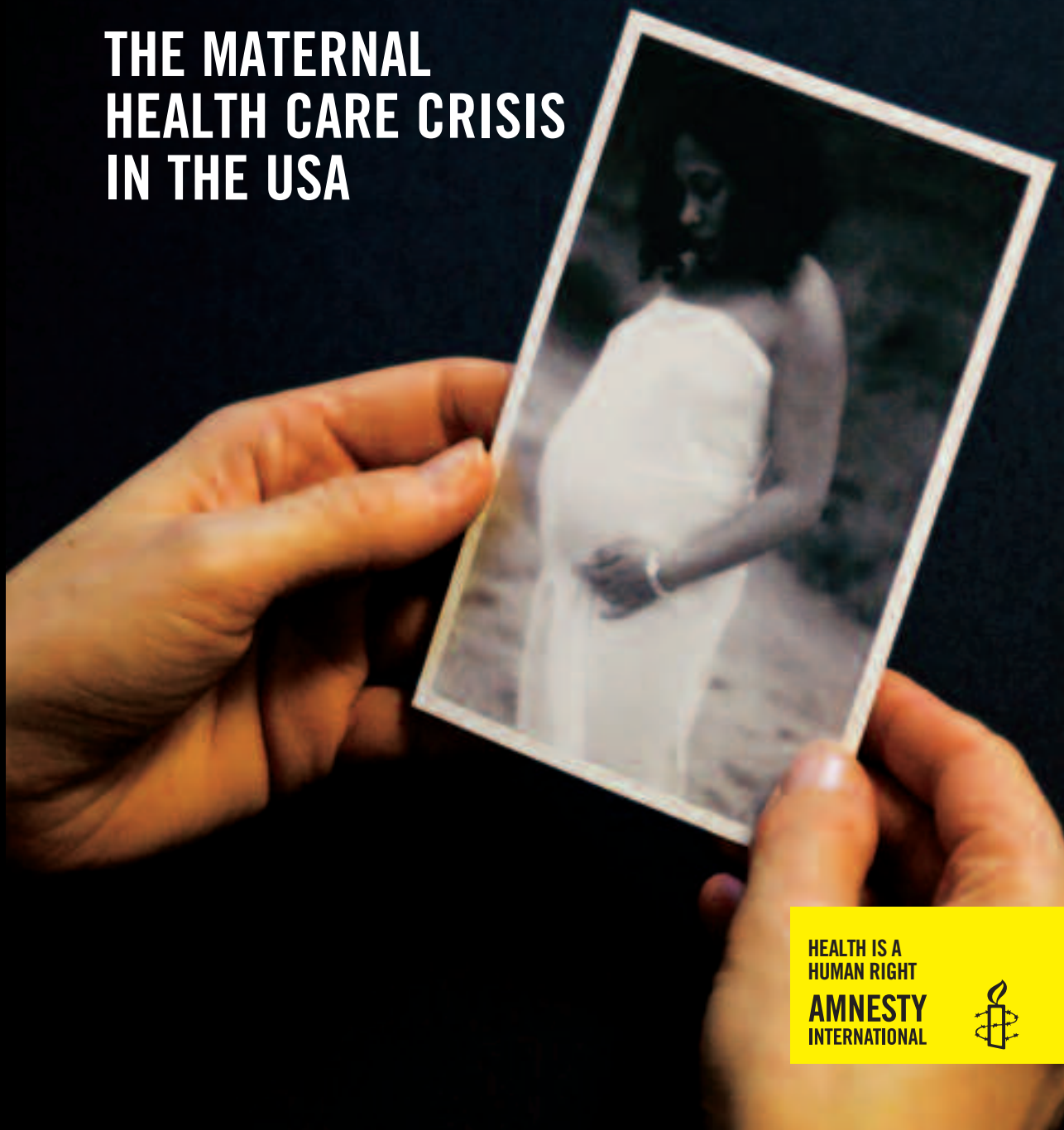
DEADLY DELIVERY

THE MATERNAL HEALTH CARE CRISIS IN THE USA



HEALTH IS A HUMAN RIGHT

AMNESTY INTERNATIONAL

DEADLY DELIVERY

THE MATERNAL HEALTH CARE CRISIS IN THE USA

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 – FUNDED MAINLY BY OUR MEMBERSHIP AND PUBLIC DONATIONS.

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Cover photo, front:
Tatia Oden French and her baby daughter, Zorah, died in 2001 after an induced labor. Her mother has since set up a foundation to prevent similar deaths (see page 89). Photo of Tatia Oden French taken by Joseph B. French and used by kind permission of Maddy Oden and Joseph B. French. © Amnesty International
Cover photo, back:
The Safe Motherhood Quilt Project, a national initiative developed by Ina May Gaskin to honor women who have died of pregnancy-related causes since 1982. © Safe Motherhood Quilt Project

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THE MATERNAL HEALTH CARE CRISIS IN THE USA

Amnesty International Publications

CONTENTS

SCOPE AND METHODOLOGY

This report is based on research carried out during 2008 and 2009 by Amnesty International USA (AIUSA). Amnesty International conducted over 100 in-depth interviews and 17 focus groups with women, their families, activists, advocates, public health experts, support workers, service providers and health workers in central Wisconsin; Memphis, Tennessee; Boston, Massachusetts; Washington, DC; Baltimore, Maryland; and New York City; as well as people from across the USA involved in maternal health care. The names and other personal details of some of those who spoke to Amnesty International have been withheld in order to respect their requests for privacy.

Amnesty International interviewed officials at federal agencies under the Department of Health and Human Services, including the Agency for Healthcare Research and Quality, the Health Resources Services and Administration, the Centers for Medicare and Medicaid Services, the Office of Minority Health, the Office of Women's Health, the Office of Population Affairs, and the Centers for Disease Control and Prevention. Amnesty International sent questionnaires to state departments of health seeking information on the maternal mortality review process in place. A separate questionnaire was sent to each state's Medicaid director regarding eligibility for coverage and the services available to pregnant women.

Amnesty International reviewed media reports of maternal deaths and available medical and public health literature on maternal health and health care, focusing its research on disparities in health provision and outcomes and on preventable deaths and complications.

Amnesty International wishes to thank all the families and women who agreed to share their experiences. Amnesty International is grateful to the organizations, experts and individuals who generously shared information, perspectives and analysis.

A NOTE ON TERMINOLOGY

Amnesty International strives to use terminology that respects the wishes of the individuals concerned. However, when referring to studies and statistics compiled by other organizations, the categorization used by the studies must also be respected in order to ensure that the findings are conveyed accurately and without distortion. In addition, terminology used in the USA itself often varies and may differ from that used internationally by those campaigning for human rights such as non-discrimination, women's rights or the right to health.

Throughout this report terms – such as African-American; black; ethnic, racial and national minorities; Hispanic; Indigenous; Latina; Native American and Alaska Native;

white; and women of color – are used as descriptors of individuals or communities, as far as possible in accordance with the self-identification of the individuals concerned, while not compromising the accuracy of the studies quoted. Another factor guiding the choice of terminology in this report is the need to ensure it is as accessible as possible to diverse audiences both within the USA and around the world. However, the choices made are in no way intended to minimize or ignore the complexity or diversity of ways in which people may identify in different contexts.

LIST OF ABBREVIATIONS

ACOG American Congress of Obstetricians and Gynecologists

AHRQ Agency for Healthcare Research and Quality, a federal agency within the Department of Health and Services that supports research designed to improve the outcomes and quality of health care, address patient safety and medical errors, and broaden access to effective services

AIUSA Amnesty International USA

CDC Centers for Disease Control and Prevention, a federal agency under the Department of Health and Human Services that works to protect public health and safety by providing information to enhance health decisions and promotes health through partnerships with state health departments and other organizations

CEDAW Convention on the Elimination of All Forms of Discrimination against Women

CESCR Committee on Economic Social and Cultural Rights

CHIP Children's Health Insurance Program, a federal program administered by the Department of Health and Human Services that provides matching funds to states for health insurance to families with children

CMS Centers for Medicare and Medicaid Services, a federal agency within the Department of Health and Human Services that administers the Medicare program and works in partnership with state governments to administer Medicaid and the Children's Health Insurance Program

COBRA	Consolidated Omnibus Budget Reconciliation Act of 1985 which states that firms with more than 20 employees are required by federal law to offer health insurance for up to 18 months after an employee loses his or her job. The former employee may be required to pay between 35 percent and 100 percent of the cost of continuing coverage
EMTALA	Emergency Medical Treatment and Active Labor Act
FPL	Federal Poverty Level
FQHC	Federally Qualified Health Centers, community health centers that meet certain federally designated requirements – such as being governed by a board with a majority of community members, offering services on a sliding fee scale, and serving all patients who seek care – in order to obtain grant funding and enhanced reimbursement rates
FBI	Federal Bureau of Investigation
HRSA	Health Resource and Services Administration, a federal agency within the Department of Health and Human Services that aims to improve access to health care services for people who are uninsured, isolated, or medically vulnerable
HMOs	Health Maintenance Organizations
ICCPR	International Covenant on Civil and Political Rights
ICE	Immigration and Customs Enforcement
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination
ICESCR	International Covenant on Economic, Social and Cultural Rights
IHS	Indian Health Service, an agency within the US Department of Health and Human Services that is responsible for providing medical and public health services to American Indians and Alaska Natives
VBAC	Vaginal birth after a prior cesarean section
WHO	World Health Organization

“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, former Director-General, World Health Organization, *Make Every Mother and Child Count*, Geneva, April 2005

1/INTRODUCTION

The total amount spent on health care in the USA is greater than in any other country in the world.[1] Hospitalization related to pregnancy and childbirth costs some US$86 billion a year; the highest hospitalization costs of any area of medicine.[2] Despite this, women in the USA have a greater lifetime risk of dying of pregnancy-related complications than women 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.[3] More than two women die every day in the USA from pregnancy-related causes.[4] Maternal deaths are only the tip of the iceberg. Severe complications that result in a woman nearly dying, known as a "near miss", increased by 25 per cent between 1998 and 2005. During 2004 and 2005, 68,433 women nearly died in childbirth in the USA.[5] More than a third of all women who give birth in the USA – 1.7 million women each year – experience some type of complication that has an adverse effect on their health.[6]

African-American women are at especially high risk; they are nearly four times more likely to die of pregnancy-related complications than white women.[7] Even for white women in the USA, however, the maternal mortality ratios are higher than for women in 24 other industrialized countries.[8] These rates and disparities have not improved in more than 20 years.[9] Maternal mortality ratios have actually increased from a low of 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 increase may be due to improved data collection, the fact that maternal mortality ratios have doubled is a cause for concern.[10]

Inamarie Stith-Rouse died in a Boston hospital in June 2003 after giving birth to her daughter. Warning signs of her decline were ignored.

INAMARIE STITH-ROUSE

Inamarie Stith-Rouse, a 33-year-old African-American woman, was 41 weeks' pregnant when she arrived at a hospital in Boston, Massachusetts, in June 2003. Doctors gave her medication to induce labor. When her baby's heartbeat dropped dramatically, she underwent an emergency c-section (cesarean section) and delivered a healthy baby girl, Trinity. Her husband, Andre Rouse, told Amnesty International how following the birth, "She started to complain of shortness of breath. I couldn't find the doctor. They kept paging her, but she wasn't around. The oxygen machine kept beeping; maybe six or seven times in half an hour. I lost count. No one was taking it seriously. Her face was burning up; I kept putting cold compresses on her forehead." He described how when they tried telling staff that she was distressed and struggling to breathe, they were told it was "no big deal" and that they were "too emotional." Andre Rouse told Amnesty International he felt race played a part in the hospital staff's lack of response to his and his wife's requests for help.

According to court papers filed by her family, Inamarie Stith-Rouse displayed symptoms of hemorrhage, including low blood pressure, high pulse, and shortness of breath. However, it was hours before appropriate tests were undertaken. By then it was too late. Doctors found internal bleeding and first removed the uterus, and later an ovary. However, Inamarie Stith-Rouse suffered severe brain damage, slipped into a coma and died four days later.

Andre Rouse said, "Her last words to me were, 'Andre, I'm afraid.' Then 'CODE RED' was called. I was pushed out the door. Everything was in slow motion. I remember being freezing cold. My teeth were chattering. I was in shock… Nobody talked to me… I felt as though everyone was trying to cover up their tracks. If someone had tried to explain, the whole thing would have been easier to accept. I understand: mistakes happen. But nobody took responsibility." He told Amnesty International that, after he filed a lawsuit in December 2004, "the hospital changed protocols after Inamarie's death. In what way and how, I don't know to this day."

While Amnesty International is unable to determine whether Inamarie Stith-Rouse would have survived if she had received appropriate medical care immediately, the delays in her treatment highlight a pattern reflected in the experiences of many of the women interviewed by Amnesty International.

Amnesty International interviews with Andre Rouse, 13 March 2009; and family attorneys, 9 January 2009; and court documents.

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 or income level can affect a woman's access to health care and the quality of health care she receives. The intersection of multiple forms of discrimination can further adversely affect a woman's access to adequate health care services in the USA. These disparities in access to maternal health care violate women's right to non-discrimination.

> **"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 Second National Convention of the Medical Committee for Human Rights, Chicago, Illinois

According to the Centers for Disease Control and Prevention (CDC), approximately half of all maternal deaths in the USA are preventable.[11] Preventable maternal mortality is not just a public health issue, it is a human rights issue.

More than half a million women die every year worldwide as a result of problems related to pregnancy and childbirth, the vast majority in Asia and Sub-Saharan Africa.[12] The experiences of women in the USA highlighted in this report show that even in wealthy countries, women are put at risk by the failure of the authorities to fulfil their rights to life, to non-discrimination and to the highest attainable standard of health. For women who are marginalized or living in poverty, the risks are particularly acute.

The international community identified reducing maternal mortality ratios as one of its priority Millennium Development Goals (MDGs); MDG 5 calls for a 75 percent reduction in the number of women who die during pregnancy and childbirth by 2015.[13]

In 1998, US federal agencies developed national health objectives – the Healthy People 2010 goals. These set a target of reducing maternal deaths to 4.3 per 100,000 live births by 2010.[14] Figures for 2006 (the latest national statistics available) show that the national maternal mortality ratio is 13.3 deaths per 100,000 live births.[15] Only five US states have achieved the 2010 goal (see Appendix A). In some areas ratios are significantly higher: in Georgia it is 20.5; in Washington, DC, it is 34.9; and in New York City the ratio for black women is 83.6 per 100,000 live births.[16]

THE FIVE MAIN CAUSES OF MATERNAL DEATH IN THE USA

Embolism 20%
A blood clot that blocks an essential blood vessel, for example in the lungs

Hemorrhage 17%
Severe blood loss

Pre-eclampsia and eclampsia 16%
Disorders associated with excessively high blood pressure

Infection 13%

Cardiomyopathy 8%[17]
Heart muscle disease

Disturbing as these figures are, they probably significantly understate the problem. There are no federal requirements to report maternal deaths and US authorities concede that the number of maternal deaths may be twice as high.[18] Amnesty International's survey suggests that reporting of pregnancy-related deaths as a distinct category is mandatory in only six states – Florida, Illinois, Massachusetts, New York, Pennsylvania and Washington. Despite voluntary efforts in some other states, systematic undercounting of pregnancy-related deaths persists.

The US health care system is failing women. For those who can afford it, the USA offers some of the best health care in the world. For many, however, that care is beyond reach. A high number of those without any form of health insurance are women of reproductive age. Women of color make up a disproportionate number of those women who do not have health insurance. Despite representing only 32 percent of women in the USA, women of color make up 51 percent of uninsured women.[19]

At the time of writing, reform of the health care system was a priority for the US administration and major changes were under consideration. However, under the existing system, the way in which the health care system in the USA is structured and financed is failing to ensure that all women have equal access to the health care they need. Although women in "active labor" cannot legally be turned away from a hospital regardless of their ability to pay, they may later be billed for thousands of dollars for medical care.[20] Half of all births are covered by private insurance.[21] However, policies that exclude coverage for maternal care are not uncommon and pregnant women may also find that they cannot get private health insurance because pregnancy is regarded as a "pre-existing condition". Some 42 percent of births are covered by a government-funded program for limited categories of people on low incomes – Medicaid. However, complicated bureaucratic requirements mean that women eligible for public assistance often experience significant delays in receiving prenatal care.

Women, above all 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 the high costs and low fees involved or because of cumbersome reimbursement procedures via Medicaid. 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 information in languages other than English or interpreters, as major barriers to health care. Again, discrimination proved to be an additional barrier for African-American, Indigenous, Latina and immigrant women and women who did not speak English.

The US government's failure to ensure that women have guaranteed lifelong access to quality health care, including reproductive health services, has a significant impact on the likelihood of having a healthy pregnancy and delivery.

"Prenatal care is expensive. And if you're undocumented or uninsured it's a luxury instead of a basic right."

Susan Moskosky, Director of Office of Family Planning, Office of Population Affairs, Amnesty International interview, 21 November 2008

Prenatal care is a key element in facilitating a safe pregnancy. Women who do not receive prenatal care are three to four times more likely to die than women who do.[22] Those with high-risk pregnancies are 5.3 times more likely to die if they do not receive prenatal care.[23] 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 41 percent among American Indian and Alaska Native women.[24]

> **"We want women to know the risks, if there is a swelling; we need to find out what is going on. [A] client who was not part of the prenatal care program had hypertension which developed into toxemia… The swelling didn't recede – she needed help [but didn't know it]. She was only 19. She was 37 weeks along when she died… They found her in a coma. Her mom had to bury her and the baby."**
>
> Clinic staff, Memphis, Tennessee, 5 February 2009

Insufficient access to quality health care services over a woman's lifetime means that women are entering into pregnancy with health conditions that are untreated or unmanaged. This poses added risks for both the woman and her child. For example, women who become pregnant with uncontrolled diabetes are more likely to have a miscarriage or develop pre-eclampsia.[25]

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 (ACOG). 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.

> **"Maternal mortality is a general report card with regard to the quality of obstetric care in the United States."**
>
> Jeffrey C. King, Chair of ACOG Maternal Mortality Special Interest Group, Amnesty International interview, 13 March 2008

According to a study conducted by the CDC, 55 percent of maternal deaths occurred between one and 42 days following birth.[26] Postpartum care in the USA is inadequate, generally consisting of a single visit with a physician around six weeks after birth.[27] 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.

In 2009, the new US Administration and Congress focused on the need to reform the health care system, in particular on improving access to care and reducing the growth in health care spending. Although the proposals under debate would reduce the number of uninsured individuals, no legislation currently under consideration would realize the human rights standards of making health care available, accessible, acceptable, and of good quality to all, without discrimination. It is estimated that the proposed reforms would still leave between 18 and 24 million people without insurance, and for many health care costs would remain unaffordable. In addition, as reform is primarily focused around health care coverage, it would leave largely unaddressed the issues identified in the report regarding discrimination, systemic failures and accountability. As efforts to reform the US health care system are developed and implemented, it is imperative that human rights standards are applied, so that all have equal access to affordable, quality health care, including maternal health care.

Maternal deaths and injuries are stark reminders of what is at stake when the government fails to put in place a health care system that respects, protects and fulfils the human right to health without discrimination. The consequences are evident every step of the way. Women have inadequate access to family planning, enter pregnancy in less than optimal health, receive late or inadequate prenatal care, are given inadequate or inappropriate care during delivery and have limited access to post-natal care.

It is essential that the debate about health care in the USA goes beyond health care coverage and addresses access to quality health care for all on the basis of equality and non-discrimination. Maternal health care services must be improved for all women, and particularly for those most affected by current disparities in health care and outcomes. For over 20 years the US authorities have failed to improve the outcomes and disparities in maternal health care. This report shows the human cost of this failure and highlights the urgent steps needed to reduce maternal mortality and morbidity rates in the USA.

Linda Coale died of an embolism a week after giving birth to her son by c-section. The hospital had failed to adequately alert her to warning signs, despite the heightened risk due to her surgery.

© Private

LINDA COALE

Linda Coale, a healthy, vibrant 35-year-old woman, gave birth to a baby boy, Benjamin, by c-section on 27 September 2007. Just one week after she returned home, she died following a blood clot. On the evening she died, Linda mentioned that she felt some cramping in her leg. She woke up around 1.30am and told her husband that her leg hurt and was swollen. They called her doctor who returned the call after an hour and a half. As Linda walked over to the phone, she collapsed. She was rushed to the hospital, and her parents, sisters and brother, followed as quickly as they could. Two minutes from the hospital, Linda's twin sister, Lori, got a call from their brother, who told her: "She didn't make it." Although the infant welcome packet included information about acclimatizing pets to a new baby, both that packet and Linda's discharge papers failed to provide detailed information on the warning signs and symptoms of serious blood clots (deep vein thrombosis), even though she was at heightened risk because of her pregnancy combined with her age and the surgery. Lori told Amnesty International: "I know you can 'what if' until the end of the world, but 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… My parents had to bury a child… It's wrong… You still can't mention her name in front of them… Thank God for Ben. He's such a wonderful little boy. He's our saving grace in all of this." Linda's sisters want to prevent more deaths, by providing better education during prenatal care, improving information in discharge papers and "just five minutes education by a discharge nurse… Even if we can save just one woman – that's one more child who will have a mother."

Amnesty International interview with Linda's sisters, Clare and Lori, 17 March 2009

KEY RECOMMENDATIONS

1 The US government should ensure that health care services, including sexual and reproductive health care services, are available, accessible, acceptable and of good quality throughout an individual's lifetime.

2 The US government must ensure that all women have equal access to timely and quality maternal health care services, including family planning services, and that no one is denied access to health care services by policies or practices that have the purpose or effect of discriminating on grounds such as gender, race, ethnicity, age, Indigenous status, immigration status or ability to pay.

3 The Office of Civil Rights, within the Department of Health and Human Services, should undertake investigations into laws, policies and practices that may impact on equal access to quality health care services, including maternal health care services.

4 State governments should ensure that pregnant women have temporary access to Medicaid while their permanent application for coverage is pending (presumptive eligibility) and that Medicaid provides timely access to prenatal care. In cases where a woman receives prenatal care before eligibility is confirmed, states should ensure that Medicaid reimburses retroactively for services provided.

5 Federal, state and local governments should ensure that an adequate number of health service facilities and health professionals, including, nurses, midwives and physicians, are available in all areas. Particular emphasis should be given to medically under-served areas, including by expanding community health care center programs, such as the Federally Qualified Health Center (FQHC) program.

6 The Department of Health and Human Services should, in collaboration with affected communities and the medical community, develop and implement comprehensive, standardized, evidence-based guidelines and protocols for maternal health care services.

