

USING HUMAN RIGHTS IN THE AMDD PROGRAM: FROM ANALYSIS TO STRATEGY

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Behind every death in pregnancy and childbirth is a personal tragedy. That tragedy can be understood and approached in many different ways. It is a biological or medical event. It is a health system malfunction. Sometimes it is a family or community responsibility. When multiplied many, many times over – nearly once every minute – then it is also a social injustice of massive proportions. When framed by its social profile – when we acknowledge that 99% of maternal deaths happen in developing countries; when we recognize that in almost every country, including the United States, some groups (virtually always marginalized or disadvantaged groups) have exponentially higher mortality rates than others – then it is also a collective badge of shame.

We use these judgmental words – injustice, shame – because of one overwhelming fact about the 570,000 maternal deaths that happen each year: nearly all of them are avoidable. That fact -- the **avoidability** of these deaths – is why maternal mortality is also an issue of human rights.

By making human rights a core part of the AMDD program, we seek to connect **what we know** with **how we act**. This is the huge challenge that the AMDD program presents to each of us individually and to all of us collectively: **Given what we know about maternal mortality, do we have a moral, ethical and/or legal obligation to act on what we know?** I will return to this question in different ways throughout this paper, because, obviously, we all know different things about the situation that prevails in each of our specific localities and systems. But let me begin at the international level where we can pool decades of experience in places across the globe, and let me venture a few statements about what we know:

First, we know that even though most fatal obstetric complications can not be predicted or prevented, they can be treated with a few well-known technologies. These technologies make up the package that we call EmOC (emergency obstetric care).

Second, we know that simply having the technical answer for how to treat complications is not enough to save lives. Both the health services and the women who need them exist in political space. Many different forces – social, economic, cultural, political forces – have combined to prevent widespread implementation of EmOC and to prevent the conditions that will make universal access to it possible.

Third, we know that we need to cut through the thicket of interlocking forces in order to create a different politics of public health around the issue of maternal mortality. After all, **which of us believes that anything will change without a focused, energetic, inspired and broad-based movement to change it?**

How can we generate such a movement in each of our own circles of action, whether in clinics, in government, in NGOs, in international agencies, in communities or in universities? Equally important, how can we make sure that a movement to reduce maternal mortality pushes beyond the rhetorical? How can we make sure that we do not stall out with denunciations of injustice because we never manage to do the incredibly hard work of putting in place the services that will save women's lives?

I suggest that a starting point is a frame of mind, a stance on the world and on our work, that does two things at once. We need simultaneously to create and maintain a grand vision about the meaning and importance and ideals of our work, while still valuing and prioritizing the concrete, grounded, sometimes even plodding, steps of health programming. We need to expand and deepen our understanding of the ways in which large scale economic and social forces influence maternal mortality, yet not allow the complexity of our analysis to detract from the clarity and directness of our strategy. We need to **see** the big picture, but to **do** focused actions.

Human rights can offer some guidance in striking this balance.

Approaches to Human Rights

When we talk about human rights in the health field, we can make a rough distinction between two kinds of human rights work. The first, which I will address only very briefly in this paper, is the more familiar use of human rights as a system of formal law based on treaties and conventions and on various enforcement mechanisms that operate in the UN and at the national

level, primarily. Because countries sign and are bound by treaties, the formal law focuses on state actors.

The second kind of human rights work – the one I focus on here -- is a much more fluid and flexible exercise that draws on the evolving law of human rights and its underlying philosophy, in order to extract some key values and principles which we then use to shape programs and policy. This approach to human rights is not a punitive venture bent on hunting out and exposing violators. In that sense, it is quite different from the classic civil and political rights work on issues such as torture or unlawful imprisonment. Instead, our approach takes human rights as a conceptual system and uses it to re-characterize and guide what we do as health workers and how we do it.

Why should we choose human rights for this purpose? First, human rights is a set of international standards that has been negotiated and accepted by governments -- indeed by every country participating in the AMDD project – as binding upon them and in their countries.¹ If for no other reason than that formal commitment by governments, these standards are relevant to the AMDD program.

But many of us who work in the health and social development fields – and I include development work in the United States – believe that we cannot approach public health simply as technocrats tinkering with systems. We know that health is profoundly driven by the social and cultural contexts in which it exists, and that context ranges from the most intimate spaces of daily life to the macroeconomic policies of international financial institutions. In a world increasingly linked together, for better or for worse, by globalization, we need ways to speak and think and act on our shared (and our differing!) understandings about what human well-being is and how to achieve it.

