

2 **DEADLY DELIVERY** THE MATERNAL HEALTH CARE CRISIS IN THE USA: SUMMARY



Cover and detail above: The Safe Motherhood Quilt Project, a national initiative developed by midwife and author Ina May Gaskin to honor women who have died of pregnancy-related causes since 1982.

This summary is based on *Deadly delivery: The maternal health care crisis in the USA* (Index: AMR 51/007/2010) which contains full citations and should be consulted for further information.

DEADLY DELIVERY THE MATERNAL HEALTH CARE CRISIS IN THE USA

More than two women die every day in the USA from complications of pregnancy and childbirth. Approximately half of these deaths could be prevented if maternal health care were available, accessible and of good quality for all women in the USA.

Maternal mortality ratios have increased from 6.6 deaths per 100,000 live births in 1987 to 13.3 deaths per 100,000 live births in 2006. While some of the recorded increase is due to improved data collection, the fact remains that maternal mortality ratios have risen significantly.

The USA spends more than any other country on health care, and more on maternal health than any other type of hospital care. Despite this, women in the USA have a higher risk of dying of pregnancy-related complications than those in 40 other countries. For example, the likelihood of a woman dying in childbirth in the USA is five times greater than in Greece, four times greater than in Germany, and three times greater than in Spain.

African-American women are nearly four times more likely to die of pregnancy-related complications than white women. These rates and disparities have not improved in more than 20 years.

During 2004 and 2005, more than 68,000 women nearly died in childbirth in the USA. Each year, 1.7 million women suffer a complication that has an adverse effect on their health.

This is not just a public health emergency – it is a human rights crisis. Women in the USA face a range of obstacles in obtaining the services they need. The health care system suffers from multiple failures: discrimination; financial, bureaucratic and language barriers to care; lack of information about maternal care and family planning options; lack of active participation in care decisions; inadequate staffing and quality protocols; and a lack of accountability and oversight.

MATERNAL HEALTH AND HUMAN RIGHTS

Maternal health is a human rights issue. Preventable maternal mortality can result from or reflect violations of a variety of human rights, including the right to life, the right to freedom from discrimination, and the right to the highest attainable standard of health. Governments have an obligation to respect, protect and fulfil these and other human rights and are ultimately accountable for guaranteeing a health care system that ensures these rights universally and equitably.

The USA has ratified two key international human rights treaties that guarantee these rights: the International Covenant on Civil and Political Rights and the International Convention on the Elimination of All Forms of Racial Discrimination. It has also signed two international treaties that address these rights – the International Covenant on Economic, Social and Cultural Rights and the Convention on the Elimination of All Forms of Discrimination against Women – and so has an obligation to refrain from acts that would defeat the object and purpose of these treaties.

UNEQUAL CARE

"Of all the forms of inequality, injustice in health care is the most shocking and inhumane."

Dr Martin Luther King Jr, 25 March 1966

The US government has a responsibility to ensure equal access to quality health care services for all, without discrimination. However, gender, race, ethnicity, immigration status, Indigenous status and income level can affect a woman's access to adequate health care services in the USA.

Discrimination profoundly affects a woman's chances of being healthy in the first place. Women of color are less likely to go into pregnancy in good health because they are more likely to lack access to primary health care services. Despite representing only 32 percent of women, women of color make up 51 percent of women without insurance.

Women of color are also less likely to have access to adequate maternal health care services. Native American and Alaska Native women are 3.6 times, African-American women 2.6 times and Latina women 2.5 times as likely as white women to receive late or no prenatal care. Women of color are more likely to die in pregnancy and childbirth than white women. In highrisk pregnancies, African-American women are 5.6 times more likely to die than white women.

Women of color are more likely to experience discriminatory and inappropriate treatment and poorer quality of care.

Because women of color make up a disproportionate percentage of those who receive publicly funded care, they are most affected by barriers to accessing health care services through these programmes. The Indian



Inamarie Stith-Rouse, a 33-year-old African-American woman, delivered a healthy baby girl, Trinity, by c-section at a hospital in Massachusetts in June 2003. Her husband, Andre Rouse, said that after the birth she was distressed and struggling to breathe, but that staff dismissed their requests for help. Andre Rouse told Amnesty International he felt race played a part in the staff's failure to react. According to court papers filed by her family, it was hours before appropriate tests and surgery were undertaken, and by then it was too late. Inamarie Stith-Rouse had suffered massive internal bleeding, and slipped into a coma. She died four days later. Andre Rouse said, "Her last words to me were, 'Andre, I'm afraid."

Health Service has suffered from severe long-term under-funding and lacks resources and staff. Federal spending on health services for Native American and Alaska Native peoples is far below spending on all other groups. A report by the US Commission on Civil Rights found that in 2003 national per capita health expenditure averaged US\$5,775, but that the comparable figure for the Indian Health Service was US\$1,900.