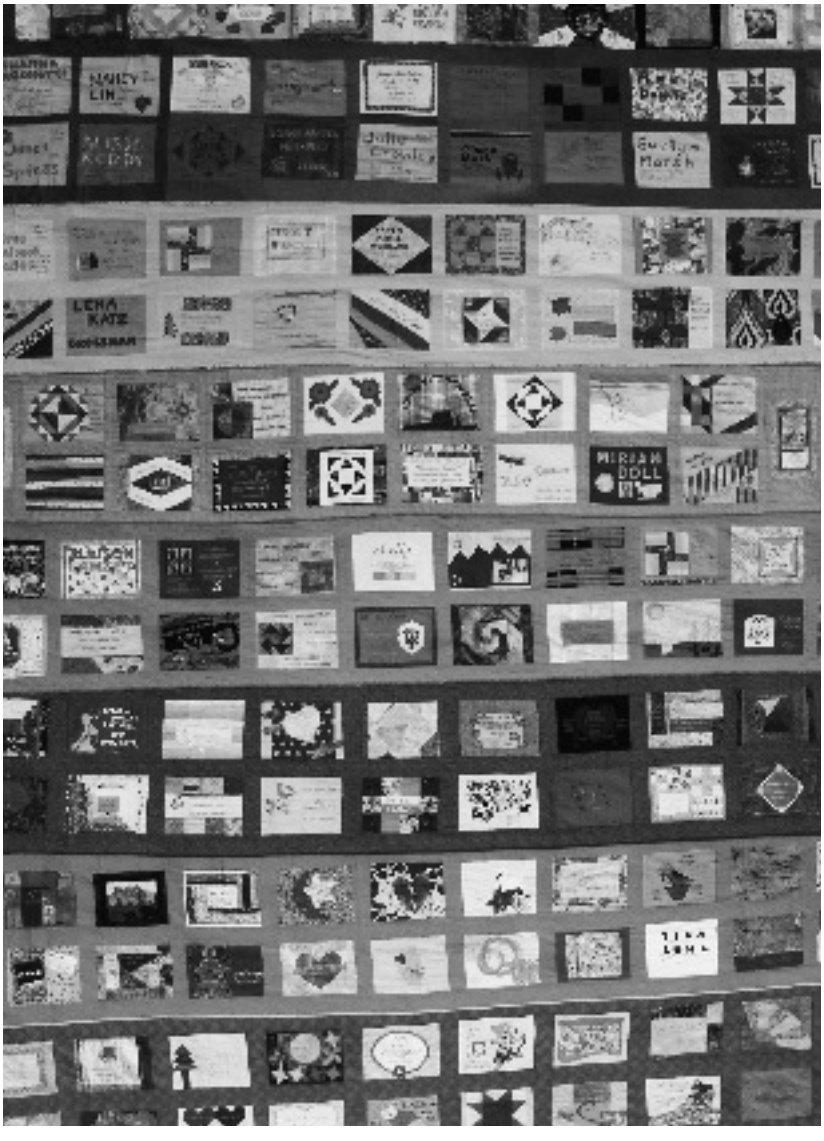
7 Health care providers should ensure that sufficient, accessible information is available to all women so that they can make informed decisions about their health care.

8 The US Congress should direct and fund the Department of Health and Human Services to establish an Office of Maternal Health with a mandate to improve maternal health care and outcomes, and eliminate disparities.

9 Washington, DC, and each of the 29 states that do not currently have a maternal mortality review committee should establish one. Committees should receive ongoing

funding to collect, analyze and review data on all pregnancy-related deaths and address disparities. Efforts at state level should be coordinated nationally by the CDC in order to identify and implement best practice.

10 State and federal authorities should devise and implement programs to improve data collection and analysis in order to better identify and develop responses to issues contributing to maternal deaths and complications. This may include requiring all states to report maternal deaths and morbidity to federal agencies, including the CDC, on an annual basis and standardizing data collection tools.



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

“EVERYONE HAS THE RIGHT TO A STANDARD OF LIVING ADEQUATE FOR THE HEALTH AND WELL-BEING OF HIMSELF AND OF HIS FAMILY, INCLUDING… MEDICAL CARE… MOTHERHOOD AND CHILDHOOD ARE ENTITLED TO SPECIAL CARE AND ASSISTANCE.”

Article 25, Universal Declaration of Human Rights

2/MATERNAL HEALTH AND HUMAN RIGHTS

This report addresses the issue of maternal health as a human rights issue. Preventable maternal morbidity (illness and injury) and 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.[28] 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 of the key international human rights treaties that guarantee these rights: the International Covenant on Civil and Political Rights (ICCPR) and the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD). The USA has also signed two important international treaties that address these rights – the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) – and so has an obligation to refrain from acts that would defeat the object and purpose of these treaties.

In addition, in June 2009 the USA supported a resolution adopted by the UN Human Rights Council. This recognized that preventable maternal mortality and morbidity are a human rights challenge that requires the promotion and protection of the human rights of women and girls.[29]

This commitment has also been reflected in statements and resolutions by the US authorities. Secretary of State Hillary Clinton has stated that maternal health is part of the US administration's global health agenda[30] and the US House of Representatives and Senate passed resolutions in 2008 making commitments to do more to reduce maternal mortality both abroad and at home.[31]

> **"The US Senate makes a stronger commitment to reducing maternal mortality both at home and abroad… and recognizes that the right to access quality and affordable health care is essential to improving maternal health.**
>
> Senate Resolution, 21 July 2008

THE RIGHT TO LIFE

The right to life is protected in a number of international human rights treaties including the ICCPR, which states that every human being has the inherent right to life and that no one shall be arbitrarily deprived of their right to life.

The Human Rights Committee, the body charged with interpreting the ICCPR, has noted that protecting the right to life "requires that States adopt positive measures."[32] In this regard, the rights to life and health are closely linked. For example, the Committee has stressed the need to employ a broad interpretation of the right to life, which includes public health measures, and has called on states to reduce preventable maternal mortality, including by ensuring access to family planning and abortion, as part of their obligation to protect the right to life under the ICCPR.[33] Like all human rights, the right to life must also be guaranteed without discrimination.

THE RIGHT TO FREEDOM FROM DISCRIMINATION

"STATES PARTIES UNDERTAKE TO PROHIBIT AND TO ELIMINATE RACIAL DISCRIMINATION IN ALL ITS FORMS AND TO GUARANTEE THE RIGHT OF EVERYONE, WITHOUT DISTINCTION AS TO RACE, COLOR, OR NATIONAL OR ETHNIC ORIGIN, TO EQUALITY BEFORE THE LAW, NOTABLY IN THE ENJOYMENT OF THE… RIGHT TO PUBLIC HEALTH [AND] MEDICAL CARE."

ICERD, Article 5 (e) (iv)

The right to enjoy human rights without discrimination is a fundamental principle underlying international human rights law.[34] International law prohibits discrimination on a broad range of factors, including race, sex, sexual orientation, religion, language, national or social origin, ethnicity or Indigenous or other status.

While under the ICCPR some rights explicitly allow for exceptions for non-citizens (for example Article 25 governing rights relating to voting and public service), "the general rule is that each one of the rights of the Covenant must be guaranteed without discrimination between citizens and [non-citizens]."[35] Accordingly, the vast majority of rights protected in the ICCPR apply without discrimination to citizens and non-citizens, including the right to life and non-discrimination.[36] Similarly, while certain distinctions between citizens and non-citizens are permitted under the ICERD, this

does not affect the USA's other international law obligations to protect non-citizens against discrimination, and distinctions based on citizenship will still amount to discrimination under the ICERD where they are not proportionate to a legitimate aim under the Convention.[37]

The ICERD prohibits policies or practices that are discriminatory in either purpose or effect.[38] The UN Human Rights Committee has also noted that the ICCPR's prohibition of discrimination should be understood to encompass both discriminatory purposes and effects.[39] Therefore, policies or practices that have a disproportionate impact on a protected group may be discriminatory in effect and so in breach of international law.[40] The USA has not adhered to this understanding of the prohibition on discrimination, and in most cases federal courts only protect against discrimination that can be shown to arise from discriminatory intent. The USA's approach has been rejected by the Committee on the Elimination of Racial Discrimination, the body charged with interpreting the ICERD.[41]

Under the ICERD, the USA must not only refrain from actions that may have discriminatory purpose or effect, but must also guarantee the right "to equality before the law, notably in the enjoyment of… the right to public health, [and] medical care."[42]

The Committee on the Elimination of Racial Discrimination has found that the US government is falling short in its duty to eliminate racial inequalities. The Committee noted that "wide racial disparities continue to exist in the field of sexual and reproductive health, particularly with regard to the high maternal and infant mortality rates among women and children belonging to racial, ethnic and national minorities, especially African-Americans, the high incidence of unintended pregnancies and greater abortion rates affecting African-American women".[43] The Committee recommended that the US government address persistent racial disparities in sexual and reproductive health in particular by:

- improving access to maternal health care, family planning, pre- and post-natal care and emergency obstetric services, including through the reduction of eligibility barriers for Medicaid coverage;

- facilitating access to adequate contraceptive and family planning methods; and

- providing adequate sexual education aimed at the prevention of unintended pregnancies and sexually transmitted infections.

THE RIGHT TO HEALTH

The right to health is guaranteed by a number of international human rights declarations and treaties and is closely related to other rights, notably the right to life and the right to non-discrimination.

The right to health does not mean the right to be healthy; good health cannot be fully ensured by governments. However, it does impose on governments an obligation to create the conditions in which everyone can be as healthy as possible. This includes not only ensuring timely and appropriate health care but also other essential conditions for health, including access to adequate food, nutrition, sanitation and housing.[44]

The USA has yet to fully recognize the right to health or establish a system that provides access to health care for all. For example, the US Supreme Court has found that the US Constitution does not impose any obligation on states to include health care as part of their provision of public welfare. However, as a signatory to two of the key international treaties dealing with the right to health – the ICESCR and the Convention on the Elimination of All Forms of Discrimination against Women – the USA should strive to take steps to realize the rights they guarantee and is obliged to avoid actions that would defeat their purpose. Furthermore, understanding the scope of the right to health is important in determining whether the USA has met its obligations under treaties it has ratified – for example, whether it has met its obligation under the ICCPR to protect the right to life or its obligation under the ICERD to guarantee equality in access to public health and medical services.[45]

The UN Committee on Economic, Social and Cultural Rights – which monitors implementation of the ICESCR – has provided the most authoritative definition of the content of the right to health to date. It has stated that in order to fulfil the right to health:

- A sufficient quantity of health facilities, trained professionals and essential medicines must be available;

- Health facilities, goods, services and information on health must be physically and economically accessible to everyone without discrimination;

- Health facilities, goods, services and information must be acceptable – that is, respect medical ethics, be culturally appropriate and sensitive to gender requirements; and

- Health facilities, goods services and information must be scientifically and medically appropriate and of good quality.[46]

The Convention on the Elimination of All Forms of Discrimination against Women requires governments to take specific measures to ensure that women can access maternal health care and other sexual and reproductive health services which are relevant to reducing maternal mortality. These include: primary health care services throughout a woman's life; education and information on sexual and reproductive health; sexual and reproductive health care services, such as family planning services; prenatal health services; skilled medical personnel to attend the birth; emergency obstetric care; and post-natal health services.[47]

Under the ICCPR, the USA has an obligation to ensure the right to freedom of expression, which includes, "freedom to seek, receive and impart information and ideas of all kinds". [48] This is crucial to enabling individuals to realize a range of other human rights, including the right to health, which encompasses the right to access information and education about health matters, including on sexual and reproductive health; and the right to participate in health-related decision-making at the community, national and international level.[49]

HUMAN RIGHTS PRINCIPLES

In addition to the rights to life, to freedom from discrimination and to health, human rights law also sets out principles that can be used to evaluate efforts by the USA to address maternal mortality and morbidity. These principles include non-retrogression, participation and accountability.

Although the right to health cannot be implemented immediately, governments have an obligation to demonstrate that they are making progress in fulfilling this right and that there is no retrogression. The failure of the USA to reduce maternal mortality rates over the last 20 years demonstrates a clear failure to make progress in addressing this issue.

A rights-based approach to addressing maternal health also calls for meaningful participation by the individuals and communities the health system is supposed to serve, and health care professionals. The limited options available to women in terms of maternal health care reflect the failure to include community members and advocacy groups in the decision-making process regarding what constitutes appropriate, quality maternal care. An individual woman's ability to actively participate in her care is hampered by a lack of information about care options and the failure to involve women in decision-making regarding their own health care. The current lack of comprehensive information and data related to maternal health and disparities in both the provision of care and in health outcomes, and the absence of effective systems to analyze the data consistently across the country, are a barrier to effective participation in and evaluation of programs and policies to reduce maternal mortality and morbidity.

“THE MATERNAL MORTALITY RATES ARE APPALLING. HOW CAN YOU LIVE IN OPPRESSION AND GET SECOND-RATE CARE AND NOT HAVE IT REFLECTED IN OUTCOMES?… BLACK WOMEN WILL BE MORE LIKELY TO DIE UNTIL WE ARE TREATED EQUALLY.”

Shafia Monroe, President of the International Center for Traditional Childbirth, Portland, Oregon, Amnesty International interview, 28 August 2008

“EVERYTHING THAT CAME OUT OF HER MOUTH WAS THE COLOR OF MY SKIN. SHE GOES ‘YOU’RE THE FIRST DARK PERSON I’VE EVER HAD.’ IT JUST KEPT GOING ON FOR LIKE 20 MINUTES. I SAT THERE AND HAD TO DEAL WITH THAT. AFTER THAT, I LEFT AND NEVER WENT BACK.”

Native American woman seeking prenatal care, Wisconsin, Amnesty International focus group, July 2008

“YES. I SPEAK SPANISH. BUT AT THIS HOSPITAL WE ONLY SPEAK ENGLISH.”

Woman interviewed by Amnesty International recalling the response of an intake coordinator to a woman seeking an ultrasound in 2008 at a private hospital in the District of Columbia[50]

3/DISCRIMINATION AND MATERNAL HEALTH

Women of color are more likely to die in pregnancy or childbirth than women from other sections of the population. Black women are nearly four times more likely to die from pregnancy-related causes than white women.[51] In high-risk pregnancies, the disparities are even greater, with African-American women 5.6 times more likely to die than white women. Among women diagnosed with pregnancy-induced hypertension (eclampsia and pre-eclampsia), African-American and Latina women were 9.9 and 7.9 times more likely to die than white women with the same complications.[52]

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 of a lack of access to primary health care services. They 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.[53] They are also more likely to experience poorer quality of care, discrimination or culturally inappropriate treatment.

There is a long history of discrimination in the USA, including in the area of women's sexual and reproductive health. For example, in the 1970s, a pattern emerged of women on low incomes being coerced into accepting sterilization and threatened with the withdrawal of welfare benefits if they refused.[54] Some doctors refused to deliver babies or perform abortions for black women on low incomes unless they first agreed to be sterilized.[55] Between 1972 and 1976, thousands of Indigenous women were sterilized when there was no medical necessity and without their informed consent.[56] Such policies and practices have contributed to a profound distrust of the medical system within affected communities.

It is the responsibility of the US government to ensure that all women are able to enjoy the highest attainable standard of health at all stages of their lives by providing them with the necessary services and information on the basis of equality and non-discrimination. The evidence available shows that it is failing to fulfil this obligation.

INADEQUATE AND INAPPROPRIATE CARE

Discriminatory attitudes that prevent or discourage women from accessing the health care they need when they need it can have very serious health consequences. For example, it is widely acknowledged that prenatal care is a key element in facilitating a safe pregnancy. It is therefore deeply disturbing that women of color are much more likely to receive late or no prenatal care. In South Dakota, for example, a Native American woman is only half as likely to receive adequate prenatal care as a white woman.[57] A study on disparities in access to prenatal care found that the majority of women wanted earlier care but faced significant obstacles in getting it.[58]

Women of color are also less likely to have access to family planning services and have higher rates of unintended pregnancies. The health consequences of unintended pregnancy include an increased risk of morbidity for women and adverse effects for the health of their infants.[59] Again, the figures show that unintended pregnancies have a disproportionate impact on women of color. One study found that 69 percent of African-American women and 54 percent of Hispanic women reported that their pregnancies were unintended, compared to 40 percent of white women.[60]

A national study has found that members of ethnic and racial minorities are disproportionately likely to receive care in lower-quality hospitals.[61] Studies have also found disparities in the quality of care received by women of color and immigrant women. A study of maternal deaths in one state found that 46 percent of maternal deaths among African-American women were potentially preventable, compared with 33 percent of such deaths among white women. The same study noted that the need for quality care was a factor in more than half of preventable deaths.[62] Another study found that in comparison with US-born white women, Mexican-born women had lower rates of complications overall, but had higher rates of those complications (such as postpartum hemorrhage, severe lacerations, and major infections) that were linked to sub-standard obstetric care.[63]

Isabel (not her real name) with her three-year-old son. She was left unattended overnight while in labor in a hospital in Tennessee.

ISABEL

Isabel (not her real name), an undocumented immigrant, speaks limited English. She was 27 years old when she went into labor with her first child in 2005. She sought admission at a private hospital close to her home in Memphis, Tennessee. The receptionist initially turned her away, saying she needed to go to the public hospital, but Isabel insisted her doctor had told her he would meet her there. She told Amnesty International "I started falling down with pain. In the end they took me in a wheelchair… I thought I would die, the pain was so bad. They just came in and said, 'Shut up!' A nurse said, 'Everyone can hear you. Shut up or we'll throw you out.' They still had me in a wheelchair the next morning, and I felt the baby coming. I was afraid he would fall on the ground. I was ready to catch him… When my own doctor finally came, I cried. I felt so relieved. If he hadn't come, I would have given birth alone. It's cruel to leave you alone in a hospital."

Isabel, Memphis, Amnesty International interview, 3 February 2009

ELIZA

In October 2008, Eliza (not her real name), a 21–year-old Latina woman, was two months' pregnant when her ex-spouse severely beat and raped her. According to her police statement, "he strangled me with his hands causing me to black out... Then he began hitting me with his fist. He kicked me in the stomach [and] in the back, causing damage to my liver, kicked me in the face, knocking out two teeth... After he finished beating me and I was all bloody and could not move, he raped me." After the attack, Eliza was taken to a hospital by her current boyfriend. Staff in the emergency room said they didn't understand what she was saying, and told her to wait because there was no interpreter available. A support worker told Amnesty International, "After three or four hours they left – she was in so much pain, she just wanted to clean up and lie down... Why were staff waiting for an interpreter to see her? Even if you don't speak the language – her entire face was caved in. The perception is that 'These people are not worth it.'" The next morning Eliza was seen at another hospital. Despite the extent of her injuries, the fetus was unharmed.

Amnesty International interview, with advocate and police report provided by domestic violence advocates, YWCA, Memphis, Tennessee, February 2009

"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, Amnesty International interview, 28 August 2008

Amnesty International heard reports of inappropriate behavior and care experienced by women of color in a variety of health care settings, affecting both access to and quality of services.

The intersection of discrimination on the basis of gender, race, Indigenous status, immigration status, language and poverty may create a climate where women's needs and rights are routinely disregarded. Only four states currently have legislation requiring that medical students or physicians complete cultural competency courses as part of their licensing or accreditation programs (see Appendix A).[64] The Office of Minority Health within the Department of Health and Human Services has developed 14 National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS) in order to provide a consistent approach to cultural and linguistic competence in health care, but these standards are not implemented nationwide.[65]

KIM

Kim (not her real name) told Amnesty International she wanted a home birth but ended up having a c-section. She said, "I could have been able to better handle the situation if they gave me some medical reason for why I needed to have a cesarean. But there was no explanation as to why I could not have a vaginal birth. It was cesarean and that's it. All other options were taken off the table." One doctor reportedly took Kim aside after the delivery and told her, "We don't get many black patients. They're just not used to your personality, asking the questions that you're asking, saying what you're saying. Challenging and holding them to their diagnoses." Kim noted, "I was quite aware of their perceptions of me. There's that assumption – I'm a young black girl so obviously I'm poor and uneducated… [but] I was asking questions every step of the way. And the more I asked, the more animosity the doctors built up towards me. After my c-section, they had a representative from Medicaid come talk to me. I said, 'You haven't even asked me if I even qualify! I make US$60,000 a year'… On my daughter's birth certificate they checked that I was not college educated. But I have an advanced degree. It was devastating. I asked that they change this. They said, 'No. We can't change it. It's already been sent out. Nobody is going to see it so it doesn't really matter.'"

Amnesty International interview, Asheville, North Carolina, 6 March 2009

Amnesty International received reports that women who were, or were assumed to be, uninsured or insured through a public health program were treated with indifference and sometimes dissuaded from seeking services. Latina women said they usually experienced long delays in waiting rooms and felt they were ignored or treated with disdain by staff.

> **"When they say, 'What do you want!?' Well, I want to leave".**
>
> Latina woman, Memphis, Tennessee, Amnesty International interview, 3 February 2009

> **"We hear it all the time from the women. They treat those who come and ask for services like they are bothering the system. Communities in Memphis are so segregated."**
>
> Service providers, Memphis, Tennessee, Amnesty International interview, February 2009

Reports from women, health providers and advocates suggest that the information women are given is often inadequate and undermines their right to informed consent. In particular, women of color, women who are uninsured or receive Medicaid, and women who do not speak English are less likely to be involved in decisions about their care. A maternal health advocate told Amnesty International of one African-American woman living in Memphis who was laid off from her job in 2005 and so became uninsured. When she became pregnant, she qualified for Medicaid coverage. The advocate described how the woman, who experienced serious complications during her pregnancy, found the attitude of staff inhibited the quality of her care: "It was really frustrating. She was talked down to, things were not explained. She told me she was stunned by the way she was treated… It was a real eye opener. She had to struggle to get the information she needed." The woman eventually lost her baby. Today, she works at an agency that provides home visits and support for pregnant women.[66]

Native American and Alaska Native women also reported culturally inappropriate and discriminatory treatment. This was a particular problem for the many women who have to seek health care services at some distance from their communities.

> **"There's not a respect of the American Indian values that are important… [during birth]. You're shipped out to the clinic in the white town or the white hospital. And they treat you like a second class citizen because they know they're not going to get paid as much as someone who has regular insurance who's not getting care through contract health [from the IHS]. It's like you're a piece of cattle as opposed to a human being that deserves the same care and respect as someone else."**
>
> Isaiah Brokenleg (Sicangu Lakota), Epidemiologist, Great Lakes Inter-Tribal Epidemiology Center, Lac du Flambeau, Wisconsin, Amnesty International interview, 9 July 2008

POVERTY AND HEALTH

"THE SALIENT ISSUES ARE NOT THE DISEASES THAT AFFECT WOMEN OF COLOR, BUT THE POVERTY, HOMELESSNESS, INADEQUATE HEALTH CARE, AND THE DENIAL OF HUMAN RIGHTS THAT ARE THE ROOT CAUSES OF MANY PROBLEMS."

