



Unaccountable

Addressing Reproductive Health Care Gaps

HUMAN
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Unaccountable: Addressing Reproductive Health Care Gaps

Summary

When a woman dies in childbirth, amid the shock is the haunting question of why? What went wrong? Sadly, in countries with the highest burden of maternal mortality and poor records on reproductive health care—countries such as India, Afghanistan, or Nigeria—these questions are rarely answered.

Answering the question of “what went wrong?” is important not only in addressing the inevitable grief of those left behind. It is critical to strengthening health systems and ensuring improvements in reproductive health services more generally. Investigating what went wrong is the first step toward accountability.

Accountability is a fundamental element of the right to the highest attainable standard of health. It entails addressing past grievances, monitoring progress, correcting health system failures to prevent future harm, and reducing disparities in access to health care.

Accountability is fundamental to the right to health.

Human Rights Watch has documented utter failures in accountability for the provision of reproductive health services around the world. This report draws on that research to illustrate accountability failings in two key areas: (1) the response to grievances and (2) establishing standards and monitoring health systems.

Response to Grievances

Hundreds of women and girls around the world have described to Human Rights Watch the pursuit of reproductive health care as an obstacle course. Logistical, cultural, and financial barriers to services and information, inadequate care, discrimination, and abusive health providers block the way to reproductive health.

Such obstacles, mistreatment, and discrimination are human rights abuses. They also constitute grievances that health system administrators and policy makers should solicit, assess, and respond to. Unfortunately, the barriers to lodging grievances and obtaining a remedy can be as insurmountable as the obstacles to seeking adequate health care.

Broad Range of Grievances

The abuses and grievances Human Rights Watch has documented span a wide array of reproductive health services.

In Mexico, for example, Human Rights Watch documented astonishing obstacles that women face in obtaining legal abortions after rape. Mexican women and girls made pregnant by rape described reporting the crime, then being passed from one public agency to another as each refused to authorize a legal abortion. Some prosecutors told women that they were going on vacation or were too busy, and the women would have to wait weeks for an answer. In some cases, authorization was delayed so long that it was no longer possible to terminate the pregnancy safely and legally. Several officials aggressively discouraged legal abortions, such as a social worker who talked a 12-year-old girl raped by her brother out of an abortion.

In India, where a little under a quarter of the world's maternal deaths occur, Human Rights Watch documented barriers to emergency obstetric care, poor referral practices, gaps in continuity of care, and bribes for health services. Access to maternal health services is particularly difficult for Dalit (so-called "untouchables") and tribal communities. The father of Kavita K., a woman who died from post-partum complications, told us they took Kavita from one government health facility to another, and none would admit her. After five days of seeking care, a hospital finally admitted her. They provided medical treatment for one hour before she died. Many other women and girls face a similar fate.

In Kenya, women living with obstetric fistula, a childbirth injury that results in constant leakage of urine or feces from the vagina,

described abusive treatment by health professionals. Several said nurses rebuked them for “urinating” on their beds and refused to change their bedding. Nyakiro C. told us that hospital staff asked her how an “old woman” like herself could wet the bed, told her to go to another hospital, and said they were “tired” of her. Kenyan women also described health care costs as an obstacle to care, and said that hospital staff withheld information on fee waivers.

In Ireland, Human Rights Watch documented active government efforts to deny women information about obtaining safe, legal abortions. Irish law tightly restricts what health providers can say about abortion, and the threat of criminal penalties effectively silences them. Moreover, the Irish government does not regulate private organizations that provide blatantly false information on abortions. The lack of accurate abortion information can result in delays, such as for Aoife C., who lived in rural Ireland and was unable to obtain information until she was almost 28 weeks pregnant. Claire A. visited an organization that held itself out as providing information on accessing abortion in England. This unregulated organization forced her to watch a video of ultrasound pictures, put a model of a fetus in her hand, told her to name the fetus, and asked how she would feel if she “killed the baby.”

In Argentina, even after the government enacted a law on sexual and reproductive health and issued guidelines on abortion and certain forms of contraception, access remains elusive. Women described to Human Rights Watch major hurdles to accessing oral contraception, and providers admitted flouting the law on tubal ligation (female sterilization) by requiring that married women’s husbands consent to the procedure.