'Yes. I speak Spanish. But at this hospital we only speak English.'

Woman recalling the response of an intake coordinator to a woman seeking an ultrasound in 2008 at a private hospital in the District of Columbia

BARRIERS TO Maternal Health Care

"The fear of the bill that is sent to them [is a barrier to seeking services]. When somebody goes for an ultrasound and they get a bill for US\$1,000 – they freak out."

Felicia Marboah, midwife, Mary's Center for Maternal and Child Care, Washington, $\ensuremath{\mathsf{DC}}$

The way in which the health care system is organized and financed fails to ensure that all women have access to affordable, timely and adequate maternal health care. For many women, health care costs are beyond reach.

Half of all births are covered by private insurance. However, policies that exclude maternal care are not uncommon and most insurance companies will not provide coverage for a pregnant woman unless she had insurance before she became pregnant.

'We don't insure a house on fire.'

Statement reportedly made by an insurance company representative when turning down a request from Tanya Blumstein. In July 2008 it was reported that she was unable to purchase private health care insurance with any US company while she was pregnant.

Some 42 percent of births are covered by Medicaid, the government-funded program for some people on low incomes. However, complicated bureaucratic requirements mean that eligible women often face significant delays in receiving prenatal care. Undocumented immigrants are not eligible for Medicaid.

Over 4 percent of women give birth without either private insurance or government medical assistance.

TRUDY LAGREW

Trudy LaGrew, a Native American woman living on the Red Cliff reservation in Wisconsin, died on 7 January 2008 from an undiagnosed heart problem, months after giving birth to her second child. Although her pregnancy was considered high risk because of complications during her first pregnancy and obesity, Trudy LaGrew did not see an obstetrician or high risk specialist for prenatal care because the closest one was a two-hour drive away.

'If you go to apply to the Medicaid system, you need a "proof of pregnancy" letter, with the due date, the date of your last period, and the gestational age of the baby. Where do you get that kind of a letter? – A doctor. If you have no Medicaid, how are you going to get to the doctor to get that letter?'

Jennie Joseph, certified professional midwife, Winter Garden, Florida

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LACK OF COVERAGE

In 2009, an estimated 52 million people in the USA – more than one in six – had no health insurance. As many as 87 million people have found themselves without health insurance at some point in the last two years.

Uninsured individuals who need health care have limited options. The cost of care can drive families into poverty. While no woman in "active labor" may be turned away from a hospital emergency room under federal law, she may later be billed for that care.

Women, especially women on low incomes, can face considerable obstacles in obtaining maternal health care, particularly in rural and inner-city areas. Doctors may be unwilling or unable to provide maternal health care because of bureaucratic complexities and low fees for the services they provide to women covered by Medicaid.

TRINA BACHTEL

Trina Bachtel, a 35-year-old white woman, was insured at the time of her pregnancy, but the local clinic had reportedly told her that it required a US\$100 deposit to see her, because she had incurred a medical debt some years earlier – even though the debt had since been repaid. Trina Bachtel delayed seeking care, unable to afford the fee at the local clinic. She finally received medical attention in a hospital but her son was stillborn. She was later transferred to another hospital in Ohio where she died in August 2007, two weeks after the birth. Community health clinics, including Federally Qualified Health Centers (FQHCs), are an important source of care for people on low incomes. Such clinics served over 16 million patients in 2007, almost three quarters of whom were either uninsured or covered by Medicaid. However, FQHCs are only available in about 20 percent of medically under-served areas, leaving many people without this critical safety net.

OTHER BARRIERS

A central component of the right to health is the availability of sufficient health facilities and trained professionals. In the USA the shortage of health care professionals is a serious obstacle to timely and adequate health care for some women, particularly in rural areas and the inner cities. Finding specialists for women presenting complications or risk factors affecting their pregnancy is particularly difficult.

Women interviewed by Amnesty International also cited lack of transport to clinics, inflexible appointment hours, difficulty in taking time off work, lack of child care for other children, and the absence of interpreters and information in languages other than English, as major barriers to health care.

'We've had women tell us that they're afraid to miss time from work when they have prenatal appointments. They are faced with the choice of coming to work or missing work and losing their jobs. That is their reality.'

Eleanor Hinton Hoytt, President, Black Women's Health Imperative

SYSTEM FAILURES

US federal agencies developed national health objectives in 1998 – the Healthy People 2010 goals. These aimed to reduce maternal deaths to 4.3 per 100,000 live births by 2010. Figures for 2006 (the latest national statistics available) show a national maternal mortality ratio of 13.3 deaths per 100,000 live births. Only five states have achieved the 2010 goal: Indiana, Maine, Massachusetts, Minnesota and Vermont. In some areas ratios are significantly higher: in Georgia it is 20.5; in Washington, DC, 34.9; and in New York City the ratio for black women is 83.6 per 100,000 live births.



