
 - b. Dr. Don Hopkins' Issues Arising From the Presentations
5. Photos from the meeting
6. Other resources/references
 - a. UNFPA Obstetric fistula website address
 - b. Bjorklund systematic review of symphysiotomy
 - c. Shiffman paper on political will
 - d. Seim perspective in the Bulletin of the WHO on the catalyst approach to public health