The international human rights law that applies to states can help. But the whole human rights endeavor – with human dignity as its core value -- is also meant to inspire profound and fundamental change in the most everyday interactions of life. Of course, such change does not happen by blueprint or by edict. It does not happen by trampling blindly over dearly-held beliefs and values. It must happen through a kind of locally-sensitive but still daring venture -- one that requires creativity and a feel for the unique dynamics of the places where each of us lives and works, as we strive to bring about real and lasting change.

¹ Of the treaties containing provisions most directly relevant to maternal mortality, every AMDD country has ratified the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and the Convention on the Rights of the Child (CRC). Virtually every AMDD country has ratified the International Covenant on Economic, Social and Cultural Rights. The glaring exception is the United States which, to its shame, has signed but still failed to ratify any of these three treaties.

In this room, meeting as a Program, we need to put together the words “daring” and “change”, and to speak them out loud. It is precisely the role of human rights to identify the workings of power that keep unacceptable things as they are, and to challenge that power with a different vision of human well-being. The challenge does not have to be confrontational or angry; it can proceed softly, through dialogue and consensus. But it will always be daring because it requires us to dare to imagine a different reality, and to have the courage to call, each in his or her own voice and with his or her own means, for the re-arrangements of power necessary to change the unacceptable.

So in the AMDD program we need ourselves to begin with the consensus that death in pregnancy and childbirth is unacceptable. Maternal mortality is not just a “natural” phenomenon that randomly strikes out at pregnant women. Of course, it does have biological dimensions. But when we look more deeply, when we see the patterns of maternal mortality both within and across countries, then we must acknowledge that death in pregnancy and childbirth is amenable to change. Its defeat lies within the human grasp.

Still, is death in pregnancy and childbirth really any different from the millions of other deaths that happen each year? After all, we are not immortal. We all will die sometime and often in circumstances that seem agonizingly unfair. Here is where the “big picture” looms so large. When we begin to paint that picture, to give it detail and shadings, depth and perspective, we confront a deprivation of human dignity so profound that it really is death of a different order. It is not simply that women’s lives and health are devalued; it is the intersection of such gender discrimination with imbalances of power by race/ethnicity, class and age, within households, across societies, and between countries, that shape the patterns of maternal mortality.

The specifics are all too familiar: For example, there are factors that put some women at risk to start with, including unwanted pregnancy because of lack of access to contraception (a human rights violation) or because of violent, forced intercourse (also a human rights violation). Unsafe abortions, presumably stemming from unwanted pregnancies, account for as much as a third of maternal deaths in some parts of the world. Once a woman is pregnant, physiological factors such as a small pelvis increase individual risk of obstetric complications. These factors can also have social origins such as discriminatory feeding practices or child marriage and very early pregnancies.

Once complications start, the road to maternal death is defined by barriers that block a woman in labor from the care that could save her life. Using the three-delays model, danger begins with delay in the decision to seek care. That delay can be exacerbated by the absence

of information about when and where to run for care, by gender and generational power dynamics in the family, by the low status of women generally, and by poverty – all human rights issues. The second delay is in getting to the appropriate facility. That delay is shaped by infrastructural deficiencies – the scarcity of functioning health facilities; poor communications services, roads and transport – all of which can be re-framed as human rights issues. The third delay is in receiving care at the facility. Again we can identify a whole range of rights-related problems from the dismissive attitude of some providers, to a massively unfair international economic system that puts essential drugs and life saving equipment beyond the financial means of hospitals.

The upshot is that pregnant women are dying at the rate of one per minute. When the answer to death on this scale lies within our grasp, then we have an obligation, as individuals, as health professionals, as societies, as governments, and as an international community. What is the content of that obligation?

To show how human rights can answer that question, I need to back up briefly to lay a very basic foundation. From the “big picture,” the paper will then move to focused actions and demonstrate some specific ways that human rights can be used in AMDD projects.

A. Basic Principles and Values of a Human Rights Approach

Human rights as a system of legal and ethical principles builds from the basic notion of universality articulated in the Universal Declaration of Human Rights adopted by the UN General Assembly in 1948:

“All human beings are born free and equal in dignity and rights.” (Art.1)

“Everyone is entitled to all the rights and freedoms . . . without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.” (Art. 2)

In essence, every person – every woman, man and child – simply by virtue of being human is entitled to be treated with dignity.