Diane Rizk McCabe's mother and children hold a photo of Diane, who died in September 2007. She suffered excessive bleeding after she had delivered her healthy baby girl by c-section.

FAMILY PLANNING GAPS

In the USA, nearly half of all pregnancies are unintended. The rates are significantly higher for women on low incomes and women of color. Women with unintended pregnancies are more likely to develop complications and face worse outcomes for themselves and their babies.

Access to family planning services is constrained by budgetary restrictions and policy and legislative measures.

The federal government has failed to ensure that family planning services and contraceptives are adequately covered by private insurance providers. Only 27 states require health insurance policies that cover other prescription drugs to include prescription contraceptives.

About 17.5 million women in the USA are estimated to be in need of publicly funded family planning services and supplies. However, Medicaid and government-funded clinics (known as Title X clinics) cover just over half of them, leaving more than 8 million women without affordable family planning information and services.



Julie LeMoult holds her baby boy shortly before her death in April 2003. Meningitis due to an infection was discovered too late and she suffered massive brain damage. The hospital has since tightened up its efforts to maintain a sterile environment.



Maria and her one-year-old daughter, 3 February 2009. Maria's immigration status prevented her accessing publicly funded health care when she was pregnant and she could not afford to pay for prenatal care herself. When she went into labor in 2008, the first hospital she went to turned her away because she had not received any prenatal care. She later gave birth at a different hospital.

TAMEKA MCFARQUHAR

In December 2004, 22-year-old Tameka McFarquhar bled to death in her apartment in Watertown, New York. She had given birth to her first child, Danasia Elizabeth, on 14 December and was discharged a day later. Mother and baby were found dead on Christmas morning. Friends and family, unable to reach her, had pleaded with police and her landlord, but it was a week before they were able to gain access to the apartment. The Jefferson County medical examiner reported that the death resulted from part of the placenta being left inside her uterus following the birth. According to one expert, a postpartum check-up visit could have identified symptoms before her condition became life-threatening.

LACK OF PRENATAL CARE

Women who do not receive prenatal care are three to four times more likely to die of pregnancy-related complications than women who do. Those with highrisk pregnancies are 5.3 times more likely to die if they do not receive prenatal care.

The Healthy People 2010 goals include an objective to ensure that at least 90 percent of women receive "adequate prenatal care", defined as 13 prenatal visits beginning in the first trimester. However, 25 percent of women still do not receive these. This figure rises to 32 percent for African-American women and 41 percent among American Indian and Alaska Native women.

INADEQUATE CARE FOLLOWING THE BIRTH

More than half of all maternal deaths occur between one and 42 days following birth. Postpartum care in the USA is inadequate, generally consisting of a single visit to a physician around six weeks after birth. Although women with recognized complications may receive more attention, the lack of care for women in the weeks after they have returned home with a new baby can mean complications are missed.

VARIABLE QUALITY OF CARE

There is significant variation in obstetric practice across the country. A range of guidelines on maternal care have been produced by various state and federal agencies as well as by the American Congress of Obstetricians and Gynecologists. However, the USA has no nationally implemented comprehensive guidelines and protocols for maternal health care and for preventing, identifying



and managing obstetric emergencies. There is an urgent need for a coordinated, comprehensive system of maternal health care.

According to some estimates, improving the quality of maternal care could prevent 40 to 50 percent of deaths. For example, studies in other medical fields show that embolism (blood clot) following surgery has been reduced by approximately 70 percent by using either compression stockings or drugs. However, these simple measures are not routinely used following c-sections, which account for 32 percent of births.

UNDERSTAFFING

"The policy of the hospital, due to finances, is to keep the fewest nurses on the floor."

Retired maternity nurse, Minnesota

Understaffing results in fatigue, stress, increased staff turnover and little time for ongoing training. Staffing shortages also mean that nurses work more overtime. There is little regulation of overtime. Patients and health professionals have identified the inadequate number of nurses as a key cause of poor quality care and medical errors.

PATIENT PARTICIPATION RESTRICTED

Many women are not given a say in decisions about their care and do not get enough information about the signs of complications and the risks of interventions, such as inducing labor or c-sections. C-sections are performed in nearly one third of all deliveries in the USA – twice as high as recommended by the World Health Organization. The risk of death following c-sections is more than three times higher than for vaginal births.

Linda Coale, a healthy 35-year-old woman, gave birth to a baby boy, Benjamin, by c-section on 27 September 2007. One week after returning home, she died of a blood clot. She was given information about acclimatizing pets to a new baby, but no detailed information on the warning signs for blood clots, even though she was at heightened risk because of her age and the surgery. Her sister Lori said: "knowing Linda was once an Emergency Medical Technician, if those discharge papers had said it could be a sign of a blood clot, in my heart of hearts I believe that she would have acted on it."