The Sistersong Collective, Women of Color, Reproductive Health and Human Rights [67]

Social and economic conditions are intrinsically linked with health. Women on low incomes may have limited access to adequate nutrition, safe housing and information about health. Investments in health care infrastructure, such as facilities and services, are often concentrated in wealthier areas.[68] Research has demonstrated that maternal and fetal health may suffer from the effects of stress associated both with low income and with lifelong exposure to racism – stress which has been found to have a cumulative impact on the body that appears to have an adverse effect during pregnancy.[69]

Historic and current disparities and discrimination mean that people of color are disproportionately represented among lower income groups in the USA and women are more likely to be poor than men. Women of color are at least twice as likely as white women to be living in poverty; approximately a quarter of black and Latina women have incomes below the Federal Poverty Level (FPL).[70] Women living alone with small children are especially at risk – 46 percent of households headed by women with children under five had incomes below the FPL in 2000.[71]

> **"[D]octors are outside the community… there's a limit to their understanding and that limits the quality of care. [For example], food access is a real issue here, and that's not addressed".**
>
> Maternal child health nurse, Native American reservation, Midwest, Amnesty International interview, 16 December 2008

DISPARITIES IN HEALTH COVERAGE

An individual's ability to access health care depends on whether they have insurance and, if they do, whether it is private or public. Access is often precarious, tied to jobs, economic status, the state or city where an individual lives, and the nature of a person's medical problems. (See Health care insurance in the USA, page 28). Disparities in access and outcomes are considerable.

A significant proportion of the US population of 308 million people lack health coverage (see Appendix D). In 2008, a staggering 46 million people – one in every six people living in the USA – had no health insurance at all.[72] This number has since risen, as a result of the economic recession, and current estimates put the number closer to 52 million in 2009.[73] As many as 87 million people have found themselves without health insurance at some point in the last two years.[74] Although members of ethnic and racial minorities make up only about 34 percent of the population,[75] they constitute approximately half of the uninsured.[76]

> **"Take a family that earns US$1,200 a month out of which you have to pay rent, food, gas – add in the fact that a family of four has to pay US$300 for medical insurance? They don't have the money to pay for that. Or they pay for the insurance and aren't able to eat."**
>
> Latina woman, rural Wisconsin, Amnesty International focus group, 8 July 2008

More Americans were uninsured in 2008 than in 1999.[77] Low-income workers are less likely to be offered employee insurance, but many do not qualify for Medicaid and cannot afford to buy private insurance.[78] About a third of Hispanics (36 percent) and Native Americans (33 percent), and 22 percent of African-Americans are uninsured compared to 13 percent of the white population.[79] Over 44 percent of those living in the USA who are not US citizens, 9.5 million people, were uninsured in 2008, largely due to barriers in accessing public insurance programs,[80] and among undocumented immigrants, nearly 60 percent of adults had no insurance in 2008.[81] Until recently, documented immigrants were barred from receiving public insurance for five years. States now have the option of covering documented immigrants, but are not required to do so.[82] Undocumented immigrants do not qualify for Medicaid.[83] Emergency Medicaid for a limited range of "emergency medical conditions" does not require citizenship, provided other eligibility standards are met.[84]

Ina May Gaskin (front row, left), midwife, author and activist, with Amnesty International staff, including former Secretary General Irene Khan (front row, second from left), during a visit to the Morris Heights Health Center's Women's Health and Birthing Pavillion. Bronx, New York, 14 October 2009.

Uninsured individuals who need health care have limited options. While no one with a severe medical emergency may be turned away from a hospital emergency room under federal law (at least until their condition is stabilized),[85] the cost of treatment can drive families into poverty and leave them facing long-term debt or bankruptcy.

Community health clinics, including Federally Qualified Health Centers (FQHCs), are an important source of care for people on low incomes and provide services on a sliding scale based on income and family size. Such clinics served over 16 million patients in 2007, almost three quarters of whom were either uninsured or covered by Medicaid.[86] However, FQHCs are only available in about 20 percent of medically under-served areas,[87] leaving many people without this critical safety net.

HEALTH CARE INSURANCE IN THE USA

The USA has several types of privately and publicly funded health insurance. Health insurance can be provided as a direct benefit through an individual's employer; through individual purchase of health insurance; or through government-funded programs such as Medicaid. Lack of insurance results in an estimated 45,000 deaths each year – one every 12 minutes.[88] Illness or medical bills are a leading cause of bankruptcy, contributing to 62 percent of bankruptcies in the USA in 2007.[89]

The existence of hundreds of insurance companies with multiple types of plans and reimbursement systems results in considerable waste and high administrative overhead costs. The most recent in-depth study found that approximately 31 percent of US health care costs, more than US$1,000 per person, was spent on administrative services in 1999, more than three times the amount spent in Canada (US$307) which has a national single payer system.[90] Health insurance companies' primary responsibility is to shareholders and decisions about health care coverage and services may be influenced by financial concerns rather than driven by an assessment of the benefit to the public and to the individual.

> **"The top priority of for-profit companies is to drive up the value of their stock… To help meet Wall Street's relentless profit expectations, insurers routinely dump policyholders who are less profitable or who get sick…"**
>
> Former insurance executive Wendell Potter, Testimony before the US Senate Committee on Commerce, Science and Transportation. Philadelphia, Pennsylvania, 24 June 2009[91]

Employment-based health insurance

Approximately 58 percent of the US population receives health insurance through their employer.[92] The benefits offered and the cost of the package to the employee vary enormously.[93] The average employee contribution to health insurance costs for family coverage has increased more than 128 percent since 1999.[94] During the same period, average wages have increased only 36 percent.[95] For some, therefore, the contribution costs have become prohibitive.

Not all employers offer health insurance. In a recent poll, 30 percent of people on low incomes (less than US$27,000 a year) were not offered health insurance through their employer.[96] Even if an employer offers health insurance, some employees may not be eligible, for example part-time workers.[97] Because employee insurance is tied

to a particular employer, changing or losing your job often means a gap in coverage or the loss of insurance altogether.

Although federal law requires firms with more than 20 employees to offer health insurance through COBRA (Consolidated Omnibus Budget Reconciliation Act of 1985) for up to 18 months after an employee loses his or her job, the cost of the plan is often prohibitively high for unemployed individuals who are required to pay between 35 and 100 percent of the premium themselves.[98]

Individual health insurance

More than 26 million people pay for their insurance individually.[99] Private insurance is generally significantly more expensive for individuals than employer-based insurance and often includes fewer services; maternal health care may not be covered. Insurance companies may also deny coverage for pre-existing conditions such as pregnancy, cancer, diabetes and high blood pressure. Only six states guarantee that people with pre-existing conditions can access insurance at the same rates as others.[100]

Public health insurance

Approximately 87 million people receive health care services financed by the government, approximately half of whom are eligible because they are over 65 years old and half because they are on low incomes.[101] Publicly funded medical assistance is available only to individuals who meet specific criteria. The largest government public financing programs, including Medicaid and the Children's Health Insurance Program (CHIP), are run by the Centers for Medicare and Medicaid Services (CMS).[102]

The Medicaid program provides health care coverage to over 42 million people, two thirds of whom are children.[103] Low income by itself is not sufficient to qualify for medical assistance. Medicaid is limited to individuals who also fit into certain categories: children and their parents, pregnant women, and some disabled and elderly individuals.[104] CHIP is intended to provide insurance coverage for children whose family income is too high to qualify for Medicaid but too low to pay for private health insurance.

Medicaid and CHIP are jointly financed by individual states and the federal government. Although state governments must comply with certain federal rules, they have considerable discretion in how to implement the Medicaid program. The result is that access to services provided under Medicaid differs significantly from state to

state. Medicaid income thresholds are generally very low (see Appendix D). For example, in 33 states, a woman with two children must earn US$18,310 or less per year (the FPL for a family of three in 2009) to qualify. However, in 13 states, a woman with two children earning US$9,155 (50 percent of the FPL for a family of three) would not qualify.[105]

The federal poverty guidelines were created in the 1960s and have been criticized by economists, politicians, local governments and academics as underestimating poverty because they are outdated, inaccurate and incomplete and do not take into account certain criteria, like housing costs, which vary across the country.[106]

Burdensome procedures pose significant bureaucratic and financial obstacles to accessing services.[107] Nearly 75 percent of eligible uninsured children and 28 percent of uninsured parents were not enrolled in 2004.[108]

The uninsured

An estimated 52 million people living in the USA had no health insurance at all in January 2009.[109] The majority of uninsured individuals have been without coverage for at least a year.[110] The percentage of those without insurance varies considerably by state from a high of 25.2 percent (Texas)[111] to a low of 2.6 percent (Massachusetts).[112]

> **"When the economy is in recession… coverage quickly unravels further. When insured workers lose their jobs, they also lose their job-based health insurance coverage… For every increase of 1 percentage point in the national unemployment rate, it is estimated that an additional 1 million Americans turn to Medicaid for coverage and another 1.1 million go uninsured."**
>
> Diane Rowland, Executive Director, Kaiser Commission on Medicaid and the Uninsured, Washington, DC[113]

The downturn in the economy has resulted in a rise in unemployment. It has also prompted cuts in the benefits offered by employers and in state budgets for Medicaid. As a result the number of uninsured has grown. With the national unemployment rate reaching 10.2 percent in October 2009 (the highest in 26 years),[114] 45 states and the District of Columbia face budget shortfalls. By early 2009, half of all states and the District of Columbia had enacted or proposed cuts to Medicaid and CHIP, including further restrictions on eligibility and cuts in benefits and reimbursements.[115]

DISPARITIES IN ACCESS TO HEALTH CARE SERVICES

"THE COMMITTEE RECOMMENDS THAT THE [USA] CONTINUE ITS EFFORTS TO ADDRESS THE PERSISTENT HEALTH DISPARITIES AFFECTING PERSONS BELONGING TO RACIAL, ETHNIC AND NATIONAL MINORITIES, IN PARTICULAR BY ELIMINATING THE OBSTACLES THAT CURRENTLY PREVENT OR LIMIT THEIR ACCESS TO ADEQUATE HEALTH CARE, SUCH AS LACK OF HEALTH INSURANCE, UNEQUAL DISTRIBUTION OF HEALTH CARE RESOURCES, PERSISTENT RACIAL DISCRIMINATION IN THE PROVISION OF HEALTH CARE AND POOR QUALITY OF PUBLIC HEALTH CARE SERVICES."

Concluding observations of the UN Committee on the Elimination of Racial Discrimination, United States of America, 5 March 2008.

Women of color make up a disproportionate percentage of those who rely on Medicaid or CHIP and are therefore most affected by barriers to accessing health care services through publicly funded programs.[116] Legislation and policies that limit eligibility and impede or delay access to public health care perpetuate these profound inequalities in access to quality health care services, including maternal health services.

The 2005 Deficit Reduction Act allows states to impose premiums or co-payment on Medicaid recipients and to deny health care to those who cannot afford to pay. For example, states may require prepayment of premiums before allowing enrolment in Medicaid. The Act also requires individuals to present proof of citizenship or immigration status when applying for Medicaid. This has been found to particularly affect US citizens on low incomes who do not have the necessary documentation (such as a birth certificate or a passport) and cannot afford the fees required to apply for it.[117] In Alabama, for example, within six months of the implementation of this requirement, 3,500 children previously enrolled in Medicaid had been removed because they had failed to meet the documentation requirement; 60 percent of them were African-Americans.[118]

Inequalities persist within the Medicaid system in terms of per-patient expenditure. The average per-patient expenditure for white patients (US$6,134) is significantly higher than for other parts of the population – close to 1.5 times that for African-American patients (US$4,202) and double that of Hispanic patients (US$2,563).[119]

"You will not be seen unless you are in labor."

Sign at an Indian Health Service facility[120]

The Indian Health Service (IHS), part of the US Department of Health and Human Services, operates health facilities for Native American and Alaska Native Peoples. IHS services, however, have suffered from severe, long-term underfunding and lack resources and staff.[121] A report by the US Commission on Civil Rights found that in 2003 national per capita health expenditure for the average person in the USA was US$5,775. The comparable figure for the IHS was US$1,900.[122]

Unlike Medicaid, the IHS receives its funding via annual appropriations bills. Which services and facilities are funded, and how much money the system receives, have varied hugely from year to year. Setting funding in this way also means that money routinely runs out by June, leaving tribal members without access to care – other than emergency care – until October, when new grants are awarded. As one Native American advocate put it: "Don't get sick after June."[123] Making IHS funding an entitlement in the same way as Medicaid would make IHS funding more predictable.

Non-US citizens are less likely to be insured and many have great difficulty accessing adequate care. Amnesty International received a number of reports of undocumented immigrant women who had not seen a doctor before arriving at a hospital to give birth, even though some had serious conditions requiring monitoring and care.

One midwife told Amnesty International, "I saw a 17-year-old uninsured Mexican woman. She had two surgeries as a child to repair a congenital heart defect. I immediately referred her to a high risk clinic." Following an initial evaluation, the clinic stated that the 17-year-old should be transferred there for continuation of care and both mother and baby should receive echocardiograms and closer medical observation, "once she has her Medicaid." The midwife noted, "They know she's undocumented. She's not going to get it. And the appointment that she had, you can bet they're going to send her a really ugly bill… she's too high-risk for my clinic to take on and we can't risk losing our license, but no one else will see her." Seven months pregnant, the woman could "barely breathe and was tired all the time," but was still unable to find prenatal care. An obstetric clinic specializing in high-risk pregnancies eventually agreed to treat the 17-year-old and she delivered safely at full term. In October 2009, the midwife told Amnesty International:

"She's pregnant again – just a few months after giving birth. She had no follow-up [post-natal] care, and she didn't get any contraceptive information or supplies. She is back with us, because no one else will take her. There is such a lack of thinking things through. She is a prime candidate for support, especially understanding how dangerous it is for her to be pregnant at all."

A bulletin board at the Developing Families Center, a birth center in a medically under-served community in Washingon DC, covered with photos of the babies born to women who received maternal health care at the center.

“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.

4/BARRIERS TO MATERNAL HEALTH CARE SERVICES

TRINA BACHTEL

In August 2007, two weeks after her baby was stillborn, Trina Bachtel, a 35-year-old white woman, died. She had reportedly suffered from pre-eclampsia during her pregnancy, a condition that requires careful monitoring during prenatal care. Although insured at the time of her pregnancy, the local clinic had reportedly informed 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. When she fell ill, Trina Bachtel delayed seeking care, unable to afford the fee at the local clinic. She finally received medical attention in a hospital 30 miles away, where her son was stillborn. She was later transferred to Columbus, Ohio, 75 miles away, where she died. The two local clinics in her area later denied having seen Trina Bachtel as a patient. The associate administrator at one clinic said they may place "credit restrictions" on patients believed to be able but unwilling to pay their bills.[124]

The way in which the health care system in the USA is organized and financed is failing to ensure that all women have access to affordable, timely and adequate maternal health care services. As a result, women, and in particular women of color, women living in poverty and immigrant women, are more likely to enter pregnancy with untreated or unmanaged health conditions; to receive little or no prenatal care because of delays in receiving coverage; to face crippling debt following labor and delivery; and to have limited access to postpartum care.

In order to respect human rights standards and principles related to maternal health, the USA must address obstacles that currently impede women, in particular women living in poverty or from marginalized groups, from having access to quality health care on an equitable and non-discriminatory basis. Human rights principles on the right to health require states to place particular emphasis on at-risk groups. The USA is failing to fulfil these obligations.

FINANCIAL BARRIERS

"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, DC, Amnesty International interview, 6 November 2008

Having a baby is the most costly health event families are likely to encounter during their childbearing years.[125] The ability to access adequate care depends in part on whether or not the woman has insurance, the type of insurance, the location and type of facility where the woman gives birth, and whether or not the woman or baby experience health complications.

"Even today I'm paying off the delivery of my girl – it was a c-section and very expensive. I am paying in instalments – I've just managed to pay off the anesthesia and it's been almost two years! And still I owe almost US$6,000."

Latina woman, rural Wisconsin, Amnesty International focus group, 8 July 2008

Some 99 percent of women give birth in hospitals where facility fees alone average between US$8,300 and US$10,700 for a vaginal delivery and between US$14,800 and US$18,900 for a c-section, depending on whether complications occur.[126] This does not include the health professional fee for prenatal care and delivery, which adds on average between US$4,350 and US$6,000.[127]

"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.[128]

Federal anti-discrimination legislation requires companies with more than 15 employees to treat pregnancy, birth and related conditions in the same way as other

"temporarily disabling conditions," and prohibits employers from charging women higher premiums than men. As a result, most company health plans cover care related to pregnancy and childbirth at no additional cost to women.[129] Employer-based plans which cover maternity care also cannot deny a newly employed pregnant woman insurance based on her pregnancy, provided she was covered by other insurance before being hired.

Women who are insured through their employer usually have to contribute towards health care costs, including premiums (cost of insurance) and deductibles (amount that must be paid out before insurance coverage begins), depending on the type of insurance the employer provides. The protections linked to employer-based insurance are lost if a woman loses her job. In companies not covered by federal legislation, for example in smaller companies, employer-based plans are obliged to offer coverage for pregnancy-related care in only 18 states; 32 states do not offer such protection.[130]

STARLA

Starla, aged 27, was close to her due date with her second child when she learned that the Ohio cookie plant where she had worked for eight years was shutting down and her insurance benefits would be terminated just three days later. The bill for the delivery of Starla's first son in 2005 had been US$9,000 and she knew she could not pay for delivery costs with no job and two children at home. She asked her midwife to induce labor two days before her health insurance expired. She had to have an emergency c-section the next day. "I was forced into something I did not want to do." Starla assumed that her insurance would cover the delivery costs since the birth occurred before the termination date, but her claim was denied and she was left with almost US$18,000 in medical bills. Starla said, "We are two months behind on rent. The light bill is past due." Under federal law (COBRA), a person who is laid off can usually apply to be covered under their company's health plan for up to 18 months, but must pay the full premium themselves. Because Starla's company had filed for bankruptcy, however, she was not covered by COBRA.[131]

Individual health insurance is subject to even fewer regulations than employer-based schemes. Women can be charged higher premiums, and there is no requirement to cover maternity care services. Individual insurance for maternal care is frequently hard to get as well as expensive. In California, for example, the insurance coverage of approximately 805,000 people (78 percent of those with individual insurance) excludes maternity care.[132] Insurance companies often refuse to provide coverage for pregnant women on the grounds of their "pre-existing condition", namely pregnancy. A study of over 3,600 individual insurance policies found that only 13 percent of health insurance policies provide comprehensive maternity coverage.[133]

Some companies require an additional fee (which can be as high as US$1,100 per month) to cover maternal care and may only cover part of the costs.[134]

Insurance companies may also charge women who have undergone a c-section higher premiums, may refuse to cover another c-section or pregnancy for a period of time, or may deny the women coverage altogether.[135] A state government investigation in California discovered that insurance companies were employing staff to research clients with potentially expensive conditions, including pregnancy, in order to find a pretext for dropping their coverage. Any minor omission in reporting prior medical history was used as cause for withdrawing coverage.[136]

Public health insurance may be available for pregnant women on low incomes and financial eligibility requirements for Medicaid are less restrictive for pregnant women. However, they vary significantly from state to state (see Appendix B).[137]

> **"The cost of health insurance is ridiculous… No one should have to not eat in order to afford a trip to the doctor."**
>
> Latina woman, rural Wisconsin, Amnesty International focus group, 8 July 2008

LACK OF INSURANCE

A HOMELESS WOMAN VIOLATED THE TERMS OF HER PROBATION IN ORDER TO BE TAKEN INTO CUSTODY, WHEN SHE WAS NEARLY EIGHT MONTHS PREGNANT, BECAUSE SHE WAS DESPERATE TO GET HEALTH CARE AND SHELTER. HER FRIEND TOLD AMNESTY INTERNATIONAL THAT SHE "TURNED HERSELF IN… JUST SO SHE COULD GET SOME CARE FOR HER CHILD, TO HAVE HER KID".

Amnesty International focus group, Wausau, Wisconsin, 11 July 2008

A high percentage of women of reproductive age do not have any health insurance. Nearly 13 million women between the ages of 15 and 44 – one in five women – are not insured.[138] Women whose earnings exclude them from coverage by Medicaid as well as undocumented immigrants are not eligible for public assistance to cover prenatal care in most states. However, they may not earn enough to pay for private insurance. Over 4 percent of women give birth without either private insurance or

government medical assistance.[139] Amnesty International spoke to a number of women who had received no prenatal care at all because they could not afford it.

JULIA

Fifteen-year-old Julia (not her real name) came to the USA from Mexico to take care of her five younger siblings so her mother could work. In July 2007 her mother's boyfriend raped Julia and she became pregnant. Support workers told Amnesty International that no one was willing to provide her with prenatal care unless she agreed to give up her child for adoption, which she refused: "Julia was adamant about keeping the baby – she couldn't imagine having a baby and not taking care of it yourself. The only exam she had was the confirmation of pregnancy for the criminal case."

YWCA Immigrant Women's Services, Amnesty International interview, 11 March, 2009, and Memphis Police Incident Report, 14 September 2007

Under the Emergency Medical Treatment and Active Labor Act (EMTALA), hospitals cannot turn away a woman in labor, regardless of her ability to pay.[140] However EMTALA does not protect a woman from being billed for care after delivery, which may send her into debt or bankruptcy, especially following a c-section or a complication requiring additional medical intervention. While some hospitals sometimes write off these bills as charitable care if a woman cannot pay, this is not always the case. EMTALA also fails to guarantee prenatal and postpartum care as well as any treatment beyond "stabilizing" any health emergencies during pregnancy or birth.

MARIA

Maria (not her real name) did not have access to public assistance during any of her five pregnancies because of her immigration status and so was unable to afford prenatal care. In 2008, when she went into labor with her last baby, the hospital she went to turned her away because she had not received prenatal care. The second hospital she visited admitted her. After six hours waiting to be seen "I spoke to an interpreter via the phone because they wanted to check my insurance. I asked him 'Please, please send someone… please tell them the baby is coming.' Everyone spoke English. I was so afraid. At last a nurse came in and examined me". Maria gave birth to her daughter, but soon after she began to feel unwell. "I started crying out and screaming, 'I can't breathe!'… Then I [passed out]." Maria was discharged after three days, but no one ever explained what had happened. She did not receive any follow-up care or get any of the recommended medications: "I had no way to pay, so I never got any".