What are the fundamental attributes of a life of dignity? The human rights system answers that question with principles about both the end result and the process or conduct needed to get to that result – i.e., human dignity is not only about material well-being (e.g., adequate food, shelter, health); it is also about the ways in which we interact in society. When it comes to civil and political rights, this is an obvious point, since clearly human rights concerns procedural, interactional issues such as fair trials, or rights concerning voting, assembly and

speech. But, significantly, questions of process and interaction are also deemed to be critical attributes of social and economic rights such as the right to health. Thus dignity in health is not *only* a question of being free from avoidable disease – though it is certainly is that. Dignity is also a function of the way in which individuals, communities, whole societies engage in the process of obtaining and maintaining a standard of health.

As health professionals, we all know that the health of a population is not a “one-off” deal: either you have it or you don’t. Rather public health is a perpetual process, a dynamic, ongoing, moving set of relationships. In short, matters such as systems of accountability or community participation, issues such as the treatment of patients and staff within health facilities, are not just instrumental tools for getting once to an end goal of good health. They are integral elements of securing human dignity in health in a sustainable way, generation after generation.

B. Applying human rights principles to maternal mortality

The complex web of causality sketched out by the “big picture” sometimes threatens to overwhelm us. How can we break through this level of analysis and use human rights to get to meaningful, focused strategies as well? We need to shift our thinking about human rights from the descriptive mode, in which human rights helps paint the “big picture,” to the action mode, in which evolving human rights practice is meant to assist states in moving expeditiously toward fulfillment of the substantive right. In that mode, human rights functions almost as a health planning tool, drawing on many other health-related disciplines such as epidemiology, medicine, and operations research. Human rights sets the standard against which to evaluate actions; health disciplines supply the technical rationale for applying the standard.

(1) Taking “appropriate measures” toward “progressive realization” of the right to health

First, human rights addresses the overall direction of policy. The right to health is articulated most broadly in the International Covenant on Economic, Social and Cultural Rights (Article 12): every person has “the right to the highest attainable standard of physical and mental health”. The scope and meaning of the right has been elaborated by the Committee that oversees compliance with the Covenant, in a General Comment adopted in May 2000.² In that document, the Committee makes clear that the right to health *must not be understood as a right to be healthy*. Recognizing that a person’s health is a function of biological factors, lifestyle

² General Comment 14. E/C.12/2000/4, CESCR.

choices, as well as social structural context, the Committee states that the right to health encompasses both freedoms and entitlements. (¶18). Freedoms include the right to control one's health and body and to be free from certain interferences, such as torture. Entitlements include both access to health care and enjoyment of the broad range of conditions that make good health possible.

It would be naïve, even ridiculous, to suppose that the full scope of this right can be met simply by signing a treaty and willing it to be so. Thus the standard of compliance relates to the *direction* of policy implementation and pace of change. The human rights standard articulated in the treaties is that states must take “appropriate measures” toward the “progressive realization” of the right, and must do so to the “maximum of available resources.” (Art. 2) In other words, it is not enough simply to say, “We publicly recognize this issue –surviving pregnancy and childbirth -- as a human right” and then hope for the best when it comes time to count the deaths and report on progress. Rather, once an issue is recognized as a human right, there is a legal obligation to take steps that are “deliberate, concrete and targeted” toward realization of the right.³

When it comes to applying this standard to maternal mortality, we know from health research and experience that **not all interventions are equal**. All pregnant women may want to have a smooth delivery in the hands of a caring attendant; but training TBAs will *not* save the life of a woman with a potentially fatal complication.⁴ Similarly, all people have the right to adequate nutrition and anemia is certainly an important women's health issue. But a major hemorrhage, untreated, will kill any woman, anemic or not.

In short, if the human right in question is the right not to die an avoidable death in pregnancy and childbirth, then the first line of appropriate measures that will move progressively toward the realization of the right, is the implementation of EmOC. In a human rights analysis, EmOC is not just a good idea, one among many. It is an obligation.

Recognizing the challenge that even the most well-intentioned and committed governments face in organizing and implementing effective health policy, the Committee in its general comment on the right to health has actually articulated a subsidiary “right to health indicators and benchmarks by which progress can be closely monitored.” (¶43(6)). If EmOC is the first line of “progressive realization” of the right to health as it relates to maternal mortality,

³ General Comment 14, ¶30.