'Black women are often not taken seriously at health care facilities; our symptoms are ignored.'

Shafia Monroe, President, International Center for Traditional Childbirth, Portland, Oregon

ACCOUNTABILITY

"Following postpartum hemorrhages in two Latina women, there was a meeting to look at what went wrong. But the assessment process didn't include much about 'let's examine why this happened to non-English speaking women.' The questioning was, 'How can we avoid liability in the future.'"

Jill Humphrey, labor and delivery registered nurse, community hospital, Washington State

Disturbing as the published figures for maternal mortality are, they do not reflect the full extent of the problem. There are no federal requirements to report maternal deaths, and the authorities concede that the number of maternal deaths may be twice as high. Reporting of pregnancy-related deaths as a distinct category is mandatory in only six states and despite voluntary efforts in some other states, systematic undercounting of pregnancy-related deaths persists.

'When there is a problem and someone dies, no one talks to the family. A steel curtain comes down, and the only way for families to get any answers is to get a lawyer and sue.'

Marsden Wagner, former director of Women and Children's Health at the World Health Organization

Another significant factor contributing to the failure to improve maternal health is a lack of comprehensive data collection and effective systems to analyze the data. This masks the full extent of maternal mortality and morbidity and hampers efforts to analyze and address the problems. 'The ability to investigate deaths in depth does not exist with the exception of Massachusetts, California and maybe Florida... Frankly, it's a disgrace.'

Federal official

Maternal mortality review committees seek to identify patterns in preventable deaths and are an important element in analyzing problems and proposing possible solutions to improve maternal health. However, 29 states and the District of Columbia reported to Amnesty International that they have no maternal mortality review process at all. In the 21 states where maternal mortality review committees do exist, their effectiveness is variable. They are not uniform in design or mandate and approach the work in different ways. Some rely exclusively on volunteers; others have professional staff. Some review all maternal deaths, while others analyze a sample. In addition the work of the committees is not coordinated nationally, which can result in duplication of efforts.

'Who owns responsibility for [best practices not being implemented]? The short answer is: "Everybody and nobody".'

Carolyn Clancy, Director, Agency for Healthcare Research and Quality

ACTION NEEDED

For more than 20 years, the US authorities have failed to improve the outcomes and disparities in maternal health care. Much of the debate in the USA around health care focuses on improving access to care and reducing the growth in health care spending. However, focusing on health care coverage alone would leave largely unaddressed the issues of discrimination, systemic failures and accountability. It is essential that the debate goes beyond health care coverage and addresses access to quality health care for all, equitably and free from discrimination. 'Mothers, the newborn and children represent the well-being of a society and its potential for the future. Their health needs cannot be left unmet without harming the whole of society.'

Lee Jong-wook, Director-General, World Health Organization, 2003-2006



States without a maternal mortality review board



Women rally in New York City in 2004 calling for a reduction in the rate of c-sections, currently performed in almost one in three births in the USA.

ACT NOW

The US government should realize the human rights standard of making good quality health care available, accessible and acceptable to all, without discrimination.

The following steps should be taken as a matter of urgency:

1. The US Congress should direct and fund the Department of Health and Human Services to establish an Office of Maternal Health with a mandate that includes:

- improving maternal health data collection and review, in collaboration with agencies such as the Centers for Disease Control and Prevention;
- protecting the right to non-discrimination in maternal health care, in collaboration with the Department of Health and Human Services' Office for Civil Rights and the Department of Justice; and
- recommending necessary regulatory and legislative changes to ensure that all women receive access to good quality maternal care.

2. The US Congress should increase funding for the Federally Qualified Health Center program in order to ensure an adequate number of health service facilities and health professionals in all areas, in particular in medically underserved areas.

3. Health departments in all states should ensure that pregnant women have "presumptive eligibility" or temporary access to Medicaid while their permanent application for coverage is pending.

4. Health departments in all states should improve maternal health data collection and review by:

- establishing a maternal mortality review board;
- including a maternal death checkbox on their standard death certificate; and
- mandating reporting of maternal deaths.

HEALTH CARE IS A HUMAN RIGHT AMNESTY INTERNATIONAL



Amnesty International is a global movement of 2.8 million supporters, members and activists in more than 150 countries and territories who campaign to end grave abuses of human rights.

Our vision is for every person to enjoy all the rights enshrined in the Universal Declaration of Human Rights and other international human rights standards.

We are independent of any government, political ideology, economic interest or religion and are funded mainly by our membership and public donations.

March 2010 Index: AMR 51/019/2010

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