Maria, Memphis, Tennessee, 3 February 2009

While insurance companies and Medicaid negotiate rates with hospitals, which generally results in considerable discounting of actual charges, uninsured patients are often expected to pay the full amount.[141] In some cases asking for a reduced charge can lead to a reduction, but those without insurance often do not know that this is a possibility and a number of those interviewed by Amnesty International stated that some hospitals and case workers omit information about, or refuse to acknowledge, available options to reduce bills or pay for care in instalments.[142] An advocate told Amnesty International about one case worker who was reprimanded for helping Latina patients find cost-reducing solutions.[143]

> **"People don't realize these options are available, and the hospitals around us won't tell people they have [financial assistance] programs. They will take you to collections and take people's homes before they tell you they have a program."**
>
> Amnesty International focus group, Stevens Point, Wisconsin, 10 July 2008

Women who are unable to secure either public assistance or private insurance can seek prenatal care in low-cost clinics which offer services at a reduced fee based on ability to pay. Some community-based clinics are Federally Qualified Health Centers (FQHCs) and receive federal funding in exchange for a commitment to treat all patients seeking care, regardless of ability to pay. However, even with federal funding, FQHCs depend on state and local government grants, as well as on private donations, and many remain inadequately funded to meet community needs.

Low-cost clinics are often overcrowded and underfunded, and cannot always treat women who experience complications during their pregnancy and require specialized care. Amnesty International was told about one woman on low income who was enrolled in a clinic program that provided free prenatal care. When she started bleeding heavily, she went to a hospital emergency room for treatment. When she returned to the clinic she was told that they could no longer treat her because she was "high-risk" and needed a specialist. She incurred approximately US$8,000 in debt in order to receive necessary prenatal care.[144]

Even a reduced fee may be beyond the ability of some women to pay. At a Memphis clinic, low-income women pay US$150 per prenatal visit, totalling US$1,200 for women who follow the recommended program of eight visits.[145] Amnesty International was also told that some low-cost facilities require proof of income in order to qualify for reduced fees. Women who are unemployed or are undocumented immigrants and have jobs in the informal sector (such as domestic workers) had difficulty providing the required documentation quickly or at all. This sometimes resulted in women having to pay full price or foregoing services.

BUREAUCRATIC BARRIERS

"[I]T'S THE PEOPLE WHO CAN'T NAVIGATE THE SYSTEM WHO ARE LOST. YOU PUT THE INFORMATION INTO THE SYSTEM AND THEN THERE'S NOBODY THERE TO HELP YOU. YOU WAIT AND WAIT. WHEN YOU'RE PENDING, YOU HAVE NOTHING. YOU DON'T GET SERVICES, AND YOU CAN'T REAPPLY. I CALL IT 'PENDING PURGATORY'."

Jennie Joseph, certified professional midwife, Winter Garden, Florida, Amnesty International interview, 11 December 2008

SOFIA

Sofia (not her real name) is 19 years old and came to the USA from Guatemala. A victim of domestic violence, including sexual violence, she was pregnant in January 2009, when the Federal Bureau of Investigation (FBI) and Immigration and Customs Enforcement (ICE) arrested her boyfriend in a case involving trafficking of women. The agencies sequestered Sofia in a women's shelter, because she was a witness for the case. Sofia, who does not speak English, told service providers she felt extremely lonely – her isolation exacerbated by strict security requirements. The service providers told Amnesty International they were unable to obtain prenatal care for her because she was an undocumented immigrant. "In order to [apply to remain in the USA legally], she has to get an attorney: how could she afford this? We need to find a pro bono lawyer to take the case, and by the time she gets it she will have had the baby already!" Although Sofia asked to be deported so she could be with her family, the ICE and FBI kept her in the shelter, promising to "expedite" the case. After eight weeks, when she was four months' pregnant, the FBI and ICE arranged for her to receive prenatal care.

Amnesty International interviews and correspondence with advocates, YWCA Immigrant Women's Services, Memphis, Tennessee, February and March 2009

While a number of factors may influence when a woman begins prenatal care, Amnesty International's findings indicate that the Medicaid enrolment process is causing substantial delays for the majority of women who become eligible only once they are pregnant. Bureaucratic procedures, including in-person interviews and burdensome and costly documentation requirements, coupled with the shortage of case workers to process applications, pose significant obstacles and delays to accessing services,[146] in violation of the right to health.[147] Under a 2005 law requiring

documentation of citizenship or legal immigration status, a woman may have to pay fees and face long delays in order to obtain a copy of her birth certificate or a passport[148] – a process that can take up to 12 weeks.[149] A number of states have reported sharp drops in the enrolment of eligible US citizens since the restrictions were introduced.[150]

> **"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, Amnesty International interview, 11 December 2008

According to data received from state Medicaid offices responding to Amnesty International's survey, women receiving Medicaid are less likely to receive prenatal care beginning in the first trimester, than women in the state on average.

Prenatal care in the first trimester[151]

State	Women on Medicaid (%)	State average (%)
Montana	**75**	**84**
Arizona	**71**	**78**
Oklahoma	**63**	**77**
Washington	**65**	**70**

Case-workers are frequently overextended, handling hundreds of cases and unable to complete the required paperwork in a timely way.[152] Federal regulation requires Medicaid applications to be processed within 45 days, with no distinction for applications based on pregnancy.[153] New York and Nevada State Departments of Health reported that the average processing time for a Medicaid application is respectively 30 and 31 days.[154] In Washington, DC, 17 percent of Medicaid applications based on pregnancy take more than 30 days to process.[155]

> **"My Medicaid card took a long time in arriving, but it was worse for other women. Many women were almost ready to deliver and still they didn't have it".**
>
> Latina woman, rural Wisconsin, Amnesty International focus group, 8 July 2008

> **"I didn't know I was pregnant because I was taking birth control pills. I went to the hospital, and the bill came to US$3,000. When I went to ask for Medicaid, they covered me from that point on but didn't cover the first three months [of my pregnancy], so I had to pay the US$3,000."**
>
> Antonia, rural Wisconsin, Amnesty International focus group, 9 July 2008

Twenty-nine states and Washington, DC, offer "presumptive eligibility" to Medicaid, allowing pregnant women temporary access to medical care while their permanent application is pending.[156] However, even with presumptive eligibility, delays and barriers to obtaining care remain. For example, a midwife in Florida told Amnesty International that in order to obtain presumptive eligibility women must present documentation of their pregnancy and their due date signed by a doctor or registered nurse. But to get this documentation they have to pay for the visit to the doctor or nurse, which they cannot afford to do. Some women may later lose coverage because they do not realize that additional paperwork must be completed to keep their Medicaid coverage beyond 45 days.[157] In contrast, Louisiana and Connecticut have "expedited enrolment" of pregnant women; reportedly the process takes only three days in Louisiana.[158]

In some states, pregnant women whose income is too high to qualify for Medicaid, but too low to afford private insurance, may be able to obtain limited medical assistance under CHIP. Eight states offer coverage to pregnant women on low incomes during pregnancy and for some period afterwards.[159] Fifteen states[160] provide coverage to the "unborn child" which means that coverage excludes care for conditions that are not pregnancy-related.[161] In Arkansas and Louisiana coverage ends at birth which means that routine postpartum care is not covered.[162] In Wisconsin postpartum care is covered for 60 days. Although undocumented immigrants do not qualify for CHIP, some undocumented immigrants are able to obtain prenatal care in the states where CHIP coverage is provided to their "unborn child."

LANGUAGE BARRIERS

"ONE DAY [WHILE PREGNANT] I FELT BAD, SO I WENT TO BERLIN [WISCONSIN], WHERE THEY NEVER HAVE INTERPRETERS… WITH THE LITTLE ENGLISH I KNEW, I TRIED TO EXPLAIN THAT THEY'D ALREADY DONE AN ULTRASOUND, BUT AT THE END OF IT ALL, THE DOCTOR SAID, 'YOU KNOW WHAT, I DON'T UNDERSTAND YOU. I DON'T KNOW WHAT YOU HAVE.' REGARDLESS, HE SENT ME THE BILL FOR US$2,000 – THAT MUCH I UNDERSTOOD!"

Latina woman, Amnesty International focus group, St. Mary's Parish, Omro, Wisconsin, 8 July 2008

The Institute of Medicine has found that communication barriers contribute to reduced quality, adverse health outcomes and health disparities.[163] Amnesty International's research also revealed that language barriers frequently compromise access to maternal health care services for women with limited English and affect the quality of care they receive. A lack of adequate interpretation and translation services means that many women do not seek care in the first place; are not able to secure services they need; do not understand information that is provided; or are unable to participate fully in decisions related to their care. Discriminatory attitudes towards women who speak little or no English can also exacerbate language barriers.

Federal law requires agencies that receive federal assistance to "take reasonable steps" to ensure meaningful access to services to all, regardless of race, color and national origin.[164] This standard has been interpreted to mean that the failure to address limited English proficiency could constitute discrimination.[165]

Women who speak little or no English must attempt to access insurance and navigate bewildering health care systems with limited language assistance. Amnesty International was told that the lack of bilingual caseworkers and translated forms means women with little English have difficulty accessing or maintaining coverage under Medicaid to help pay for labor and delivery costs. Those who do not speak the most common non-English languages, or who live in areas with few other immigrants, may have access to even fewer services.

> **"When they operated on me so I wouldn't have more children, there wasn't an interpreter. No one arrived because the one interpreter was busy. They… didn't explain anything, they didn't say how long it would take or what they were going to do… I wanted them to explain at least something to me, and I was afraid of a lot of things."**
>
> Marta, rural Wisconsin, Amnesty International focus group, 9 July 2008

Many hospitals rely on language interpretation services by telephone. However, reports suggest that these may often not be of adequate quality since many phone interpreters lack specific training in medical terms, ethics and sensitivity. One nurse and maternity support services coordinator told Amnesty International that doctors and nurses find telephone services, "so clumsy that it's not even worth trying".[166] The National Council on Interpreting in Health Care has developed the National Standards of Practice for Interpreters in Health Care,[167] but these have not been universally adopted.[168] Currently, only five states have certification programs for medical interpretation.[169]

Written materials are often unavailable in languages other than English. Women in Wisconsin who spoke little or no English reported that written instructions for follow-up care after giving birth were often not available in other languages. Failure to provide information in a language that a woman understands compromises her ability to follow any medical instructions. All 50 states have some laws addressing language barriers in health care. However these vary greatly and may apply only to specific types of care, providers or patient groups. Only California, Maryland and Washington, DC, have statutes requiring comprehensive language provisions for health care in general. No other states require that language services be provided for all women who need them throughout their maternal care.[170]

> **"There's a point at which [doctors, nurses, and the administration] don't interest themselves in the patient because of the language barrier. Language is a tremendous barrier."**
>
> Latina woman, Amnesty International focus group, St. Mary's Parish, Omro, Wisconsin, 8 July 2008

Amnesty International received a number of accounts of dismissive, disparaging and belittling treatment of women who spoke little or no English. The power differential between providers, support staff and patients is amplified by language barriers and may be reinforced by dynamics of race, gender and economic or immigration status.

"Well, she might as well have an epidural; we're practicing veterinary medicine here."

Anesthesiologist in response to a Spanish-speaking woman who did not want an epidural, reported to Amnesty International by a registered nurse in the Labor and Delivery Department, Minneapolis, 9 February 2008

The cost of providing language assistance is borne mainly by hospitals, clinics and practitioners because public and private health insurance agencies do not pay for these services. Only 1 percent of physicians[171] and 3 percent of hospitals[172] report receiving direct reimbursement for language-related costs. Only 12 states and Washington, DC, provide reimbursement for interpretation services through Medicaid (see Appendix D).[173]

Some states have taken steps to mitigate the impact of language barriers on maternal health. For example, Montana designates the pregnancy of women with limited English as "high-risk" so they can access individual case management services.[174] Amnesty International interviewed staff in community facilities and health care programs who reported that language skills are carefully built up among their staff. For example, Mary's Center for Maternal and Child Care in Washington, DC, has more than 188 staff members who speak 30 different languages.[175]

OTHER BARRIERS

"THERE ARE A LOT OF PEOPLE WHO CAN'T PHYSICALLY GET THERE, CAN'T AFFORD GAS, THEY DON'T HAVE CARE FOR THEIR FOUR KIDS. THOSE ARE THE KINDS OF THINGS THAT ARE MAJOR OBSTACLES TO GETTING IN THE DOOR."

Maria Mascola, maternal-fetal medicine specialist, Marshfield, Wisconsin, Amnesty International interview, 15 July 2008

Women need more than health insurance to take advantage of health services. Many factors affect women's access to medical services, including how far away those services are and whether they have transport to get there, whether they have access to child care or whether they can take time off work. Other barriers that prevent

women having access to health care services and having a healthy pregnancy may include whether a woman has somewhere to live and enough food to eat, or whether issues such as domestic violence are addressed. Measures which women perceive as punitive or which penalize those with substance abuse problems or undocumented immigrants can also deter some women from seeking health care services.

> **"It's difficult for my sister, because she doesn't have a car or anyone who can take her. She's pregnant and has a small son and has to walk for nearly an hour to get to her appointment."**
>
> Paula, Latina woman, Wausau, Wisconsin, Amnesty International focus group, 9 July 2008

Women in rural areas told Amnesty International that lack of access to a vehicle and money to pay for fuel, coupled with the distances they need to travel, were significant challenges in receiving the maternal care they needed. Women with high-risk pregnancies in states with large rural areas, such as Wisconsin, sometimes have to drive 100 miles or more to obtain specialist care at a facility adequately equipped to handle potential complications. Women on low incomes living in urban areas reported spending hours on public transport getting to and from prenatal appointments. Sixty-five percent of low-income women who received no prenatal care cited transport as a barrier in a California study. [176]

> **"I don't have a car – but the center provides a car service to come here. Otherwise I couldn't make it by myself".**
>
> Ethiopian immigrant woman, 38 years old, Blues Project, Memphis Health Care Center, Tennessee, Amnesty International interview, 5 February 2009

Undocumented immigrants can face specific difficulties in getting medical care because an increasing number of states require documentation of immigration status in order to apply for a driver's license[177] – in effect forcing women to choose between driving without a license or foregoing care. A Wisconsin advocate told Amnesty International that a client called her from the police station after being arrested for driving without a license while on her way to a doctor's appointment.[178]

"[I]t can be hard to make the [prenatal support] program. It's hard to worry about transportation and the kids at home."

African-American woman, mother of four children aged between eight years and three months, Memphis, Tennessee, Amnesty International interview, 5 February 2009

Women and advocates told Amnesty International that securing child care or being able to bring children to prenatal appointments was an important consideration for many. In one study, nearly 30 percent of women on low incomes in California cited inadequate child care as a barrier to obtaining health services.[179]

"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, Amnesty International interview, 23 March 2008

For many women it is difficult to take time off work for a doctor's appointment.[180] Nearly half of all women working in the private sector, and almost 60 percent of women on low incomes do not have the right to any paid sick leave and as a result have to forego wages or risk losing their job in order to visit the doctor. One study showed that 27 seven percent of women on low incomes delay getting health care because they cannot take time off work.[181] One in six workers reported that they had lost a job or had been told they would lose their job if they took time off due to illness or to care for a family member, according to a national survey.[182]

"If you compare the maternal mortality rate between women who received prenatal care and women who did not, the mortality rate for women who did not receive prenatal care is higher. The question of how many prenatal care clinics are held on Saturday is a good place to start when you evaluate availability and access – just a handful of them are open on Saturday."

Jeffrey C. King, Chair of ACOG Maternal Mortality Special Interest Group, Amnesty International interview, 13 March 2008

Inflexible hours and excessive waiting times make doctors' appointments difficult to keep.[183] Women reported that appointment times were assigned without consultation and could not be changed, failing to take into consideration when women had

transport or child care available. An Oklahoma study found that one in five African-American women face significant barriers beginning prenatal care, including not being able to get an appointment at a time and place they can make.[184]

> **"If you don't know where the next meal is coming from – how can you then worry about whether you're going to prenatal care?"**
>
> Annette Caple, Memphis Health Care Center, Memphis, Tennessee, Amnesty International interview, 5 February 2009

Amnesty International received a number of reports about homeless pregnant women living in unsanitary or overcrowded conditions, or constantly being on the move to find temporary shelter. Women who are homeless or on low incomes face significant barriers in obtaining sufficient and nutritional food, acquiring prenatal vitamins and receiving prenatal care. Different social services often require separate and cumbersome application processes at different locations, creating additional and sometimes insurmountable barriers. A county official in Memphis, Tennessee, told Amnesty International about one 19-year-old African-American woman from Memphis who was placed on bed-rest in 2009 because of pregnancy-related complications with her first child. Unable to work and pay her bills, she faced eviction only weeks before her due date. The officil said, "The stressors in this woman's life are tremendous. She's about to become homeless, has no income and no transportation." The woman previously worked in a coffee shop. When she fell ill, her colleagues appealed to the mayor of Shelby County, who was a customer. The mayor's office helped to arrange transitional housing for her in a program that also provides child care and helps women secure a job.[185]

Amnesty International received reports that health care providers may feel unable to deal with the issue of domestic violence and are therefore reluctant to broach it. In February 2008, Ayman El-Mohandes, Chair of the Department of Prevention and Community Health at the George Washington School of Medicine and Health Sciences, told Amnesty International, "Health care workers are not prepared to deal with issues such as violence. They wind up thinking, "What am I going do about this black eye? I can't do anything so let's not discuss it."

> **"We've seen a couple of cases [of maternal mortality] where domestic violence was carefully documented, but nobody did anything about it, nobody made any referrals. All through the pregnancy they had been saying she had a black eye, etc. One woman wound up beaten to death with a baseball bat."**
>
> Charles Mahan, member of the Maternal Mortality Review Board, Tampa, Florida, Amnesty International interview, 10 April 2008

Pregnant women who have substance abuse problems may face the prospect of criminal charges or losing their children.[186] Many states provide few treatment options for such women although studies show that treatment can be particularly effective during this time.[187] Only 7 percent of substance abuse treatment facilities offer prenatal care services.[188] Nevertheless, pregnant women who test positive for drug use may be arrested, prosecuted and incarcerated.[189]

> **"For women with substance abuse problems we lack sufficient support services that are non-punitive. Especially if a woman already has kids, she can't take her kids to any support programs because of the fear of losing her children."**
>
> Health Department employee, New England, Amnesty International interview, 16 April 2008

AMBER

In Texas in 2007, during a routine probation visit, Amber tested positive for drugs for the first time since her arrest two and a half years earlier, and revealed that she was pregnant. Her attorney found a treatment program specializing in pregnant women, but the probation officer was not willing to consider that option. The prosecution stated that its reason for seeking to incarcerate Amber during her pregnancy was concern for the "unborn child." Amber was incarcerated for the remainder of her pregnancy in a county jail, which offered no special programs or care for pregnant women, no treatment for drug dependence, and where the practice of shackling pregnant women is allowed.[190]

Such policies may affect women's willingness to seek prenatal care and may result in added health risks to them and their babies.[191] One study found that women's perception of health care providers as threatening and judgmental was one of the most important barriers to seeking prenatal care for women in Washington, DC, who were homeless or involved in substance abuse.[192] Fear can also further erode trust in health providers and may dissuade those who do seek prenatal care from seeking substance abuse treatment.[193]

> **"At a hospital staff meeting, one doctor stood up and said he felt it was his duty to turn in anyone he thought was illegal."**
>
> Laura Scudiere, Community Health Clinic, Wausau, Wisconsin, Amnesty International interview, 11 July 2008

Another group whose fear of contact with authorities may deter them from seeking health care is undocumented immigrant women.[194] Although community health centers exist that offer safe places for undocumented immigrants to seek care, many women live in areas with no access to such facilities.

> **"A woman was extremely sick after giving birth. She had mastitis – very bad – she had a high fever, but was extremely afraid of going to the ER [Emergency Room] because she was afraid she'd be deported. Finally, they were able to take her, but she was very sick and was really afraid of going."**
>
> Social worker, Amnesty International focus group, Wausau, Wisconsin, 9 July 2008

LACK OF FAMILY PLANNING AND HEALTH EDUCATION

"EFFECTIVE FAMILY PLANNING SERVICES ARE PROBABLY THE SINGLE LARGEST CONTRIBUTOR TO REDUCTION IN MATERNAL MORTALITY AND MORBIDITY IN OUR LIFETIME."

Carolina Reyes, Clinical Associate Professor of Obstetrics and Gynecology, Keck School of Medicine, University of Southern California, Los Angeles, California, Amnesty International interview, 14 May 2008

A wide range of contraceptive services is available in the USA and abortion was legalized in 1973.[195] However, federal and state governments have failed to ensure adequate access to such services on the basis of equity and non-discrimination, and have imposed a number of legal and policy restrictions that limit access to sexual and reproductive health services for women. As a result, women often lack the information and services they need in order to prevent unintended and high-risk pregnancies, and to ensure safe spacing of pregnancies.

According to the CDC, women with unintended pregnancies are more likely to develop complications and face worse outcomes for themselves and their babies.[196] Women with unintended pregnancies are more likely to start prenatal care late and receive inadequate prenatal care.[197] Furthermore, pregnancies that are spaced closely together pose additional risks for both the woman and the baby.[198] For example, the risk of maternal death may be as much as 2.5 times higher when women become pregnant again less than six months after giving birth.[199]

"Half of the pregnancies in the country shouldn't be unplanned. That's absurd."

Cynthia Chazotte, Co-Chair, New York Safe Motherhood Initiative, Amnesty International interview, 18 March 2008

In the USA, nearly half of all pregnancies are unintended. The rates are significantly higher for women on low incomes and women of color: black women are nearly three times as likely as white women to experience an unplanned pregnancy.[200] The UN Committee on the Elimination of Racial Discrimination has recommended that the USA "continue its efforts to address persistent racial disparities in sexual and reproductive health, in particular by improving access to… family planning; facilitating access to adequate contraceptive and family planning methods; and providing adequate sexual education aimed at the prevention of unintended pregnancies."[201]

"First and foremost when children enter their reproductive years, they need to have the facts. These can't be hidden till 18 or until they become sexually active, because by then it's too late."