⁴ See E.A. Goodburn et al (2001) “Training traditional birth attendants in clean delivery does not prevent postpartum infection,” *Health Policy and Planning* 15(4):394-399; J.B. Smith (2001) “The impact of traditional birth attendant training on delivery complications in Ghana,” *Health Policy and Planning* 15(3): 326-331; D. Maine (1991) *Safe Motherhood Programs: Issues and Options*

then we have a way to monitor progress. The WHO/UNICEF/UNFPA process indicators⁵, developed as public health indicators, can be used as human rights indicators as well. They enable us to mobilize our resources and track our efforts to ensure that what we do is prioritized by what we know, that the steps we take first are those most essential to saving women who experience the complications that kill.⁶

(2) Using Human Rights Principles in AMDD Programming

Within the overall frame set by the obligation to prioritize the actions most essential to saving lives, human rights can be incorporated into maternal mortality programs in a variety of ways. One is the use of formal legal mechanisms, both at the international level in the UN system and also in domestic legal systems. Although this is certainly part of the AMDD strategy at the international level and in some countries, I will not address those mechanisms in detail here. Instead I will give a few examples of how human rights can shape specific activities of the kind that all the AMDD projects are doing now. These examples are chosen to make the bigger point that human rights work happens at multiple levels. It works at the individual level where it speaks to the ways in which individual people – patients and providers – are treated. It works at the institutional level where community participation and the dynamics of accountability can help the health facility to function better. Human rights also works at the larger systemic level, for example by addressing the impact of international actors and global forces.

(a) Human rights in the clinical setting

Analysis of human rights issues within the clinic has been developed most fully in the context of family planning services. When notions of human dignity, freedom and entitlements are applied to family planning, the first principles that emerge are the right to full information and the freedom to choose appropriate contraceptive methods. When it comes to treating emergencies, such as a woman who arrives at a hospital close to death, we need to think differently. The first principle has to be access to the services that will save her life.

We can think about the applicability of rights in layers. At the most general layer, the vindication of human rights means 24-hour readiness: availability of the necessary human resources, equipment and drugs, and the ability to mobilize these on an urgent basis. But human rights has more to say about how those services are delivered. In the context of EmOC, two key human rights values are human dignity and non-discrimination. It is perhaps obvious

⁵ *Guidelines for Monitoring the Availability and Use of Obstetric Services* (2d. ed. 1997)

that these values apply first and foremost to patients, and then to their families, since the whole purpose of the hospital is to provide health services to them. Yet, an obvious, but often overlooked point, is that the staff in a hospital are people too. We can hardly expect each of them to treat patients and their families with dignity and respect, if they themselves are not so treated. Thus human rights values are relevant to all the human interactions that happen in a facility.

What does it actually mean to apply these values in the clinical setting? First, of course, in each setting we need to be clear about what the attributes of dignity are. For example, privacy and respect will certainly be an important part of dignity everywhere, but what actions are experienced as a violation of privacy may differ somewhat from place to place. Once the relevant values are clarified they can be incorporated into different exercises that AMDD projects are already doing.

We can think of this as a kind of human rights audit of hospital policies, procedures and facilities. For example, some projects are looking at hospital design and building renovation. Generally technical matters such as waste disposal, lighting, location of sinks will be examined with medical considerations (such as infection control), financial considerations and sustainability/maintenance in mind. But in working through design and renovation plans, we also need to consider how the physical arrangements affect patients and providers in terms of other aspects of their well-being as well. Are there well-located toilets for women staff and patients? What measures have been taken to ensure privacy?

The same exercise can be done with the review of various hospital policies and procedures – from human resource policies, to patient flow analysis. Some of the teams have done room-to-room exercises, tracing each step in the movement of a patient from the time she arrives at the hospital gates until she leaves the facility, to ensure that every stage and every room is fully geared to deliver timely and appropriate care. A similar room-to-room walk-through could be done with human rights: considering the need to respect the dignity (as defined in more detail through previous exercises) of patients and their families, where are the points in the process at which these values are violated or threatened, or could be affirmatively promoted? The solutions may not cost a penny. It may simply be a question of *seeing* the problem, because we are explicitly *looking for it*.

This kind of human rights audit of hospital policies, procedures and facilities can obviously be done in many different ways, creatively engaging different groups of stakeholders.

⁶ A. E. Yamin and D. Maine (1999), “Maternal Mortality as a Human Rights Issue: Measuring Compliance with International Treaty Obligations,” *Human Rights Quarterly* 21:563-607.

There is another conceptually separate way in which we need to think about human rights values in the clinic setting. In many places promoting human rights means making fundamental changes in the interactions between people – easy to say, but fraught with difficult questions about power, rank and (professional, class, and social) hierarchy. We need to be clear that we can not simply have a training session and give a lecture telling hospital staff to be nice and to care about patients. In fact, we are talking about re-arrangements of power, something that can be threatening to those who choose to perceive it as a power loss, and also extremely risky for those who experience it as a power gain. Unless we acknowledge and take steps to deal with this fact, we have only scratched the surface.