Grievance mechanisms are out of reach for many, and complaints may trigger retribution.

Missing and Ineffective Grievance Mechanisms

Many governments have done far too little to establish functioning mechanisms to address health care grievances. They have neglected to inform patients of their rights and what to do when they are violated. Marginalized women, such as low-caste women, immigrants, and migrant domestic workers, often have little ability to assert grievances. Many women fear retaliation if they were to complain, and may indeed experience retribution.

In the United States, Human Rights Watch has documented the denial or delay of reproductive health services for women in immigration detention, including for life-threatening conditions, and ineffective complaint mechanisms. Some pregnant women have even died in US immigration detention. Although detention facilities are required to institute grievance systems, many women said they were never informed of the system or did not know it could apply to medical issues. Others feared retaliation if they complained. At one facility, women needed to ask the guards for the grievance form and return it directly to them, risking retribution if guards were implicated. Rose V. told us that after she and her lawyer complained about medical care, a senior officer told her, “I’m going to tell you right now, if your lawyers don’t stop it’s going to hurt your case. It’s going to make your judge mad; it’s going to make [Immigration and Customs Enforcement] mad... Call your lawyer.”

In India, although government health facilities should establish grievance redress mechanisms at the facility level, both health care providers and women patients in Uttar Pradesh state told Human Rights Watch they were unaware of such mechanisms. One woman told us, “We don’t know where to go and complain about anything.... We have no information about it.” Other women told us of submitting complaints, but being pressured by health professionals to withdraw them.

Marginalized and illiterate people face major hurdles to lodging grievances.

Governments have done little to ensure that illiterate women can submit grievances. Many illiterate women interviewed by Human Rights Watch in India said they could not use grievance options without support to file their complaints. Illiterate women we interviewed in Kenya said grievance mechanisms, such as suggestion boxes on health facility walls, were meaningless to them. Administrators in both countries admitted that suggestion boxes were rarely used.

Where individuals do successfully submit grievances, health authorities do not always conduct impartial, transparent, and efficient inquiries into specific complaints and how they may relate to broader system problems. Such inquiries are essential for building trust in grievance mechanisms and for rectifying problems.

Remedies Out of Reach

The end result of a grievance system should be a remedy, both for the person harmed and for the system. Of the hundreds of women interviewed by Human Rights Watch about health system problems, none received a remedy.

In Peru, Human Rights Watch interviewed women and girls who had experienced crisis pregnancies that could have killed them or seriously injured their health. Under Peru's laws, abortion should be legal in this circumstance. Yet women and girls who were clearly eligible were refused. Human Rights Watch found no indication that Peruvian health professionals who fail to provide legal abortions are held accountable or face disciplinary actions.

In one case in Peru, despite repeated efforts to obtain approval for a legal abortion, a girl pregnant with a fetus with anencephaly (a fatal disorder that results in an absence of a large part of the brain, skull, and scalp) was forced by hospital officials to continue the pregnancy, go through childbirth, and breastfeed for four days until the baby died. The girl's family ultimately made a complaint to the UN Human Rights Committee, which ordered Peru to compensate her and undertake policy reforms to ensure that similar violations do not recur. Peru has yet to fully comply.

Redressing grievances is central to avoiding discrimination.

In India, women told us that after they lodged complaints, no effort was made to investigate or provide a remedy. For example, Saroj S., a woman from a Dalit community, filed a complaint in 2008 about a failed sterilization surgery. When interviewed by Human Rights Watch a year later, she had not obtained any form of remedy. Another woman complained to district, state, and national authorities about inadequate post-natal care after delivering in a primary health facility. No remedy was provided, and in fact, a district health official tried to coerce the woman into stating in writing that she had not delivered in the facility.

Establishing Standards and Monitoring Health Systems

Many governments do not have sufficient standards and guidelines for core reproductive health services. Missing or unclear standards hamper efforts to monitor quality of care and whether it is reaching all who need it. Accountability is impossible without clear standards.