Wanda Jones, Deputy Assistant Secretary for Health, Director, Office of Women's Health, Amnesty International interview, 9 January 2009

LACK OF INFORMATION

Health providers and advocates have indicated that there is inadequate public health education and information about reproductive health and contraceptives in the USA. School-based education about health, including reproductive health, can provide a strong foundation for life and may prevent unintended pregnancies. However, sex education in the USA is among the least effective of any industrialized nation. Teenage pregnancy rates are almost twice as high as in Canada, and seven to eight times as high as in the Netherlands, Italy and Japan.[202] In the USA, 82 percent of teenage pregnancies are unplanned.[203] Experts have criticized the federal government's policy over the last decade of promoting "abstinence only" sex education in schools and limiting funding to those states that use this approach.[204] These programs teach that the only way to avoid pregnancy is to abstain from sexual activity until marriage. In 1995, 72 percent of teenage girls had received instruction about contraception before they first had sex. By 2002 this had fallen to 62 percent.[205]

> **"Each year, about 1,200 women die in the US during or following pregnancy. At least a couple of hundred of these women should have been advised not to get pregnant due to risks associated with their existing medical conditions. Effective contraception and family planning are important issues for all physicians who see women of reproductive age to discuss with their patient."**
>
> Jeffrey C. King, Chair of ACOG Maternal Mortality Special Interest Group, 13 March 2008

Following a pregnancy, women should be aware of contraceptive options and the recommended spacing of pregnancies. Some women may have health conditions which carry risks for complications in pregnancy, and need counselling so that they can reduce or manage the risk in collaboration with their health providers or avoid pregnancy altogether, if they so choose.[206] Reports to Amnesty International indicate that opportunities to provide such information are often missed. One study found that among women who had recently given birth and were not trying to become pregnant, more than half were not using contraceptives.[207]

> **"After my birth, I wanted an IUD [intra-uterine contraceptive device], but it was going to be US$1,000. I asked if I could pay in instalments. However, since I'd been left owing money after my daughter's birth, they said no."**
>
> Latina woman, focus group, St. Mary's Parish, Omro, Wisconsin, 8 July 2008

LACK OF CONTRACEPTION

In 2006, an estimated 36.2 million women in the USA were in need of contraceptive services and supplies – meaning they were sexually active and able to conceive but did not want to become pregnant.[208] While the US authorities have taken some steps to improve access to family planning services, budgetary restrictions and policy and legislative measures currently restrict or fail to protect access to such services.

The federal government has failed to adequately regulate private insurance providers to ensure that family planning services and contraceptives are adequately covered. Not all private health insurance plans include coverage for prescription contraceptives. Only 27 states require health insurance policies that cover other prescription drugs to include prescription contraceptives.[209] Federal law prohibiting sex discrimination in the workplace has been held to bar employers with at least 15 employees from excluding contraceptives from a comprehensive employee plan.[210] This limited protection does not apply to women who work at smaller companies or where health plans exclude all prescription drugs.[211]

Just under half of women in need of reproductive services in the USA (17.5 million), are estimated to be in need of publicly funded services and supplies, the majority (71 percent) because their income falls below 250 percent of the FPL.[212] Public funding for family planning has been found to be cost effective with one study finding that every US$1 spent on family planning saves the program US$4 by avoiding the costs of unintended births.[213] However, Medicaid and government-funded clinics (known as Title X clinics) cover just over half of the need identified, leaving more than 8 million women without affordable family planning information and services.[214] Women on low incomes in the USA are four times more likely than higher-income women to have an unintended pregnancy.[215]

"Women are broke – and don't realize they can get pregnant so soon after birth."

Social Worker, the "Blues Project," Memphis Health Center, Tennessee, Amnesty International interview, 5 February 2009

Medicaid in all states includes some coverage for family planning services. However, the federal government has imposed legal and policy restrictions that limit access to sexual and reproductive health services through Medicaid. In particular, the Deficit Reduction Act of 2005 has eroded access by permitting states to exclude family planning services for certain Medicaid recipients, including postpartum women and parents, and removing the prohibition on cost-sharing measures so that in some states women are now required to pay for contraceptives.[216]

Some states have expanded access to services through Medicaid by increasing the provision of family planning services to women who would not otherwise qualify for Medicaid. Twenty-seven states have been granted permission (known as a "waiver" of federal policy) from the CMS, to expand family planning coverage, in most cases either on the basis of increasing income thresholds or by including women for a year or two following a birth.[217] However, Amnesty International's research suggests that not all women are aware that Medicaid covers family planning services, and more outreach work is needed.

Access to abortion services is restricted for many women receiving health care services through Medicaid, even when the pregnancy poses a grave risk to the woman's health. As a result of federal law, known as the Hyde Amendment, states are banned from using federal funding for abortions, except in cases of rape, incest or where the woman's life is in danger. If her health is at risk, but she is not at risk of dying, the abortion cannot be paid for by Medicaid. Only 17 states fund all or most medically necessary abortions, where the woman's health is at risk, and six states

fund abortions covered by the federal requirements in addition to one or two other reasons, such as in cases of fetal abnormality. Twenty-six states and the District of Columbia fund abortions only in cases involving rape, incest and risk to the life of the woman.[218] One state – South Dakota – only provides abortions when necessary to protect the woman's life.

REDUCED FUNDING FOR TITLE X

> **"As the economy worsens, more people have no other place to go. Often [Title X] clinics are already at capacity."**
>
> Evelyn Kappeler, Acting Director of the Office of Population Affairs, Washington, DC, Amnesty International interview, 21 November 2008

The US government enacted Title X of the Public Health Service Act 1970 to address the gap in family planning services for women on low incomes who do not meet eligibility requirements for Medicaid but who cannot afford private health insurance. The Title X program now offers services to nearly 5 million women, approximately half of whom are women of color.[219] Title X clinics perform an important function for these women, who are dependent on the program to provide affordable reproductive health services.[220] However, federal funding for Title X is 61 percent lower than in 1980, taking inflation into account.[221] As a result the program is unable to meet its goal of "making comprehensive voluntary family planning services readily available." [222]

UNDERFUNDING OF THE INDIAN HEALTH SERVICE

> **"Our reproductive choices are decided for us by the federal government through the Health and Human Services – the Indian Health Service. And it's up to them as to whether or not they want to provide various services. For instance, we cannot access emergency contraceptives [unless] there's been a sexual assault."**
>
> Charon Asetoyer, Executive Director of the Native American Women's Health Education Resource Center, cited in Center for American Progress, "The Failing State of Native American Women's Health, an interview with Charon Asetoyer", 16 May 2007

Native American and Alaska Native women face a number of specific barriers in obtaining sexual and reproductive health care services. Treaty obligations require the federal government to provide health services to Native American and Alaska Native Peoples through the Indian Health Service (IHS). However, access to services is restricted by the severe underfunding. The federal government's per person allocation of funds for those covered by the IHS is equivalent to approximately one third of the average amount spent on health care per person in the USA.[223]

Native American and Alaska Native women do not have access to a full range of family planning services. According to the Native American Women's Health Education Resource Center, women may not always be provided with adequate information or access to all contraceptive options.[224]

Native American and Alaska Native women experience difficulty in obtaining emergency contraception. Plan B is a form of emergency contraception, approved by the federal government to be available without prescription in pharmacies. According to the Native American Women's Health Education Resource Center, however, only half of IHS pharmacies stock Plan B and only 15 percent offer it without a doctor's prescription.[225] Adequate access to timely emergency contraception and abortion services is critical, particularly in cases of rape. Failure to provide access to emergency contraception has a disproportionate impact on American Indian and Alaska Native women, who are 2.5 times more likely than other women in the USA to be raped or sexually assaulted.[226]

"We're the only race in the country that is denied access to abortion merely because of our race."

Amnesty International interview with Charon Asetoyer, Executive Director of the Native American Women's Health Education Resource Center

Indigenous women are also denied equal access to abortion services. Because Native American and Alaska Native women receive health care services from the federal government, abortion services are determined by the Hyde Amendment, which forbids federal funding for abortions except in cases of rape, incest, or danger to the life of the woman.[227] In 2008, the Vitter Amendment to the Indian Health Care Act singled out Native American and Alaska Native women for permanent restrictions on access to abortion services and counselling.[228]

REFUSAL TO PROVIDE FAMILY PLANNING SERVICES

Some states have policies or legislation (also known as "conscience clauses") which allow health care providers and pharmacists to refuse to provide services or dispense medication, including contraception, if it conflicts with that person's religious or moral beliefs.

- 43 states allow health care institutions, as well as individual providers, to refuse to provide abortion services (see Appendix C).[229]

- 12 states allow some health care providers to refuse to provide contraception or contraception-related services (see Appendix C);[230] five of these states permit pharmacies or pharmacists to refuse to dispense contraceptives, without any requirement to refer the woman to another pharmacy or ensure timely access to the medication.[231]

- 17 states allow some health care providers to refuse to provide sterilization services.[232]

The National Women's Law Center (NWLC) has documented refusals by pharmacists to dispense contraceptives in 24 states. The NWLC also found that pharmacists have confiscated prescriptions, refused to transfer a prescription to another pharmacy, and lectured or harassed women.[233] Refusals to provide emergency contraception are particularly problematic because the drug is most effective at preventing pregnancy when taken as soon as possible following intercourse.

Women may also be refused reproductive health services when they seek care at religious hospitals.[234] Policies may prohibit sterilization, the provision of contraception, emergency contraception and abortion, even when the woman's health is at risk.[235] Physicians have reported that when practicing medicine in such facilities, there may be interference with their medical judgment, endangering women's health.[236] For example, Catholic hospitals[237] are required to follow the Ethical and Religious Directives for Catholic Health Care Services, which restrict treatment of ectopic pregnancies (pregnancy outside the uterus that cannot survive but poses a risk to the woman's life if untreated) and the medically indicated treatment of some women suffering miscarriages.[238] A doctor in a Catholic hospital reported that a woman came in with a partial miscarriage, and developed a severe systemic infection. Her temperature rose to 106 degrees, her blood pressure was dropping, and the physician needed to completely evacuate the uterus in order to complete the miscarriage and treat the woman's infection. "This woman is dying before our eyes, [but the ethics committee] wouldn't let me because there was still a [fetal] heartbeat… I'll never forget this; it was awful." The doctor decided to treat the woman in accordance with his professional judgment and so was able to save her life.[239]

“MY DAUGHTER CHOSE TO HAVE A MIDWIFE DELIVER HER BABY AT HOME, FOR A COST OF US$2,500. IN THE HOSPITAL SYSTEM IT WOULD HAVE COST US$12,000, BUT BECAUSE IT WAS AT HOME, INSURANCE WOULDN’T PAY FOR IT.”

Amnesty International health advocate focus group, Wausau, Wisconsin, 10 July 2008

5/SYSTEMIC FAILURES

Trudy LaGrew, a Native American woman, died in Wisconsin in January 2008, three months after giving birth, following severe complications.

© Joseph LaGrew

TRUDY LAGREW

Trudy LaGrew, a Native American woman living on the Red Cliff reservation in Wisconsin, was 30 when she died of an undiagnosed heart problem, just months after giving birth. Her husband, Joseph LaGrew, told Amnesty International, "We were high school sweethearts, went our separate ways, but we found each other again. We had a relationship that I didn't think was possible. Why was it cut so short?... I know the kids are scared – what if something happens to me."

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. Her prenatal records do not include any indication that her weight and blood pressure were measured at every clinic appointment – standard components of prenatal care.[240]

When she went into labor a month early, she went to the nearest hospital where she was told she needed a c-section. She was afraid of anesthesia and asked to have family with her, but this was not allowed. One health care provider was who present told Amnesty International, "She was deathly afraid when she went under." After the operation, she woke up in an agitated state, pulled out her breathing tube, and had a heart attack.

Trudy LaGrew was resuscitated and transferred to a larger hospital, where she was placed on a respirator and kidney dialysis. She also developed a severe infection of

her c-section wound. It was three weeks before she was able to hold her son for the first time, and almost two months before she returned to her home.

Despite continuing, complex health problems, the follow-up care Trudy LaGrew received was limited, because health facilities were so far away and her poor health restricted her mobility. She was also reluctant to connect with the health care system. One health care provider noted, "She was just, I think, traumatized by her experiences." Health care providers at the local Red Cliff clinic described how they were worried they did not have adequate resources to help her. "The care was very hit or miss, and just not specialty level care. It was a high-risk situation."

Trudy LaGrew died during the night, on 7 January 2008. Her husband told Amnesty International that he is frustrated that none of her health care providers have explained why they did not diagnose her coronary artery disease or whether there may have been a way to prevent her death. "It was a shock to find out that it was coronary artery disease… We were just told once she had a weak heart [but not that her arteries were blocked]… Her son is never going to get to know her… We'd made plans to do all these things with Baby. I look at the places we wanted to go – the trips with the kids, the things we wanted to do, and we will never get to do them. It's not the same without her."

Amnesty International interviews with Joseph LaGrew, Red Cliff Reservation, Wisconsin, 4 May 2009; Erin Tenney, Maternal Child Health Nurse, and Salena Bressler, Community Health Coordinator and Doula, Red Cliff Reservation Community Health Center, Wisconsin, 9 June 2008; and additional health care and support providers, Red Cliff Community Health Center, Wisconsin, 4 May 2008

A central component of the right to health is the availability of sufficient health facilities and trained professionals. However, 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. The USA has a relatively small proportion of obstetricians per birth (just 9.6 per 1,000 births) and has the lowest proportion of midwives to birth (0.4 per 1,000 births) of any of the industrialized countries reporting these figures.[241] Advocates noted that an increased use of family practitioners and midwives to provide care for women with low-risk pregnancies could increase the availability of maternal health care providers.

The way that the US health care system is structured contributes to the lack of availability of maternal health care providers. Maternal health care providers face prohibitively high malpractice insurance premiums and receive very low fees for the services they provide to women covered by Medicaid. This serves as a disincentive to practicing medicine in this field and to treating women on low incomes. In addition, many facilities are inadequately staffed because of a shortage of health professionals, lack of funding, or pressure to keep costs down in order to generate a profit.

Maternal care in the USA all too often fails to meet women's need for comprehensive care. Counselling for pregnant women on nutrition, domestic violence, mental health, and the benefits of stopping smoking have been found to be effective and important elements of prenatal care.[242] However, the limited time allotted for most prenatal visits means there are few opportunities for in-depth interactions with providers to identify possible issues affecting maternal health and to offer counselling or other assistance.

SHORTAGE OF HEALTH CARE PROFESSIONALS

"MALPRACTICE INSURANCE IS THE REASON WHY I AM NOT PRACTICING. IN THE LAST YEAR OF OUR PRACTICE IN NEW MEXICO, OUR MALPRACTICE INSURANCE COST 70 PERCENT OF OUR INCOME."

Heidi Rinehart, former obstetrician serving a low-income community, New York, Amnesty International interview, 8 February 2008

The shortage of obstetric providers may be linked with the high cost of malpractice insurance. Obstetricians face some of the highest malpractice insurance rates of any medical specialty.[243] The impact of malpractice insurance costs is disputed.[244] However, a 2009 ACOG survey found that almost 60 percent of obstetricians reported making changes to their practice because of the affordability or availability of liability insurance. Of those, 21 percent reported reducing the number of high-risk patients, 10 percent reported reducing the number of births that they attend, and 6.5 percent had stopped practicing obstetrics altogether.[245] Staff at a community-based birth center in the District of Columbia told Amnesty International that malpractice insurance costs had more than tripled from US$90,000 in 2005 to US$300,000 in 2008.[246]

For women on low incomes, the shortage of health care professionals may be linked to delays or shortfalls in payment. Pregnant women covered by Medicaid often find that doctors are reluctant or unwilling to care for them because of the low payment rates for services provided and cumbersome reimbursement procedures.[247] In New York State, health care providers who participate in the Medicaid Obstetrical and Maternal Services program receive "enhanced" Medicaid fees of US$1,440 for all prenatal visits, delivery, and postpartum care.[248] However, this is still well below the average provider service fees paid by privately insured patients, which is approximately US$3,000.[249]

"[Medicaid] reimbursement doesn't even cover expenses let alone put anything in your pocket... Bureaucracy is a big problem. One time, Medicaid owed the practice US$17,000 in back bills, and sent us a US$2 check. We had pending claims over 15 months old... I liked serving the Medicaid population, but I couldn't afford it."

Heidi Rinehart, former obstetrician, New York, Amnesty International interview, 8 February 2008

"I remember calling all the doctors' offices in the yellow pages, and having people hang up on me when I said the patient I was calling for had Medicaid. The payout is so bad that doctors have made the decision not to accept Medicaid patients."

Jill Humphrey, labor and delivery registered nurse and Community Health Maternity Support Services Coordinator, Amnesty International interview, 12 February 2008

In 2008, 64 million people were living in areas designated by the federal government as "health professional shortage areas" for primary care.[250] Community health centers, which serve a large proportion of uninsured and Medicaid patients, face major barriers recruiting and retaining health care providers, and shortages are particularly serious for obstetricians. Nationwide, 21 percent of community health center positions for obstetricians remain unfilled; this percentage rises to 38 percent nationally in isolated rural areas and reaches 100 percent in the state of Tennessee.[251] The USA is also facing a shortage of nurses; the shortfall is projected to reach more than a million by 2020.

LACK OF AVAILABILITY OF SPECIALIST CARE

"I HAD A PATIENT WHO HAD DIABETES. SHE DROVE ONE AND A HALF HOURS EACH WAY TO SEE ME 16 TIMES IN HER PREGNANCY BECAUSE THE LOCAL DOCTOR WOULDN'T SEE HER [DUE TO THE RISK FACTORS]. THE BURDEN ON HER WAS ENORMOUS. THERE IS NO QUESTION THAT DISTANCE POSES A PROBLEM – AND IT RESULTS IN A LOT OF PATIENTS NOT GETTING WHAT THEY NEED. PATIENTS WHO LIVE VERY FAR WOULD BE DRIVING FIVE HOURS EACH WAY, SO THEY SIMPLY CAN'T GO TO A HIGH-RISK DOCTOR."

Maria Mascola, maternal-fetal medicine specialist, Marshfield, Wisconsin, Amnesty International interview, 15 July 2008

Finding specialists for women presenting complications or risk factors affecting their pregnancy is particularly difficult. Obstetricians and maternal-fetal medicine specialists (obstetricians specializing in high-risk pregnancies) are often difficult to access or not available in rural areas. Women in rural Wisconsin told Amnesty International that they had to drive up to five hours to obtain care from a specialist.

A maternal child health nurse based on an Indian reservation told Amnesty International that the lack of available specialist care has resulted in deaths: "We have had some mothers [and babies] come back postpartum with some major issues, and we do try to take care of those people as best we can… It's just not enough. We lost people because we could not do enough for them."[252]

Women in low-income urban areas may also face barriers to seeing a specialist.[253] A New York City study found that low-income areas had on average the fewest maternal care providers and that the further women had to travel for care, the more likely they were to have no or late prenatal care.[254]

> **"The system… has fallen apart because of greed. HMOs [Health Maintenance Organizations] push patients being kept in smaller hospitals so that they don't lose money from a transfer of the patient to a larger hospital. It's structured so that if you transfer Jane Doe from a little rural hospital to a big [regional] care center, they do not get paid for the care that they already provided her with. So, by the time they transfer the patient, she's dead."**
>
> Charles Mahan, member of the Maternal Mortality Review Board, Tampa, Florida, Amnesty International interview, 10 April 2008

Women at risk of complications during childbirth may need specialist care that is not available at smaller hospitals and may require referrals to larger regional hospitals. However, smaller hospitals do not always transfer high-risk patients. Some insurance companies and Medicaid HMOs pay a single fee for prenatal care, labor and delivery combined. This creates a financial incentive for the physician, clinic or hospital that has already invested time in a woman's prenatal care to avoid transfers and continue a patient's care through labor and delivery.[255]

INADEQUATE STAFFING LEVELS

TINA LONG

Tina Long was eight and a half months' pregnant when she was admitted to a hospital in Honolulu, Hawaii, in April 2005. She complained of headaches, vision problems and swelling. Her blood pressure was high and protein was detected in her urine – all symptoms of pre-eclampsia, a potentially fatal condition. However, after running some tests, staff placed her alone in a room. Insufficient staffing may have contributed to the lack of attention Tina Long received. A doctor reportedly asked her mother to retrieve medication from the downstairs pharmacy since no hospital staff member was available to get it. Some 90 minutes later, when a nurse checked in with Tina Long via a speaker system, she was discovered to be unresponsive. Tina Long and her unborn son were pronounced dead. According to autopsy reports, the cause of death was probable peripartum cardiomyopathy (weakened heart related to pregnancy), with toxemia of pregnancy (pre-eclampsia) noted as a contributing cause. The hospital told reporters that it maintains staffing standards similar to or more stringent than those used by some other hospitals and reviews and adjusts staff levels as needed.[256]

Maternal care providers told Amnesty International that understaffing creates pressure to see a high volume of patients, making it impossible for them to provide good quality care. At an inner-city hospital, largely serving low-income and ethnic minority communities, two obstetric health care providers care for up to 11 women in labor. Families of women who have died of pregnancy-related causes have reported repeatedly trying to get the attention of health care providers when the women showed obvious signs of distress, but to no avail.[257]

Experts told Amnesty International that observing subtle changes in a woman's mental state can indicate blood loss, but this requires a health worker to spend enough time with a woman to notice such a shift. Although the Association for Women's Health, Obstetric, and Neonatal Nurses (AWHONN) staffing guidelines recommend a 2:1 patient to nurse ratio for care during labor, that ratio is often not met.[258]

Financial considerations also have an impact on decisions about staffing levels.[259] Private hospitals, under pressure to generate profits, may seek to limit staffing costs. Underfunded public facilities may not be able afford to hire and retain qualified staff. As a result, hospitals and clinics, particularly those serving low-income communities, are often overcrowded and understaffed.[260] The current economic downturn is likely to exacerbate the pressure on facilities in medically under-served areas, as more

people become uninsured. With state and federal budget cuts, many public hospitals have faced closure in recent years because of lack of funding.[261]

JASMINE GANT

Jasmine Gant was "a star student and the apple of her mother's life."[262] Her mother was with her when she went into labor on 5 July 2006; they were playing cards, talking and laughing, and thinking of names for the baby. Jasmine Gant was diagnosed with an infection and the doctor prescribed penicillin in order to protect the baby. However, instead of the penicillin, a nurse mistakenly administered epidural anesthetic directly into her bloodstream. Within five minutes Jasmine Gant had a seizure and was gasping for air. Efforts to save her life failed, but her son, Gregory, was delivered via emergency c-section. The Wisconsin Department of Justice filed a felony charge against the nurse, citing her for neglect of a patient causing great bodily harm. A number of medical associations, individual experts and health providers voiced concern that criminal prosecution ignored systemic failures, would discourage open reporting of mistakes, and would make it difficult to recruit and retain nurses. According to her attorney, the nurse had worked a double shift of 16 hours then slept at the hospital before beginning another shift the next morning. A hospital official stressed that overtime is voluntary: "When we are busy, our nurses step up and… work a ton of overtime."[263] Wisconsin does not have any limitation on the amount of overtime nurses may work. According to her attorney, at the time of Jasmine Gant's death, the nurse may not have been trained in a new safety procedure that required bar codes for medication to be scanned; this could have prevented the mistake. The nurse pleaded no contest to two misdemeanor charges and was sentenced to two years' probation, during which time she could not work as a health provider. Jasmine Gant's mother, who is now raising her grandson, said: "It's breaking my heart every single day. It could have been prevented."[264]

> **"The policy of the hospital, due to finances, is to keep the fewest nurses on the floor."**
>
> Amnesty International interview with retired maternity nurse, Minnesota, 14 February 2008

A rally in 2004 in Frederick, Maryland, calling for the reversal of a recent hospital decision to ban vaginal births after a prior c-section (VBAC). After 18 months of activism, the hospital changed its policy and permitted VBACs to be offered again.