Remedies are needed for patients and the health system.

Health system monitoring helps governments better understand progress and failures, and can form the basis for effective public health strategies. Effective monitoring must include tracking health budgets and spending to avoid corruption. It must also include collecting and analyzing data, including through registration of births and deaths.

Standards and Guidelines

The existence of health standards and guidelines can drastically improve the realization of the right to health and are important for monitoring the adequacy of health services. In Mexico, for example, a handful of states have administrative guidelines on access to legal abortions. In those states, the guidelines have reassured public health and justice officials, enabling them to facilitate access to legal abortion without fearing sanctions. Unfortunately, the majority of Mexico's states have no such guidelines. There, confusion reigns. As a result, many officials are afraid to take action to facilitate access to legal abortion, and deny that they have any mandate to do so.

The existence of guidelines is not enough, of course, to guarantee implementation. After Nicaragua enacted a total ban on abortion, which carries prison sentences for women who seek and doctors who perform abortions under any circumstances, the government developed guidelines to mitigate some harmful effects of the ban, such as deterring live-saving emergency obstetric care. Human Rights Watch found that the government was not monitoring implementation nor sanctioning medical personnel who failed to comply with the guidelines.

Effective health system monitoring requires clear standards.

Monitoring Health Budgets and Spending

Increased global and national funding is unquestionably needed to tackle maternal mortality and meet reproductive health needs. However in some instances, funding is available, but is lost to corruption or left unspent. Mechanisms for tracking health budgets and spending are essential.

Human Rights Watch investigated corruption and mismanagement of health budgets in several states in Nigeria, a country with massive numbers of preventable maternal deaths. Since the 1990s, local government budgets rose dramatically in connection with higher oil income. Sadly, local leaders failed to direct the windfall to important obligations, including reproductive health care.

Much of the money that could have gone to health care in Nigeria was squandered or outright stolen. One local government chairman deposited government money into his private bank account. Another allocated money to a "fish pond" with neither water nor fish and a "football academy" that he never built. One governor budgeted tens of millions of dollars to a jet, fleets of new cars, foreign travel, and "gifts" and "souvenirs" to unspecified recipients.

This malfeasance was devastating. Human Rights Watch visited more than a dozen primary health care centers. All but a few lacked even a basic supply of medicines and other equipment and did not have access to a reliable supply of water, any toilets, or electricity. Some were housed in structures nearing the point of collapse. One local government health care coordinator said that his demoralized staff had given up, padlocking and abandoning their posts because their salaries were in arrears and they lacked the materials needed to do their jobs.

In some parts of India such as Uttar Pradesh state, the government has inexplicably left huge portions of its health budget unspent for years. According to a study for the Indian Planning Commission, 30 to 40 percent of the state's budget under the National Rural Health Mission, which is meant to improve the public health system and reduce maternal mortality, was left unspent between 2005 and 2008. Health advocates told Human Rights Watch that nearly

Health budgets must be tracked to avoid corruption and mismanagement.

US\$140 million of Uttar Pradesh's health budget remained unspent in the fiscal year 2008-2009. Recent national information by the highest government auditing authority shows that millions of dollars allocated to health were left unspent between 2005 and 2008, and the trend continues.

Data Collection

What is counted is often what counts. Collecting accurate data is critical for guiding health policies and programs. Although measuring maternal mortality and access to reproductive health care is difficult, innovative methodologies have been developed. For example, the United Nations has established key indicators for monitoring emergency obstetric care and has published guidelines for using them. In many countries, however, data collection on reproductive and maternal health has been neglected.

In India, even though official policy holds that data collection should cover the UN obstetric care process indicators, in practice many states do not take those indicators into account. Key information is missing, such as on whether the need for emergency obstetric care was met and the proportion of maternal deaths among women with obstetric complications admitted to facilities. Instead, the Indian government monitors progress on maternal health by looking at the number of childbirths in health facilities. The government's own data shows that these facilities are under-equipped, under-staffed, and cannot handle pregnancy complications. Human Rights Watch has documented cases where women have died in public health facilities or shortly after they are discharged. Merely looking at the number of institutional deliveries in poor-quality health settings will not provide accurate information on maternal health and needed health reforms.

Birth and death registration is neglected, confounding efforts to track maternal mortality.

The Irish government does not appear to collect data on the number of legal abortions carried out within Ireland, nor does it estimate the numbers of illegal abortions. There are no statistics about the numbers of women who cannot travel because they cannot afford to, do not have the necessary travel permissions, or lack information about services available outside Ireland.

In Kenya, although the government has made strides in collecting and disaggregating some health data, it does not routinely collect data on obstetric fistula.

Accurate and reliable systems to register births and deaths (civil registration systems) help to establish the health issues that governments will address. The failure of governments to address maternal mortality often begins with a failure to measure births and deaths and to estimate the size of the problem. Improving civil registration systems and ensuring that the millions of people who are born, and die, without any record are counted is essential for long-term monitoring of the progressive realization of the right to health and for determining public health policy, as well as for a myriad of other reasons such as reducing child marriage and safeguarding the rights of children.

In India, registration of births and deaths is mandatory, but it often does not happen. An estimated 26 million births and 9 million deaths occur in India every year, of which only 53 percent of births and 48 percent of deaths are registered. Some parts of India have "zero" birth and death registrations. Estimates of maternal deaths each year in India range from 60,000 to nearly 120,000, but without better civil registration and improved data collection systems, the actual numbers are impossible to know.

Recommendations

To Governments

- **Grievance mechanisms** : Health system grievance mechanisms should be accessible, including to marginalized communities and people with low literacy. Governments should conduct impartial, transparent, efficient inquiries into grievances, address the conduct of health workers as well as systemic problems, and provide remedies.
- **Monitoring and data collection** : Governments should monitor the provision of reproductive and maternal health care, including by using UN guidelines. They should improve data collection and civil registration systems, and release health data to the public. Data should be disaggregated to ensure

health care provision is nondiscriminatory and reaches marginalized communities.

- **Reproductive health guidelines** : Governments should develop guidelines on reproductive health services in consultation with civil society, and in line with international standards. They should ensure that the guidelines are understood and implemented by health care providers.
- **Budget tracking** : Government health budgets must be sufficiently detailed to allow tracking of reproductive health spending. Governments should establish independent anti-corruption units to uncover possible waste and fraud with health funds, and should make budget information available to the public.

To International Health Organizations and Donors

- **Grievance mechanisms** : Provide technical and financial assistance for governments to improve the quality and accessibility of health system grievance mechanisms. Support civil society organizations to promote patients' rights, to represent patients and persons excluded from care, and to advocate for accountable and responsive health facilities. Provide funding for health related legal services.
- **Monitoring and data collection** : Provide technical and financial assistance to ensure that governments monitor the provision of reproductive health care based on appropriate standards, and gather data needed to assess progress and make improvements. Ensure that monitoring and evaluation data is made public and shared with relevant communities.
- **Independent oversight** : Insist on independent oversight mechanisms to deter corruption and mismanagement of health care funds. Support civil society and journalists to engage in oversight.

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Answering the question of “what went wrong?” is important not only in addressing the inevitable grief of those left behind. It is critical to strengthening health systems and ensuring improvements in reproductive health services more generally. Investigating what went wrong is the first step toward accountability.

In interviews around the world, hundreds of women and girls have described to Human Rights Watch the pursuit of reproductive health care as an obstacle course. Logistical, cultural, and financial barriers to services and information, discrimination, and abusive health providers block the way. This report draws on those interviews to illustrate health system accountability failings in Asia, Latin America, Africa, the United States, and Europe.

Accountability is a fundamental element of the right to the highest attainable standard of health. It entails addressing past grievances, monitoring progress, correcting health system failures to prevent future harm, and reducing disparities in access to health care.

Leaders from around the world admit that they are not meeting their goals to reduce maternal mortality and improve reproductive health. Momentum is building for new approaches to tackling these issues. As plans are made, policy makers should put human rights, including the key element of accountability, at the heart of the response.

An 18-year old woman with her newborn baby at the Katsina General Hospital in Katsina, Nigeria.

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