Understaffing results in fatigue, stress, increased staff turnover and little time for on-going training. Staffing shortages also mean that nurses work more overtime. There is little regulation of overtime. The American Medical College Association guidelines allow interns and residents to be on duty 80 hours every week.[265] Nursing unions have won curbs on compulsory overtime in a few places, for example in Maine, where they have the right to refuse additional work after 12 hours. Patients and health professionals have identified the inadequate number of nurses as a key cause of poor quality care and medical errors. Studies have shown that accident rates increase during long shifts, with rates rising after nine hours, doubling after 12 hours, and tripling by 16 consecutive hours of work.[266] The US Department of Health and Human Services has also found that increases in nurse staffing were associated with reductions in hospital-related mortality.[267]

LACK OF IMPLEMENTATION OF PROTOCOLS AND STANDARDS

Valerie Scythes died in 2007 soon after giving birth. Despite her heightened risk of developing a blood clot because of having a c-section, she was not given any preventative care.

© James Scythes

VALERIE SCYTHES

In 2007, Valerie Scythes, a 35-year-old teacher in a New Jersey elementary school, died after giving birth to a healthy baby, Isabella Rose. The cause of death was a blood clot (embolism). She had had a scheduled c-section and an ovarian cyst was removed at the same time. Despite her heightened risk of developing a blood clot, because of her age, weight and surgery, she received no preventative care. She was not provided with compression stockings or a blood thinning drug and staff failed to ensure that she walked around as soon as possible – she had been in bed more than a day following her c-section when she died. Valerie Scythes' attorney told Amnesty International, "I would like to see a national standard of care implemented, similar to what they have in place in England."

More than two years after her death, Valerie Scythes' husband, James Scythes, told Amnesty International, "How am I going to tell Isabella about her mom? Now she just tells people, 'My Mommy's in heaven', and she kisses Val's picture on the tombstone when we go visit her at the cemetery. At some point I'm going to have to explain to her what happened, and I have to explain it's not her fault. It's something that's hard to come to grips with, even two and a half years later. At 35, no one should have to bury their wife. It hurts when I think about it. I have three pictures of me and Val and Isabella and those are the only three pictures I'm ever gonna have. And I'm grateful I even have those." He also told a reporter, "I don't have my best friend, I don't have the person I did everything with. I'm lost. It's absolutely devastating."

In an unrelated and tragic coincidence, Valerie Scythes' close friend and teacher at the same elementary school, Melissa Farah, died following a c-section at the same hospital two weeks later. The cause of her death was shock as a result of hemorrhage. A hospital spokesman stated: "Our treatment protocols seem to be well in line with or consistent with what I'll call appropriate treatment care."[268]

Amnesty International's research indicates that there is significant variation in obstetric practice across the country. There are no comprehensive, nationally implemented, evidence-based guidelines and protocols for promoting safe and quality maternal care and for preventing, identifying and managing obstetric emergencies. The failure to establish and implement such standards can result in increased risk of error, preventable complications and deaths. According to some estimates, improving the quality of maternal care could prevent 30 to 40 percent of near misses and serious complications, and 40 to 50 percent of deaths.[269] The Leapfrog Group, a US health care quality organization, found that in 2008 only 32 percent of hospitals participating in their annual review adhered to nationally endorsed evidence-based guidelines and measures for high-risk deliveries, "known to save lives."[270]

Amnesty International has documented instances where lack of or inconsistent implementation of protocols and procedures appears to have been involved in cases of four of the five main causes of maternal death in the USA. Standardized protocols and procedures to assist with the identification of risks, early warning signs, and establishing teams able to respond in a efficient and timely manner to issues as they arise, could improve the quality of maternal health care services.[271] There is no national evidence-based set of guidelines for the use of medical procedures related to childbirth. There is also a lack of sufficient attention to the training of teams and hospital administration systems focused on tracking and maintaining quality improvement initiatives. All these are crucial elements in ensuring that standardized protocols are effectively implemented.

While a variety of guidelines on maternal care have been produced by various state and federal agencies, ACOG and other groups, they may only cover certain aspects of maternal health care, may not be specific enough to guide clinical practice, and often are not available to patients to review. The Hospital Corporation of America, a large private operator of health care facilities in the USA, has stated that uniform, unambiguous processes and documentation guidelines have been shown to lead to improved outcomes including lower maternal and fetal injury, fewer c-sections and reduced litigation.[272] Sadly, such guidelines are currently not widely implemented in the USA.

The federal Agency for Healthcare Research and Quality (AHRQ) is responsible for improving the quality, safety, efficiency and effectiveness of health care. It has produced guidelines on certain aspects of maternal health care, but these are not comprehensive and do not address the five most common causes of maternal death. AHRQ also operates the National Guideline Clearinghouse, which collects and makes available guidelines produced by other entities, where additional obstetric guidelines and studies can be found.[273] However, AHRQ currently does not have the funding or a specific mandate to develop comprehensive national maternal health care guidelines. Some organizations have developed quality measures for maternal care, including the National Quality Forum and the Leapfrog Group, but these are voluntary.

Those standards that do exist are inconsistently implemented and there is no system-wide monitoring. Tracking mechanisms to determine whether protocols are implemented do not currently exist for maternal care. The CMS told Amnesty International that they were planning to develop standards for maternal and infant care reflecting best practice and requiring that hospitals adhere to these in order to receive Medicaid. However, it is not clear when this will be implemented.[274]

ELISHA CREWS BRYANT

Eighteen-year-old Elisha Crews Bryant was seven months' pregnant when she was admitted to a Florida hospital with early labor pains in May 2006. Three hours later, she was pronounced dead. A doctor had ordered magnesium sulfate to slow early labor, but the nurse mistakenly administered four times the prescribed amount. Elisha Crews Bryant's husband, Preston Bryant, stated, "I knew something wasn't right… I tried to tell them, and they wouldn't listen." An overdose of magnesium sulfate can cause respiratory failure, low blood pressure and cardiac arrest. The physician delivered their son, Levi, by emergency c-section. The hospital reported her death to the Florida Agency for Health Care Administration, and underwent an investigation to determine flaws in protocols that contributed to Elisha Crews Bryant's death. Among other steps, the hospital implemented a procedure to ensure magnesium sulfate was readily available only in 4mg bags, and required two registered nurses to sign off on the drip, to avoid mistakes made by rushing to administer the medication. However, the Florida Agency for Health Care Administration only required these changes to be made in the hospital where the death occurred and no changes were required for other hospitals in the state.[275]

Liz Logelin died in March 2008 from a blood clot. She was at heightened risk because of her prolonged bed-rest and a genetic condition.

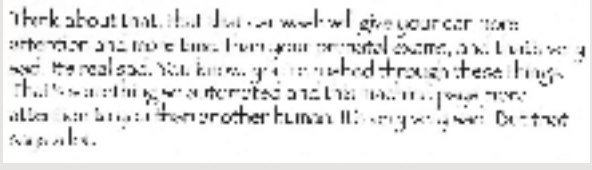
© Matthew Logelin

LIZ LOGELIN

Liz Logelin died on 25 March 2008 as a result of a blood clot (pulmonary embolism). She had been placed on bed-rest for five weeks prior to giving birth to her baby girl, Madeline, via c-section. Staff told her that she needed to stay in bed for the following 24 hours. The next day her husband, Matthew Logelin, and a nurse came in to take her to see her baby daughter. As Liz went to sit in her wheelchair, she said, "I feel light-headed," and then passed out. Doctors and nurses rushed her to the bed, but it was too late. Matthew Logelin told Amnesty International that his wife was at heightened risk of pulmonary embolism because of her prolonged bed-rest and a genetic condition and that he does not know whether she was given medication or compression stockings to prevent blood clots from developing. He decided not to file suit against the hospital, and told Amnesty International, "What good would money be to me? Liz was already dead and there was nothing that could bring her back. I don't blame anyone for her death."[276]

> **"In the US, every obstetrician seems to have a different protocol and it may vary from best practice. Someone who comes in half an hour later may receive different treatment."**
>
> Maternal mortality expert, from outside the USA, interviewed by Amnesty International, 13 May 2008

Embolism – a blood clot that can be fatal if it blocks blood flow to the lungs, heart or brain – is the most common cause of maternal death in the USA, accounting for 20 percent of maternal deaths.[277] Pregnant women are at increased risk of forming blood clots and suffering an embolism. Other risk factors include obesity, prolonged bed-rest, being over 35 years old and surgery, including c-sections.[278]



Photovoice 2009: Red Cliff, Wisconsin. An initiative using cameras to engage families, looking at the childbearing year and family wellness. Red Cliff Tribal Health Center and the Wisconsin Area Health Education Centers (AHEC) program.

Families from the Red Cliff Indian Reservation in the Bayfield Peninsula, Wisconsin, were asked to photograph things that represented the positives and negatives of pregnancy, childbirth, and raising a family in Red Cliff and the surrounding area. A tribal elder served as the project's cultural and spiritual adviser, and included his thoughts on each image. The woman who took this photo said: "A car wash takes about 5-8 minutes. And that's how long the typical prenatal appointment with a doctor takes. . . That's how I felt when I'd leave my prenatal appointments, disappointed because I didn't have the time that I wanted or I deserved for an appointment."

> **"Hospitals only need to give the level of care to pregnant women that they have been giving to non-pregnant women and men for years".**
>
> Dr. Steven Clark[279]

Preventative care includes the provision of drugs to prevent the formation of clots, and ensuring that a patient walks around as soon as possible and wears compression stockings. A CDC study estimated that 17 percent of maternal deaths due to pulmonary embolism were preventable.[280] Studies in other medical fields show that embolism following surgery has been reduced by approximately 70 percent by using either compression stockings or drugs. Experts expect they would show similar benefits in maternal care.[281] However, these simple measures are not routinely used following c-sections, which account for 32 percent of births.[282] In one study of maternal deaths in a group of hospitals in 20 states, nine women died due to fatal blood clotting following birth. None of the women had received preventative care.[283] The UK has implemented a nationwide protocol ensuring that women receive preventative care to avoid blood clots following c-sections, which has resulted in a substantial and ongoing reduction in deaths from pulmonary embolism.[284]

A protocol addressing the risk of blood clots should also emphasize that women must receive information about warning signs that a blood clot is developing and the measures that should be taken. Reports to Amnesty International indicate this is not done consistently or in an effective manner.

Hemorrhage – massive blood loss – accounts for 17 percent of maternal deaths and is another area where protocols could assist in preventing deaths. A CDC study found that improved quality of care could have prevented almost all maternal deaths due to hemorrhage.[285] Although black women are no more likely to suffer a postpartum hemorrhage than white women, another CDC study found that they are 2.5 times more likely to die as a result.

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.

DIANE RIZK MCCABE

Diane Rizk McCabe was 32 years old when she died in September 2007. She gave birth via c-section to a healthy baby girl following an uncomplicated, full-term pregnancy. Her six-year-old son Louie was at the hospital and happy to be a big brother. According to family members, she arrived at the hospital expecting a vaginal birth, but after 10 hours of labor, her obstetrician recommended a c-section. Diane Rizk McCabe suffered excessive internal bleeding in the 15 hours following the c-section, reportedly losing more than three quarts of blood out of five that are typically in a pregnant woman's circulatory system. Her body eventually went into shock. Reportedly, understaffing was a chronic problem at the hospital, including in the surgical intensive care unit. There were 25 to 30 other patients in the intensive care unit that day and only one attending physician and one resident on duty. Around 1.30pm, a critical care physician recognized the emergency and informed Diane Rizk McCabe's doctor that she was bleeding internally and needed further surgery. Two other physicians confirmed this diagnosis within an hour or two. Nevertheless, no physician or nurse called an obstetric hemorrhage code (a process to initiate emergency treatment). She was not returned to surgery until 7pm. According to court documents, none of the physicians involved in her care had participated in drills to practice recognizing and managing obstetric hemorrhages, despite recommendations from the state department of health for hospitals to implement these training drills. The family's attorney filed a lawsuit against the hospital charging that by failing to call an obstetric hemorrhage code, physicians did not follow standard hospital procedures. A spokesperson for the hospital stated the hospital met all of its statutory requirements, but could not comment further because of the lawsuit. In legal documents, the hospital and its staff have denied any wrongdoing. Diane Rizk McCabe's sister, Joanne, told a reporter "Louie keeps saying, 'I miss my mommy... I'll never see my mommy.' It breaks my heart."[286]

The signs that a hemorrhage is developing may be subtle, and the window of opportunity to effectively address a life-threatening complication may be brief. In response to data showing a high percentage of deaths from obstetric hemorrhage identified by New York's Maternal Mortality Committee, New York City and State Departments of Health and New York ACOG developed and distributed a poster on how to respond to obstetric hemorrhage. At Stony Brook University Medical Center, a large university hospital, a multi-disciplinary team of physicians, nurses, and blood-bank staff also developed a series of protocols including criteria for identifying high-risk patients, recognizing hemorrhages early, and treating them rapidly.[287] These protocols are now publicly available on the New York State Department of Health website.[288] Such steps are important. However, when good practices are developed these should be shared and implemented nationwide. So far, the authorities have failed to ensure this happens.

An obstetric and public health expert who reviewed the case of a woman who died of eclampsia at a public hospital told Amnesty International she was shocked to see that the woman's rising blood pressure levels had not been identified during her pregnancy. Because she saw a different doctor every time she visited and no one was charting the progression from month to month, clear danger signals had been missed. "There wasn't a simple piece of paper or blood pressure chart to eyeball changes in blood pressure. It was handwritten in the notes every visit but not one chart – the visual clue wasn't there, so the doctors missed the fact that it was going up."[289]

Hypertensive disorders of pregnancy account for 16 percent of pregnancy-related deaths. In a CDC study, 60 percent of all deaths due to pregnancy-induced hypertension were found to be preventable.[290] Tracking women's blood pressure during and after pregnancy allows the condition to be identified before it becomes life threatening. The risks can then be managed by working with women, careful monitoring and possibly delivering the baby early. Again, consistent protocols in this area are lacking and reports to Amnesty International indicate that maternal care is often fragmented and systems to document and share information with women as well as between different provider systems about warning signs or potential risk factors are frequently not well developed.

© Private

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.

JULIE LEMOULT

Julie LeMoult died on 4 April 2003 after giving birth to a healthy baby boy – Logan Donnelly. She was given two epidurals during labor. After giving birth, she complained of an intense headache. Her family could not find anyone to help. Her mother recalls: "For the five or six hours I was there, the nurse never came back." When the headache worsened and she developed a fever, the obstetrician ordered an antibiotic over the telephone. Her husband says it was not administered: "No one ever followed up to see if she had received it." She started to have a seizure and was rushed to the Intensive Care Unit where doctors discovered she had meningitis – an inflammation in the brain and spinal cord, causing her brain to swell – brought on by an infection. Julie LeMoult suffered massive brain damage. Faced with the prognosis that she would never recover from her coma, her husband chose to take her off life support. Her family filed a lawsuit against the hospital, charging that her death was the result of a "failure to maintain a sterile environment" and that she contracted the infection from "the introduction of a needle into the patient's spinal canal without use of sterile face masks." The hospital stated they had "met the standard of care in every respect." Hospital officials told reporters they believe the autopsy findings indicated that she entered the hospital with an infection, calling the case a "medical mystery." The hospital now requires physicians (and anybody else in the room) to wear a mask while administering an epidural.[291]

Infections account for 13 percent of maternal deaths in the USA. Infections affecting maternal health may be contracted in a number of different situations, particularly following c-sections, where the risk of infection is nearly five times higher than that for a vaginal birth.[292] A CDC study found that improved quality of care could have prevented 43 percent of maternal deaths caused by infection.[293] The Society for Health care Epidemiologists of America and the CDC, among others, have produced a list of straightforward preventative measures, but these are not always required or implemented.[294]

> **"We spend outrageous amounts of money and bankrupt the system by performing unnecessary interventions. Look at where the US stands on rates of interventions and then where it stands in terms of outcomes.**
>
> Maria Freytsis, certified nurse-midwife, New York City, Amnesty International interview, 5 March 2008

The percentage of births involving inductions and c-sections has gone up substantially since the 1990s,[295] and are now each twice as high as the World Health Organization recommendation.[296] Administering drugs to start or stimulate labor is used in at least 23 percent of births[297] and c-sections are used in 32 percent of births.[298] US experts and institutions including the Institute of Medicine, the CDC and the National Priorities Partnership agree current rates are too high,[299] and the US government's Healthy People 2010 initiative set a goal of reducing the c-section rate to 15 percent for low-risk first time mothers.[300]

The risk of death following c-sections is more than three times as high as for vaginal births.[301] C-sections have been shown to increase a woman's risk of infection, hysterectomy, and kidney failure, and have been associated with a 52 percent increase in the risk of developing a life threatening blood clot (pulmonary embolism).[302] C-sections result in greater risks for future pregnancies[303] and the risk of death of the newborn may be one and a half to two times greater.[304] Inducing labor significantly increases the likelihood of a c-section for first-time mothers[305] and has been associated with a higher risk of hemorrhage.[306] Despite a Healthy People 2010 goal of increasing the rate of vaginal birth after a prior c-section (VBAC) rate to 63 percent,[307] the current rate is less than 10 percent.[308] However, there is no national evidence-based set of guidelines for the use of medical procedures and there is significant variation from hospital to hospital and from state to state.[309] For example, state c-section rates range from 22 percent (Utah) to 38 percent (New Jersey)[310] and the variation between hospitals is even greater; in New Jersey rates range from 18 percent to 62 percent.[311] One study concluded the variation seemed to demonstrate "a pattern of almost random decision-making."[312]

LACK OF INFORMATION AND AUTONOMY

All women should receive balanced information about the risks associated with medical interventions and procedures. They should also have the opportunity to actively refuse unwanted medical interventions. Standardized approaches to providing information enhance women's ability to exercise these rights, and written documentation of consent discussion can assist in holding health care providers accountable for ensuring the right to informed consent. Unfortunately, standardized protocols on information-giving and consent are not currently implemented in the USA.

Reports from providers, advocates and women suggest that women may not always be sufficiently informed about risks of medical interventions and procedures or given the opportunity to actively participate in health care decisions. A member of a Maternal Mortality Review Committee told Amnesty International that the consent process in obstetrics is highly variable and can depend on who provides information, what information is shared, and how that information is presented to a pregnant woman. "For example, someone who will benefit financially from the woman's decision may provide information differently than someone who is not financially affected by her decision. Currently, there is limited documentation on what information is shared, how and by whom."[313]

Women who prefer, if possible, to avoid medical procedures – such as c-sections – have reportedly faced pressure and coercion by providers to accept unwanted medical procedures.

> **"My doctor seemed eager to do a c-section. At 8 months the doctor wanted to induce and was trying to tell me that the baby weighed 9 lbs. I said, 'No way'… I kept asking about other ways, because I didn't want a c-section. My baby was right on time and was only 8 lbs 9 oz when she was born."**
>
> Native American woman, Wisconsin, Amnesty International interview, May 2009

Inducing labor significantly increases the likelihood of a c-section for first-time mothers when the cervix is not ready for labor[314] and has been associated with a higher risk of hemorrhage.[315] A national survey found that 25 percent of women who had either a primary or repeat c-section reported feeling pressurized by a health provider to have a c-section; 11 percent reported pressure to induce labor. According to the survey, only 16 percent of white women had any choice in the decision about episiotomy (a surgical incision through the perineum); for African-American women the figure was only 4 percent.[316]

> **"We talk about health care and autonomy, but in reality, in the US, that does not apply to childbearing and pregnant women… The environment is structured to be coercive."**
>
> Obstetrician/gynecologist interviewed by Amnesty International, 2008

Failure to adequately inform women of the risks and benefits of potential care options violates international human rights standards regarding key principles of autonomy and informed decision-making.[317] In the USA, informed consent is an ethical obligation recognized by medical associations [318] and a legal requirement based in statutes and case law. While there is some variation of the legal standard by state,[319] all 50 states have informed consent requirements. Physicians must always disclose risks of treatment for a patient's consent to be valid.[320] However, these standards are not always applied.

The care options available to pregnant women in the USA are more limited than in many other industrialized countries with better maternal and infant health outcomes. In many countries midwives or family practitioners are the usual maternal care providers for low-risk pregnancies, and specialist doctors – obstetricians – are asked to step in only in high-risk cases and in cases where complications develop unexpectedly.[321] In contrast, in the USA, although 83 percent of women have low-risk pregnancies,[322] the vast majority receive care from obstetricians and only 8 percent are attended in childbirth by a midwife.[323] One of the factors contributing to the limited nature of the options available is the failure to include community members and advocacy groups in the decision-making process regarding what constitutes appropriate, quality maternal care. An individual woman's ability to actively participate in her care is hampered by a lack of information about care options and the failure to involve women in decision-making regarding their own health care.

Studies both in the USA and in other countries have documented the safety, benefits and positive outcomes for mothers and infants of a midwifery model of care. Often women are able to spend more time with health care providers, such as a midwife or family physician, than with an obstetrician during prenatal care, which facilitates the provision of advice and information as well as developing trust and improving communication. Health care providers who are focused on and dedicated to a holistic, patient-centered model of care may also be more comfortable addressing mental health issues and social issues that are important to maternal health.

Care by family physicians also results in positive outcomes with reduced likelihood of pregnancy-induced hypertension and pre-eclampsia.[324] Continuous support in labor is more likely to result in a vaginal birth[325] and studies also demonstrate that midwifery care reduces interventions, including episiotomies and c-sections.[326]

However, in the USA, women who want to explore the option of having a midwifery model of care face a number of barriers. Certified nurse-midwives, who work primarily in hospitals, are allowed to practice in every state. However, Certified Professional Midwives who complete accredited training programs and pass national certification exams are not authorized to practice in 24 states or Washington, DC.[327]

Midwifery care options are frequently not reimbursed by public or private insurance. In 27 states, there is no requirement that private insurance reimburse nurse-midwife services at all.[328] In the 33 states where private insurers are required to reimburse for care by midwives, this often is limited to nurse-midwives who perform deliveries in hospitals. Medicaid reimburses facility fees for hospitals in all states, but only reimburses fees for birth centers in 21 states and Washington, DC.[329] This means that cost is a significant barrier to obtaining care by midwives for many women. Enhancing women's choices of maternal care options can play an important role in ensuring the right to health.

In some cases physicians or hospital staff have treated midwives and even their patients with hostility and disrespect that compromises the quality of care women receive. One midwife told Amnesty International about a woman from Iowa, who had been declared "a perfect candidate" for home birth by a specialist a week before and went into labor at home. The midwife became concerned when labor did not progress and referred them to the hospital. At the hospital, staff tried to prevent the midwife from entering, but the husband insisted she accompany them. The woman's pain was "excruciating," the midwife told Amnesty International. "Upstairs we wait 45 minutes – but nobody comes to see us. She was sobbing profusely from the pain. She was very scared for herself and her baby… Finally, a staff member says: 'We can't get a doctor to come in as long as you [the midwife] are in the room.'" The doctor told the couple that the woman needed an emergency c-section because, he said, the woman's history of bleeding during pregnancy indicated placenta previa – a potentially life-threatening condition where the placenta blocks the cervix. After completing the operation the doctor admitted that the complications had been caused by a polyp, not by undiagnosed placenta previa. The couple was very upset at having been coerced into an unnecessary c-section. The family did not file a complaint because they said they feared retaliation or mistreatment should they seek care at that hospital in the future.[330]

"The US has the least amount of available options as compared to other industrialized countries. We spend the most money, but we don't have tubs, birthing balls, ropes, available for women giving birth. There are so many non-pharmacological techniques, that make it more comfortable and safer, but we don't use them."

Debra Pascali-Bonaro, Childbirth Educator, DONA International Doula, River Vale, New Jersey, Amnesty International interview, 9 April 2008

LACK OF ADEQUATE POSTPARTUM CARE

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 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. Her mother, Frances McFarquhar, said "We never even get a chance to meet our granddaughter... not even that." According to one expert, a postpartum check-up visit by a nurse or midwife could have identified symptoms before her condition became life-threatening.[331]

A number of complications that require prompt medical attention may occur after giving birth and after a woman and her baby have returned home. Wounds or lacerations may become infected. Hemorrhage and pulmonary embolisms, the two most common causes of maternal death, can develop in the days and weeks following discharge from the hospital. According to a study conducted by the CDC, 34 percent of maternal deaths occurred within 24 hours of childbirth. However, an additional 55 percent of deaths occurred between 1 and 42 days following birth.[332] Although no systematic data is collected on maternal illness or injuries occurring after birth, one national survey of new mothers found that a number of problems began in the first two months following birth, including infection of the c-section site (19 percent) and blood clots (8 percent).[333] One study found that for African-American women and Latina women, a higher percentage of maternal deaths occur within the first week following delivery.[334]

Postpartum care in the USA is inadequate, generally consisting of a single office visit with a physician around six weeks after birth,[335] although women with complications and those with c-sections may have additional visits. The limited care available often fails to meet women's needs, by not following recommendations to screen for conditions such as hypertension or diabetes, or for postpartum depression, which affects 10-25 percent of women.[336]

"Early and frequent contact through regular home visits by a midwife help prevent certain problems and identify others before they can escalate."

Julie Bosak, certified nurse-midwife, Amnesty International interview, 7 March 2008

Home visits and community-based care may significantly improve access to health care. This can be particularly important after childbirth when physical discomfort, exhaustion, and caring for a newborn baby make it difficult for women to leave the home. Some local programs have established limited home visit programs for new mothers, particularly for at-risk groups such as teenage mothers. For example in South Carolina, new mothers receive a home visit from a public health nurse within a few days of being discharged from hospital.[337] However, the majority of women in the USA do not have access to such care, unless they can afford to pay for the services of a doula (a person who assists the woman by providing various forms of non-medical and non-midwifery support in the childbirth process) or have a midwife or family physician who provides home care.

"You're home, you're still hurting, you could be infected, you could still have something in your uterus. All these things can be dangerous, and they can be easily fixed if you spot the trouble in time... They used to keep women in the hospital for 10 days after birth because they were so worried about complications."

Ina May Gaskin, midwife, recommending home visits for mothers by a postpartum doula, nurse, or midwife, quoted in *Harper's Bazaar*, September 2009 [338]

“I HAVE COUNTLESS QUESTIONS THAT I’LL PROBABLY NEVER GET THE ANSWERS TO.”

Joseph LaGrew, husband of Trudy LaGrew who died following complications of childbirth, three and a half months after giving birth (see page 61 for more information)

6/ACCOUNTABILITY

The US government must be held accountable for the significant systemic human rights failures described in this report. No matter whether a health care system is centralized or decentralized, private or public, or a mix of the two, the government is responsible for ensuring that health care is available, accessible, acceptable and of good quality without discrimination. Yet in the USA inequalities in health care – conditioned by gender, race, ethnicity, immigration status, Indigenous status and income – persist. The consequences are seen in the failure to reduce the number of women dying in pregnancy and childbirth over the past 20 years and entrenched disparities in the care available.[339] The failure to meet either international or domestic targets for improving maternal health in the USA is linked to a fundamental breakdown in accountability.

NEED FOR COORDINATED OVERSIGHT

The fragmented nature of health care financing and delivery also leads to a fragmented and uncoordinated approach to oversight. The federal government's involvement in reducing maternal mortality and addressing disparities lacks coordination; efforts are split between a number of federal agencies. Regulation at federal and state level of the private insurance industry and its role in providing maternal health care is inadequate.

While litigation provides an avenue for individuals or families to seek redress, it rarely leads to systemic reform. Even when improved procedures and policies do result from such litigation, they are often piecemeal and localized. Fear of litigation among providers may also limit transparency for families and review bodies seeking to understand what went wrong.

> **"Who owns responsibility for [not implementing best practices]? The short answer is: 'Everybody and nobody.'"**
>
> Carolyn Clancy, Director, Agency for Healthcare Research and Quality, Amnesty International interview, 7 January 2009

Federal agencies that are involved in improving access to and the quality of health care are mainly housed within the Department of Health and Human Services and include the Centers for Medicare and Medicaid Services (CMS); the Agency for Healthcare Research and Quality (AHRQ); the Health Resources and Services Administration (HRSA); the Office of Women's Health; the Office for Minority Health; and the Centers for Disease Control and Prevention (CDC).

CMS informed Amnesty International that they were planning to develop standards for maternal health care and that they would require hospitals to adhere to them in order to receive Medicaid funding. However, to date these have not been developed, and no date has been provided for when they will be completed.

Officials at AHRQ, which focuses on health service research and evaluations, told Amnesty International, "We're acutely aware that very little has been done" on maternal health.[340]

HRSA indicated that it was seeking to improve maternal health outcomes and access to health care services, including maternal health care, to under-served communities. However, because of a lack of funding they are currently unable to meet the need. The Office of Women's Health does not at present focus on maternal health, morbidity or mortality. The Office for Minority Health is seeking to address disparities in infant mortality rates, but is not currently focusing efforts on the disparities in maternal mortality rates. The CDC collects and analyzes data on maternal mortality. However, these efforts are hampered by the fact that states are not obliged to provide information, although some do so on a voluntary basis. In addition, the CDC can make recommendations, but it has no mandate to enforce their implementation. The Healthy People 2010 initiative measures include objectives on prenatal care, maternal mortality and morbidity, yet inadequate implementation and inconsistent data collection and public reporting have hampered their impact.

LACK OF COMPREHENSIVE AND ACCURATE DATA

"IT'S CRUCIAL TO GET THE EVIDENCE BASIS TO DECIDE WHAT WE NEED TO DO TO BRING THE NUMBERS DOWN – YOU NEED THE DATA TO SEE THE PATTERNS."

Cynthia Berg, medical epidemiologist, CDC, Division of Reproductive Health, Atlanta, Georgia, Amnesty International interview, 13 December 2007

A lack of comprehensive data collection and effective systems to analyze the data is contributing to the failure to improve maternal health. According to the CDC, the number of maternal deaths may be twice as high as current estimates.[341] The lack of comprehensive data collection is masking the full extent of maternal mortality and morbidity in the USA and is hampering efforts to analyze and address the problems and so improve maternal health overall.

Many maternal deaths are never identified as pregnancy-related. Only six states – Florida, Illinois, Massachusetts,[342] New York, Pennsylvania and Washington – currently require pregnancy-related deaths to be reported as a distinct category; there is no national requirement to do so.[343] Despite voluntary reporting efforts in other states, many maternal deaths are not reported to state departments of health, the CDC, or local maternal mortality review boards.

Across the USA, there is a lack of standardization in the data collected. For example, death certificates can help track pregnancy-related deaths.[344] To increase reporting accuracy, the CDC has long recommended that all death certificates include a checkbox to indicate whether the woman was pregnant at the time of death, in the six weeks prior to death, or during the previous year. However, 10 states told Amnesty International that they do not have such a checkbox on death certificates.[345] States that do have checkboxes do not all follow the US Standard Death Certificate, introduced by the CDC in 2003, which contains five specific questions to determine more precisely the timing of a woman's pregnancy in relation to the date of her death. This can result in collection of partial data and hampers the analysis of trends across states.[346]

> **"People frequently do not fill out death certificates correctly. Often it's an intern in the middle of the night, exhausted and rushing and untrained. The fact that a woman had been pregnant 6-8 months ago is usually overlooked."**
>
> Jeffrey King, Chair, ACOG Maternal Mortality Special Interest Group, Amnesty International interview, 13 March 2008

The CDC has also noted that physicians and others receive only minimal training in correct completion of death certificates in order to document whether or not it was pregnancy-related and that this results in uncounted pregnancy-related deaths.[347]

Reporting based solely on death certificates, however, can also lead to undercounting of maternal deaths.[348] "Enhanced surveillance" methods include reviewing medical examiner records and comparing the death certificates of women of reproductive age with birth certificates to establish whether a woman had given birth within a year of her death.[349] These methods can be far more effective, identifying as many as

90 percent more maternal deaths than providers reported on death certificates.[350] Linking death certificates for deceased mothers to the full birth certificate data may also allow for a more complete recording and analysis of related information. However, 17 states told Amnesty International that they do not cross-reference death and birth certificates.[351]

> **"Unless you review and evaluate near misses, you will have a hard time correcting system issues or finding prevention strategies."**
>
> Jeffrey King, Chair of ACOG Maternal Mortality Special Interest Group, Amnesty International interview, 13 March 2008

Public health experts and researchers told Amnesty International that studying complications and injuries can provide a more effective basis for a systemic review of maternal health, because they are more common than deaths. Maternal complications are the fourth leading cause of infant death in the USA, so reducing maternal complications and improving women's health would also reduce infant deaths.[352] However, little data is currently available on maternal complications or near misses [353] and few maternal mortality review committees review or analyze these cases.[354] In the UK, for example, a system has been introduced to track selected maternal morbidity cases in all hospitals with an obstetric unit across the UK.[355] Such a system could provide data to help targets for improving the quality of care for federal and state authorities as well as for hospital management structures. However, no such system currently exists in the USA. According to one expert, "A hospital leader may be in the midst of a quality care crisis but have a limited opportunity to recognize the severity of the situation or the need for an infusion of support."[356]

Under the Patient Safety and Quality Improvement Act of 2005,[357] and with the support of AHRQ, the National Quality Forum (a non-profit organization) has undertaken to develop a standardized set of 17 quality and safety measures in order to improve monitoring of some data on maternal morbidity and medical errors in maternal care. Although these developments will provide standards for performance measurement, additional data on near misses and maternal morbidity is needed in order to reduce the current high rates of complications.

Data collection systems frequently fail to adequately categorize the woman's race or ethnicity, preventing more detailed analysis of which women are suffering disproportionately from maternal mortality and complications, and hampering efforts to eliminate disparities.[358]

INADEQUATE REVIEW OF DATA

"TATIA WAS 32... AND ALWAYS CONSCIOUS ABOUT HER HEALTH. SHE AND HER BABY DAUGHTER, ZORAH, PASSED AWAY IN DECEMBER 2001, AFTER HER LABOR WAS INDUCED TO DELIVER HER FIRST CHILD... TWO YEARS LATER, I FORMED A NONPROFIT ORGANIZATION, THE TATIA ODEN FRENCH MEMORIAL FOUNDATION. WE HAVE MEDICAL EXPERTS... ON THE BOARD AND OTHER FAMILY MEMBERS AND STARTED TO ORGANIZE. SO MANY OF THESE DEATHS WERE PREVENTABLE. THEY SHOULD NOT HAVE OCCURRED."

Maddy Oden, Tatia Oden French's mother, Oakland, California, Amnesty International interview, 8 February 2008

> **"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 interviewed by Amnesty International, December 2007

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 (see Appendix A). In the 21 states where maternal mortality review committees do exist, their effectiveness is hindered by a number of factors. State maternal mortality review committees are not uniform in design or mandate, and approach the work in a variety of ways. Some rely exclusively on volunteers; others have professional staff. Some review all maternal deaths, while others analyze a smaller sample. Almost none review morbidity, although several told Amnesty International they were working on incorporating this into their work.[359] In addition the work of the committees is not coordinated which can result in duplication of effort; several review committee participants interviewed by Amnesty International were unaware of work by committees in other states.[360]

Although maternal mortality reviews are usually kept confidential and published data does not identify specific places or individuals, reviewers often experience difficulty in accessing information. Eighteen of the 21 states with maternal mortality review committees[361] have legal or administrative protections for the confidentiality of

information disclosed for public health investigations. However, even in those states providers apparently remain concerned that the protections are not sufficient to shield them from litigation. In other states, no such protection exists.

> **"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, Amnesty International interview, 12 February 2008

> **"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's and Children's Health at the World Health Organization, Amnesty International interview, 27 February 2008

While numbers and statistics can give an indication of what the problem areas are, solutions often require a more detailed study, both in terms of the actual cause of death, the medical event itself, and the root causes. For this reason, the UK maternal mortality review body sends written questionnaires to everyone involved in the patient's care, including social workers, and the WHO recommends home interviews with family members as part of reviews. In the USA, the Fetal and Infant Mortality Review (FIMR) includes a home interview as well as collaboration with community advocacy organizations.[362] When it comes to maternal health, however, US maternal mortality review committees are often limited to reviewing medical records, which do not convey information about social factors or failures of medical systems that may have contributed to a death. Only four states may interview providers, family or others directly involved in the woman's care.[363]

> **"If a death certificate says 'hemorrhage,' you don't know if the hemorrhage wasn't recognized in time, if the blood bank wouldn't release the blood quickly enough, or if the elevator got stuck."**
>
> Cynthia Chazotte, Vice Chair of the Department of Obstetrics and Gynaecology and Women's Health Einstein/Montefiore, Bronx, New York, and Co-Chair NYS Safe Motherhood Initiative, Amnesty International interview, 18 March 2008

Multidisciplinary review bodies should include community representatives – such as activists, service providers, and policy makers – in order to improve the breadth of analysis. This would facilitate taking into account issues which may be impacting on women from at-risk communities, and may also help address real and perceived bias from medical professionals.[364] However, maternal mortality review committees in only 15 states seek to include individuals who have worked in diverse communities.[365]

ADDRESSING RACIAL AND ETHNIC DISPARITIES

The failure of the federal government to acknowledge and address systemic racial disparities in health care, including maternal health care services, violates its obligations under international law. ICERD makes clear that discrimination includes not only intentional discrimination but also laws, policies and practices that have a disparate impact on certain groups. US obligations include a duty to review both national and local law and policies, and to amend or nullify those which have the effect of creating or perpetuating discrimination.[366]

Title VI of the Civil Rights Act of 1964 prohibits discrimination on the basis of race, color or national origin in any program or activity receiving federal financial assistance.[367] The role of federal funding in health care services (for example through Medicaid or other maternal and child health grants) means that most hospitals, clinics and health care services fall within the scope of Title VI. The federal government is responsible for ensuring compliance with Title VI. Currently proof of intent is required before a finding of discrimination will be made under Title VI in individual cases. The US Supreme Court held in *Alexander v. Sandoval*[368] that individuals cannot bring lawsuits in cases of disparate racial impact under Title VI. The Court did, however, leave open the possibility of government enforcement in such cases.

The Office for Civil Rights of the US Department of Health and Human Services, which enforces federal laws that prohibit discrimination by health care providers that receive funds from the Department, should clarify its mandate to encompass enforcement of civil rights violations based on disparate impact involving race as well as national origin. It is vital that Congress and the Department of Health and Human Services ensure that the Office of Civil Rights is adequately funded to undertake enforcement activities to eliminate the disparities in health care, including in maternal health. The Civil Rights Division of the Department of Justice should also add enforcement of Title VI in the area of health to its on-going work on discrimination in housing, employment and education.

“WHAT WORKS IS NOT FLASHY, NOT EXPENSIVE, BUT IT’S HUMAN INTENSIVE.”

Heidi Rinehart, former obstetrician, New York, Amnesty International interview, 8 February 2008

7/RECOMMENDATIONS

This report highlights the link between unacceptably high levels of maternal mortality and morbidity in the USA, and the failure of the US government to ensure that health care services are available, accessible, acceptable and of good quality to all on the basis of non-discrimination. The systemic disparities that exist in maternal health care in the USA provide compelling evidence of the authorities' failure to fulfil their obligation to prohibit and eliminate discrimination in the provision of health care services, in contravention of the International Convention on the Elimination of All Forms of Racial Discrimination.

The failure to ensure access to adequate health care before a woman becomes pregnant; to provide adequate family planning services; to ensure that women receive early and adequate prenatal care; to ensure that evidence-based guidelines are in place to address the main causes of maternal death; to respect women's right to information and informed consent and the barriers to women's active participation in their care; to provide adequate post-natal care; and to ensure systemic accountability for maternal deaths and injuries – all breach international human rights standards.

While health professionals, facilities and insurers all play a role in the US health care system, ultimately it is the responsibility of the US government to prevent and address violations of human rights, whether committed by agents of the state or private individuals or organizations (non-state actors).

These following recommendations set out specific steps that must be taken to improve maternal health care in the USA. This will require the US government to take concrete and effective steps to improve the health care system overall in a way that ensures that everyone in the USA can enjoy, on an equal basis, their human right to the highest attainable standard of health.

The US government must create a comprehensive national plan of action to improve maternal health care and eliminate systemic disparities. Relevant stakeholders should be involved in this process including a variety of health care providers (such as physicians, midwives and nurses), experts on public health and social services, and members of affected communities. In particular, measures should be taken to ensure women participate in developing solutions at the federal, state and local level.

STEPS TO IMPROVE MATERNAL HEALTH SHOULD:

ENSURE ACCESS TO QUALITY HEALTH CARE FOR ALL

1 The US government must ensure that health care information and services, including sexual and reproductive health care, are available, accessible, acceptable and of good quality throughout an individual's lifetime.

2 The US government must ensure that all women have equal access to timely and quality maternal health care services, including family planning services, and that no one is denied access to health care services by policies or practices that have the purpose or effect of discriminating on grounds such as gender, race, ethnicity, age, Indigenous status, immigration status or ability to pay.

3 he US government must ensure that gaps in the health care system are eliminated so that all communities have access to comprehensive, quality treatment and services. Publicly financed and administered health care should be expanded as the strongest vehicle for making health care accessible and accountable.

ENSURE EQUITABLE ACCESS TO HEALTH CARE WITHOUT DISCRIMINATION.

4 Federal, state and local governments should create comprehensive plans to address the fundamental inequalities that are at the root of general health and maternal mortality disparities, including by improving access to adequate nutrition, education and housing.

5 The US Congress should increase funding for the Office of Civil Rights in the Department of Health and Human Services. The Office of Civil Rights should undertake investigations to assess situations where laws, policies and practices are obstacles to equal access to quality health care, including maternal health care.

6 The US Congress should create a Health Section in the Civil Rights Division of the Department of Justice to deal with issues of discrimination in health care, including maternal health care.

7 The US Congress should rectify the chronic budgetary shortfalls affecting Native American and Alaska Native women receiving health care through the Indian Health Service (IHS). The US government should ensure that public funding levels for health care services do not discriminate on the basis of race or Indigenous status. Funding levels should be increased to that of Medicaid or higher. IHS funding should not be

dependent upon annual appropriations bill and should be made an entitlement in the same way as Medicaid.

8 Training in the culturally appropriate and gender sensitive provision of services and treatment should be incorporated into the basic training curriculum of all health care professionals, as well as in their continuing education, and licensing requirements.

9 The US government should ensure that all immigrants are eligible for Medicaid.

10 State governments should ensure that Medicaid services are offered to documented immigrants.

REMOVE BARRIERS TO TIMELY, APPROPRIATE, AFFORDABLE MATERNAL HEALTH CARE

11 The US government must ensure that all women have equal access to good quality maternal health care services.

12 The US government must ensure that fees for health services, including maternal health services, do not prevent women from obtaining the care that they need or drive them or their families into poverty or bankruptcy. Any fees for health services should be based on ability to pay according to a sliding scale starting at zero.

13 The US government must ensure that all insurance plans – whether public or private – provide comprehensive coverage throughout pregnancy, labor and delivery, and following birth. Such coverage should meet with standards set by the US Healthy People 2010 initiative for early and "adequate care", including by providing women with 13 prenatal visits and ensuring that prenatal care begins in the first trimester.

14 Federal and state governments should ensure that women who are insured through their employer receive comprehensive affordable maternal health care services. Federal and state governments should provide a safety net for those who do not receive coverage through their employer.

15 Federal and state governments should regulate individual private insurance providers to ensure that pregnant women are not denied coverage on the basis of any pre-existing conditions (including the pregnancy itself) and that policies include comprehensive maternal health care at no extra cost.

16 State governments should establish "presumptive eligibility" for Medicaid for pregnant women, and ensure that Medicaid provides timely access to prenatal care. In cases where a woman receives prenatal care before eligibility is confirmed, states should ensure that Medicaid reimburses retroactively for services provided.

17 Centers for Medicare and Medicaid Services and state governments should undertake a review and remove all barriers to women receiving maternal health care services through Medicaid that delay or interrupt access to care. Congress should amend the Deficit Reduction Act of 2005 to remove barriers that prevent women on low incomes receiving coverage under Medicaid. This should include revising unduly burdensome documentation (including citizenship and income) requirements.

18 The US government should undertake a review of the manner in which the Federal Poverty Level, which is used by states to determine eligibility for Medicaid services, is calculated to ensure that the measures used are up to date and accurate.

19 State governments should ensure that women receiving maternal health care through the Children's Health Insurance Program receive coverage for all their health needs during pregnancy and postpartum.

20 The Centers for Medicare and Medicaid Services should, as a condition of receiving funding, require state public health departments and local authorities to assess specific barriers to accessing health care affecting women, particularly women on low incomes, and develop plans to provide the needed support or services to overcome these, such as transport and child care.

21 The US Congress should review and provide legislative or regulatory protections, where needed, for women to take time off work for prenatal visits. Health care providers should offer flexible hours for women seeking prenatal care.

22 Appropriate drug addiction treatment programs and related support services should be available and offered to all pregnant women who need them. Access to such programs and support services should not be the basis for criminal charges.

23 Federal and state governments should require all health care providers to ensure that all women receive adequate interpretation and translation services when seeking and receiving medical care.

24 The US Congress should mandate compliance with the National Standards on Culturally and Linguistically Appropriate Services (CLAS) developed by the Office of Minority Health.

25 The US Congress should direct and adequately fund the Office of Minority Health to develop a clearinghouse with translations of commonly used medical forms, consent forms and information sheets on maternal care, in collaboration with affected communities and the medical community. These should be made available on-line free of charge and should be provided to all women seeking maternal health care in need of language services.

26 The US Congress should require private and public insurance to adequately reimburse translation and interpreter services.

27 State governments should require that interpreters providing services within the health care system are adequately trained and certified in order to ensure provision of medically accurate, culturally appropriate and gender sensitive interpreter and translation services.

28 Health care providers should recruit and promote linguistically and culturally diverse staff and leadership that reflect the demographic characteristics of the area they service.

ENSURE ACCESS TO FAMILY PLANNING SERVICES AND INFORMATION FOR ALL WOMEN

29 Federal and state governments should ensure access to reproductive health information and services for all women, on the basis of non-discrimination. State, and where appropriate federal, governments should ensure effective evidence-based sex education in schools.

30 Federal and state governments should regulate private insurance providers to ensure that they provide coverage for sexual and reproductive information and services. All states should require insurance companies to cover prescription contraceptives.

31 Federal and state governments should ensure that all women in need of publicly funded reproductive health services are able to access such services.

a) The US Congress should amend the Deficit Reduction Act to remove barriers for low income women to receive family planning services through Medicaid, including by removing the discretion that allows states to exclude certain recipients and to impose fees for contraceptives.

b) The Centers for Medicare and Medicaid Services should expand Medicaid coverage for family planning services. States should not have to request a waiver in order to expand coverage to Medicaid recipients for such services.

c) The US Congress should ensure that the Department of Health and Human Services receives adequate funding to allow the Office of Population Affairs to expand the Title X clinic program.

32 Indigenous women should be afforded equal access to sexual and reproductive services. Particular emphasis should be placed on ensuring that Native American

and Alaska Native women receive adequate sexual and reproductive health services through the IHS. A full range of contraceptives, including emergency contraceptives should be available at all IHS pharmacies.

33 Federal and state governments should require that all health care providers provide quality health care services to a woman whose life or health is at grave risk due to pregnancy. Pharmacists and pharmacies should be required to make contraceptives, including emergency contraceptives, available to all women. Decisions related to care or the provision of services should be based on evidence-based guidelines and protocols for maternal health care, on moral or religious grounds.

ENSURE ACCESS TO ADEQUATE, APPROPRIATE, QUALITY MATERNAL HEALTH CARE PROVISION

34 Federal, state and local governments should address the shortages of maternal health care providers and ensure that adequate numbers and a broader range of health care facilities and services, including, nurses, midwives and physicians, are available in all areas. Particular emphasis should be given to ensuring access to health care in medically under-served areas including rural and low-income urban areas.

35 The Department of Health and Human Services through the Health Resource and Services Administration (HRSA) should be adequately funded and held responsible for ensuring the provision of health care to medically under-served communities, including by expanding community health care center programs, such as the Federally Qualified Health Center (FQHC) program.

36 The US Congress should authorize and fund a review of Medicaid provider payments for maternal health care. Where appropriate, Centers for Medicare and Medicaid Services should increase rates and ensure equity of reimbursement for different types of providers and facilities providing like services. The process for reimbursement should be streamlined.

37 The US Congress should direct the Department of Health and Human Services to develop national standardized evidence-based medical guidelines and protocols for maternal health care services. These should be developed in collaboration with the medical community, women's health organizations and other relevant stakeholders and should prioritize the five most common causes of maternal death.

38 The Department of Health and Human Services should take steps to meet Healthy People 2010 goals. This should include establishing clear national guidelines – in collaboration with the medical community, women's health organizations and other relevant stakeholders – for the appropriate use of medical interventions and procedures such as c-sections.

39 Steps should be taken to ensure the nationwide implementation of evidence-based protocols and guidelines for maternal health care services. Tracking mechanisms to determine whether protocols are implemented and whether evidence-based care is provided should be put in place.

40 Congress should direct the Department of Health and Human Services to prioritize the implementation of health information technology and provide the funding to facilitate this. Standard medical records should be used for maternal care to ease information sharing and documentation.

41 In order for hospitals or other facilities to pass accreditations, a "maternal audit" should follow all maternal deaths and should be used as an in-service training for all staff, including emergency room staff, administrative staff, nurses and doctors.

42 Health care providers should ensure that all women receive balanced and comprehensive information about risks and benefits of potential medical procedures so that they can make informed decisions. The Department of Health and Human Services – in collaboration with the medical community, women's health organizations and other relevant stakeholders – should develop a standardized approach to information provided and should require written documentation of the consent discussion. Decisions by women to choose a midwife or a physician as her maternity care provider should be respected.

43 The US government should direct the Department of Health and Human Services to initiate inclusive discussions about alternative and potentially more cost effective models of care for low-risk pregnancies that could help improve the availability, accessibility, acceptability and quality of maternal health care services in the USA. Federal and state governments should revise the current legal restrictions on appropriately trained and qualified midwives. Public and private insurance should include payment for services that women may choose through qualified midwives or birth centers.

ENSURE THAT ALL WOMEN RECEIVE ADEQUATE POST-NATAL CARE

44 The US Congress should direct the Department of Health and Human Services to develop and implement national standards for postpartum care, including:

a) Access to home visits for all women during the first weeks following birth;

b) Easily accessible reproductive health information and services, including on the health benefits for both women and babies of adequate spacing of pregnancies; and

c) Adequate screening for postpartum health issues, including depression, as well as appropriate referrals and treatment.

45 Public and private insurance should include coverage for adequate post-natal care for as long as needed, including home visits by a health care professional.

ENHANCE AND IMPROVE ACCOUNTABILITY

46 The US Congress should direct and provide funding for the Department of Health and Human Services to establish an Office of Maternal Health with a mandate to improve maternal health care and outcomes, and eliminate disparities. This office should be tasked with coordinating federal and state efforts and should report to the US Congress on an annual basis on progress made, including toward reducing maternal mortality rates to 4.3 per 100,000 births, in line with the Healthy People 2010 goal.

47 State and federal agencies should track, assess and publicly report on both maternal mortality and morbidity trends. Data collection and analysis should be improved to better identify and develop responses to maternal health issues, including those contributing to maternal deaths and complications. This will require action at both state and federal levels and should include:

a) Improved data collection on racial/ethnic disparities in access to maternal health care and health care;

b) Immediate reporting of all maternal deaths to the Centers for Disease Control and Prevention (CDC) and the introduction of a national surveillance system for maternal mortality;

c) Mandatory reporting of maternal deaths by all states to provide data for federal agencies, including the CDC, on a annual basis;

d) Standardized data collection tools. Each state should be required by federal law to use the US Standard Death Certificate, which contains five questions that help identify a deceased woman's pregnancy status during the year preceding her death. The states that have failed to add these questions to their death certificates should do so immediately.

e) National requirements to link all maternal death certificates with the associated birth certificate file to allow for more complete analysis of maternal deaths. The implementation of the US National Certificate of a Live Birth, which can provide more complete information on maternal health status during pregnancy and birth, should be standardized and funded.

f) Ensuring that only qualified health professionals with adequate training on how to complete death certificates, complete them in cases of maternal deaths.

g) Ensuring all efforts are made in cases of maternal death to establish cause of death, including conducting an autopsy. In order for hospitals or other facilities to pass accreditations, a "maternal audit" should follow all maternal deaths and should be used as in-service training for all staff.

h) Improved data collection and state and national reporting on maternal complications. This should include mandatory annual public reporting of state-wide and hospital level data on severe maternal complications, including postpartum complications; mandatory reporting of the number of maternity procedures performed at each hospital. In addition, the Department of Health and Human Services should ensure that maternal complications are analyzed and thelessons learned incorporated nto national-evidence based standards for maternal care.

48 The establishment of maternal mortality review committees in Washington DC and the 29 states that do not currently have these. Committees should receive ongoing funding in order to collect, analyze and review data on all pregnancy-related deaths in order to address disparities. Findings and recommendations should be made available to the public, while maintaining the confidentiality of the hospitals and individuals involved in any medical errors. Efforts at the state level should be coordinated nationally in order to identify and implement best practices.

FULLY RECOGNIZE THE HUMAN RIGHT TO HEALTH AND INTEGRATE A HUMAN RIGHTS PERSPECTIVE

49 The US government should ratify without delay the following international human rights treaties:

- the Convention on the Elimination of All Forms of Discrimination against Women; and
- the International Covenant on Economic, Social and Cultural Rights.

It should review maternal health care and the health system more generally on the basis of human rights standards, and develop action plans to implement treaty provisions.

50 The US government should include information on maternal health and entrenched disparities in maternal health outcomes in their reports to UN treaty bodies and should implement their recommendations.

APPENDICES

APPENDIX A – MATERNAL OUTCOMES AND ACCOUNTABILITY TABLE

APPENDIX B – MATERNAL HEALTH CARE TABLE

APPENDIX C – REPRODUCTIVE HEALTH CARE TABLE

APPENDIX D – US HEALTH CARE SYSTEM TABLE

APPENDIX A

MATERNAL OUTCOMES AND ACCOUNTABILITY TABLE

State	Maternal mortality ratio (per 100,000 live births)[A]	State maternal mortality ranking[B]	Does state meet Healthy People Goal of 4.3 deaths (per 100,000 live births)?	Does the state have:			
				Death certificate pregnancy checkbox[C]	Maternal Mortality Review Board[D]	Mandatory reporting of maternal deaths[E]	Cultural competency requirements for medical licensure+[F]
Alabama	9.6	25		•			
Alaska	5.0	7			•		
Arizona	7.2	13					+
Arkansas	14.6	44		•			
California	11.3	35		•	•		•
Colorado	11.0	31			•		
Connecticut	5.1	8		•			•
Delaware	13.6	42		•			
Florida	13.1	41		•	•	•	
Georgia	20.5	50		•			+
Hawaii	4.7	6		•			
Idaho	11.1	32		•			
Illinois	9.1	23		•	•	•	
Indiana	3.3	4	•	•	•		
Iowa	7.0	12		•	•		
Kansas	5.9	9		•			
Kentucky	8.8	22					+
Louisiana	15.9	46		•	•		
Maine	1.2	1	•		•		
Maryland	16.5	48		•	•		*
Massachusetts	2.7	3	•		•	•	
Michigan	13.6	42		•	•		
Minnesota	3.7	5	•	•			
Mississippi	15.2	45		•			

* State has legislation that “strongly recommends” cultural competency training.
+ State has bill pending.

State	Maternal mortality ratio (per 100,000 live births)[A]	State maternal mortality ranking[B]	Does state meet Healthy People Goal of 4.3 deaths (per 100,000 live births)?	Does the state have:			
				Death certificate pregnancy checkbox[C]	Maternal Mortality Review Board[D]	Mandatory reporting of maternal deaths[E]	Cultural competency requirements for medical licensure+[F]
Missouri	10.5	28		•	In development		
Montana	10.5	28		•			
Nebraska	12.6	40		•			
Nevada	10.4	26		•			
New Hampshire	10.4	26		•			
New Jersey	11.3	35		•	•		•
New Mexico	16.9	49		•			•
New York	16.0	47			•	•	+
North Carolina	11.4	37			•		
North Dakota	10.7	30		•			
Ohio	8.4	18		•			+
Oklahoma	12.3	39		•	•		
Oregon	6.2	10		•			
Pennsylvania	8.5	19		•		•	
Rhode Island	9.2	24		•			
South Carolina	11.1	32		•	In development		
South Dakota	6.2	10		•			
Tennessee	11.7	38					
Texas	8.6	20		•			
Utah	8.6	20		•	•		
Vermont	2.6	2	•	•			
Virginia	8.0	17		•	•		
Washington	7.5	15		•	•	•	•
West Virginia	11.2	34			•		
Wisconsin	7.2	13		•	•		
Wyoming	7.8	16		•			
District of Columbia	34.9	51		•			
Total			**5**	**41**	**21**	**6**	**5**

APPENDIX B

MATERNAL HEALTH CARE TABLE

State	State mandates employer plans to cover pregnancy care[H]	Medicaid eligibility levels for pregnant women in dollars (calculated based on a family of three)[I]	Presumptive eligibility for Medicaid for pregnant women[J]	Percentage of women with delayed or no pre-natal care[K]	Percentage of women of color with delayed or no pre-natal care[L]	State meets WHO recommended upper limit of 15% cesarean sections	Percentage of births by cesarean section[M]
Alabama	•(1)	24,352		16.3	26.8		33.8
Alaska		40,058		19.8	23.5		22.6
Arizona		27,465		23.5	31.6		26.2
Arkansas		36,620	•	18.9	26.9		34.8
California	•(1)	36,620	•	13.0	14.5		32.1
Colorado	•(2)	36,620	•	20.5	30.6		25.8
Connecticut		45,775	*	11.9	19.7		34.6
Delaware		36,620	•	14.4	20.0		32.1
Florida		33,874	•	16.1	21.2		37.2
Georgia	•(1)	36,620	•	15.8	21.9		32.0
Hawaii	•	38,961		17.3	18.5		26.4
Idaho	•(1)	24,352	•	18.9	29.3		24.0
Illinois	•(1)	36,620	•	14.7	21.4		30.3
Indiana		36,620	•	18.8	30.7		29.4
Iowa		54,930	•	11.3	20.7		29.4
Kansas		27,465		13.0	21.7		29.8
Kentucky		33,874	•	13.3	20.5		34.6
Louisiana		36,620	*	15.5	22.9		35.9
Maine		36,620	•	12.1	20.3		30.0
Maryland		45,775	*	16.6	24.2		33.1
Massachusetts	•	36,620	•	10.2	16.5		33.5
Michigan	•	33,874	•	14.1	23.4		30.4
Minnesota	•	50,353		13.9	27.9		26.2
Mississippi		33,874		15.6	22.7		36.2

(1) State mandate applies to Health Maintenance Organizations only.
(2) State mandate applies to groups of 15 or greater only.
* Five states do not have presumptive eligibility, but have other processes to expedite enrolment or provide temporary access to care for pregnant women.

	State mandates employer plans to cover pregnancy care[H]	Medicaid eligibility levels for pregnant women in dollars (calculated based on a family of three)[I]	Presumptive eligibility for Medicaid for pregnant women[J]	Percentage of women with delayed or no pre-natal care[K]	Percentage of women of color with delayed or no pre-natal care[L]	State meets WHO recommen-ded upper limit of 15% cesarean sections	Percentage of births by cesarean section[M]
Missouri		33,874	•	11.8	18.4		30.3
Montana	•	27,465	•	16.2	28.4		29.4
Nebraska		33,874	•	16.8	27.1		30.9
Nevada		33,874		24.4	31.9		33.1
New Hampshire	•	33,874	•	9.2	15.3		30.8
New Jersey	•	36,620	•	20.2	30.0		38.3
New Mexico		43,029	•	30.9	34.4		23.3
New York	•	36,620	•	15.0	19.1		33.7
North Carolina		33,874	•	15.7	24.8		30.7
North Dakota		24,352		13.6	25.5		28.4
Ohio		36,620	*	12.2	19.3		29.8
Oklahoma		33,874	•	22.4	30.6		33.6
Oregon	•	33,874		18.9	27.0		28.2
Pennsylvania		33,874	•	14.7	23.7		30.1
Rhode Island		45,775		9.8	12.9		32.2
South Carolina		33,874	*	20.3	29.5		33.4
South Dakota		24,352		22.0	40.2		26.6
Tennessee		45,775	•	16.6	27.0		33.3
Texas		33,874	•	18.9	22.8		33.7
Utah		24,352	•	20.1	36.1		22.2
Vermont	•	36,620		10.2	17.8		26.8
Virginia	•	36,620		14.6	22.4		33.5
Washington	•	33,874		17.1	23.0		29.0
West Virginia		27,465		14.1	23.5		35.2
Wisconsin		54,930	•	15.1	27.4		25.0
Wyoming		24,352	•	14.5	22.0		26.9
District of Columbia		54,930	•	23.2	27.9		32.6
Total	18		30			0	

APPENDIX C

REPRODUCTIVE HEALTH CARE TABLE

State	Unplanned pregnancy rate per 100 live births[N]	Has policy allowing providers and/or pharmacies to refuse to provide contraceptives and related services[O]	Has policy allowing institutions to bar providers from providing abortion services[P]	Requires insurance companies to cover prescription contraceptives if other prescriptions covered [+Q]	Has a waiver under Medicaid to provide expanded access to family planning services[R]
Alabama	N/A				•
Alaska	39.3		•		
Arizona	N/A		•	•	•
Arkansas	48.4	•	•	•	•
California	N/A		•	•	•
Colorado	37.3	•	•		
Connecticut	N/A		‡	•	
Delaware	47.1		•	•	•
Florida	N/A	•	•		•
Georgia	50.0	•	•	•	
Hawaii	47.1		•	•	
Idaho	N/A		•		
Illinois	42.9	•	•	•	•
Indiana	N/A		•		
Iowa	N/A		•	•	•
Kansas	N/A		•		
Kentucky	N/A		•		
Louisiana	N/A		•		•
Maine	36.9	•	•	•	
Maryland	43.4		•	•	•
Massachusetts	30.9	•	•	•	
Michigan	N/A		•	•†	•
Minnesota	36.3		•		•
Mississippi	N/A	•	•		•

‡ State allows individual providers (though not institutions) to refuse to provide abortion services.
+ State requires health insurance policies that cover prescription drugs to include prescription contraceptives.
† State has interpreted their state anti-discrimination law to require contraceptive coverage.

	Unplanned pregnancy rate per 100 live births*[N]	Has policy allowing providers and/or pharmacies to refuse to provide contraceptives and related services[O]	Has policy allowing institutions to bar providers from providing abortion services[P]	Requires insurance companies to cover prescription contraceptives if other prescriptions covered [+Q]	Has a waiver under Medicaid to provide expanded access to family planning services[R]
Missouri	46.3		●	●	●
Montana	N/A		●	●†	
Nebraska	39.8		●		
Nevada	N/A		●	●	
New Hampshire	N/A			●	
New Jersey	35.5	●	●	●	
New Mexico	N/A		●	●	●
New York	37.4		‡	●	●
North Carolina	39.8		●	●	●
North Dakota	N/A		●		
Ohio	44.9		●		
Oklahoma	48.0		●		●
Oregon	39.4		●	●	●
Pennsylvania	44.5		●		●
Rhode Island	37.8		‡	●	●
South Carolina	44.7		●		●
South Dakota	N/A	●	●		
Tennessee	N/A	●	●		
Texas	N/A		●		●
Utah	30.9		●		
Vermont	34.0			●	
Virginia	N/A		●		●
Washington	36.1	●	●	●	●
West Virginia	46.5			●	
Wisconsin	38.3		●	●†	●
Wyoming	44.5		●		●
District of Columbia	N/A				
Total		12	43	27	27

APPENDIX D

US HEALTH CARE SYSTEM TABLE

State	Total number of uninsured[S]	Percentage of women uninsured[T]	Percentage of women of color uninsured[U]	Percentage of women living in a medically under-served area[V]	Medicaid eligibility level for working parents in dollars (for a family of three)[W]	Medicaid covers interpretation services[X]
Alabama	555,100	18.1	22.9	55	4,392	
Alaska	128,00	19.8	27.1	50	18, 648	
Arizona	1,218,700	22.3	36.5	51	35,200	
Arkansas	477,700	23.3	31.0	34	3,060	
California	6,717,700	20.9	28.5	49	18,672	
Colorado	790,200	18.0	34.4	42	11,640	
Connecticut	334,200	12.1	21.4	50	33,636	
Delaware	95,000	12.6	19.7	50	21,240	
Florida	3,633,400	23.6	33.4	51	9,672	
Georgia	1,682,400	19.7	27.6	41	9,072	
Hawaii	97,000	10.1	9.9	50	20,244	•
Idaho	222,600	17.8	35.6	40	4,884	•
Illinois	1,668,800	15.7	25.5	48	32,556	
Indiana	744,600	15.6	26.5	34	4,536	
Iowa	279,300	11.5	23.1	34	15,204	
Kansas	337,900	13.9	24.9	36	5,916	•
Kentucky	626,000	17.0	26.3	36	10,908	
Louisiana	822,700	25.9	36.3	51	4,572	
Maine	126,000	10.6	17.0	47	36,276	•
Maryland	715,300	15.1	21.0	40	20,412	
Massachusetts	346,000	11.2	17.5	45	23,408	
Michigan	1,151,100	13.2	18.8	43	11,640	
Minnesota	438,500	8.7	20.6	41	48,400	•
Mississippi	532,000	20.9	28.5	46	8,064	

State	Total number of uninsured[S]	Percentage of women uninsured[T]	Percentage of women of color uninsured[U]	Percentage of women living in a medically under-served area[V]	Medicaid eligibility level for working parents in dollars (for a family of three)[W]	Medicaid covers interpretation services[X]
Missouri	734,100	15.8	26.9	49	4,584	
Montana	151,900	20.1	46.1	47	10,248	•
Nebraska	221,600	12.8	28.4	31	10,212	
Nevada	464,100	20.4	27.6	52	16,092	
New Hampshire	135,300	12.4	15.0	28	9,000	•
New Jersey	1,274,500	16.2	27.9	29	35,200	
New Mexico	452,800	25.6	32.1	61	12,228	
New York	2,619,600	15.1	21.2	40	26,400	
North Carolina	1,465,500	18.4	27.7	28	9,000	
North Dakota	67,800	10.4	34.6	40	10,848	
Ohio	1,315,300	12.2	20.0	38	15,840	
Oklahoma	564,700	24.0	33.6	47	8,532	
Oregon	626,200	20.1	35.8	43	17,600	
Pennsylvania	1,193,200	11.6	19.5	37	6,276	
Rhode Island	118,100	11.7	19.0	40	31,872	
South Carolina	714,000	19.1	21.8	51	15,864	
South Dakota	89,900	13.3	29.4	47	9,552	
Tennessee	907,100	14.7	24.1	38	23,628	
Texas	6,023,000	27.8	39.0	50	4,824	
Utah	352,000	18.4	38.2	52	11,928	•
Vermont	62,800	12.3	16.5	41	33,636	•
Virginia	1,048,700	14.7	23.8	22	5,352	•
Washington	772,500	13.9	19.9	51	13,488	•
West Virginia	262,300	20.1	22.4	44	35,200	
Wisconsin	493,000	10.8	21.5	45	5,988	
Wyoming	71,100	17.8	25.7	54	9,480	•
District of Columbia	57,200	11.5	14.0	50	36,396	•
Total	46,339,500					13

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