So how do we actually get at these issues? There is not one answer. The methodology obviously requires an understanding of local context, of the social and cultural dynamics at play in a health facility. Different AMDD projects are using different strategies, from Appreciative Inquiry in South Asia to explicit human rights training modules in Peru, to adaptations of the COPE methodology developed by AVSC. There is plenty of room left for experimentation and innovation.

(b) Non-discrimination

Non-discrimination as a human rights value is obviously relevant to treatment of patients, their families, and providers, in the clinic. But what about the women who develop life-threatening complications and never get to the hospital at all? Are there groups of women, defined by some socially, culturally or politically-charged characteristic such as race, class, or religion who are never getting to the facility?

To answer the question obviously requires knowledge about the composition of the population in the catchment area and about who *does* come to the facility. In some settings, this can be a tricky documentation problem, since even asking people their religion or ethnicity can sometimes be a threatening act.

Nevertheless, it will be important in all AMDD projects to be attuned to this question. If there are groups not using the facility, why not and where, if anywhere, are they going? What are the barriers that prevent them from using the facility? How can such barriers be addressed and the health facility change to serve the entire population.

(c) Community Participation/Stakeholder Groups

Since at least the Alma Ata Declaration on Primary Health Care in 1978, it has been an internationally recognized principle that “the people have the right and duty to participate

individually and collectively in the planning and implementation of their health care.”⁷ The right to participate in health-related policy making at the community, national and international levels is now quite explicitly an integral part of the right to health as interpreted in the formal human rights law.⁸

In translating this right into actual programming in the AMDD projects, our first focus has been on participation at the facility level where EmOC is delivered or, in some places, at the district level where key policies and decisions related to EmOC facilities are made. There is no template for how to do community participation. In many countries there are already in place hospital management boards or other formal structures linked to hospitals which are designed to involve community representatives. In other places, there exist civil society structures at the district level – perhaps elected bodies such as district councils -- which can be engaged in issues of local health policy or hospital management. In still other countries, AMDD projects are forming stakeholder groups to serve as a participation mechanism.

Imagining a structure for community participation is fairly easy; developing meaningful engagement with a community and a process that is truly participatory can be enormously difficult. There are numerous questions to be addressed: who are the different groups of stakeholders and how should “representatives” be chosen? Who from a facility or from local government should be involved? How often should they meet and at whose initiative? What issues do they address and with what level of decisionmaking power? How does this group relate to other political structures and power dynamics in the community? The list could go on and on.

The answers to these questions must be considered with reference to the purpose. In a human rights analysis, such stakeholder groups are not meant to be public relations arms of the hospital or a conduit for a facility to communicate its views and wishes to the community. Rather the key dynamic must be *entitlement and accountability*. This does not necessarily imply an adversarial sort of complaint and punishment mechanism. Ideally, by encouraging a community to feel ownership and responsibility for a facility, and by encouraging a facility to view its first line of accountability as being to the community it serves, the result will be *sustained* high quality, responsive, rights-sensitive services. Moreover, in the community-facility relationship that develops there is ideally a strong alliance that can effectively assert its entitlements and needs to the higher reaches of government where key decisions are made

⁷ *Declaration of Alma Ata*, International Conference on Primary Health Care, Alma Ata, USSR, 6-12 September 1978, WHO, Geneva (paragraph IV).

⁸ General Comment 14, ¶11

and, when services are in place, can help insure that there is knowledge, information and the means for access within the broader community.

(d) Health Sector Policy making

Perhaps the least developed area of human rights work in health relates the large scale social and economic forces – e.g., structural adjustment programs, health sector reform strategies, often negotiated with or imposed by international actors -- that in some countries are devastating whole health systems and having profound effects on the health of the population as well. A full analysis of the trends in macroeconomic policy, its effect on health and health services, and the role of human rights in addressing it, is well beyond the scope of this paper. But we need to acknowledge that these policies have an impact on the ability of governments to provide sustainable services and on the ability of people to access even the services that do exist. As such it is quite clearly a human rights issue for the AMDD projects in the districts where they are working and at the national level. It is a human rights issue for AMDD as a global initiative interacting with donors and policymakers at the international level. And it is most certainly also a human rights issue for those of us who are citizens of countries such as the United States with greatest influence over such policies.

For purposes of this workshop where the emphasis is on policy making at the facility level where EmOC is delivered, we can focus on a few specific manifestations of the larger forces. As just one example, it is now more than a decade since people associated with this Program began to call attention to the impact that the imposition of user fees was having on patterns of maternal death and hospital use.⁹ Little has changed internationally; indeed, things may have become worse.

If access to the care that will save a woman's life is a human right, then that right must trump the administrative imperatives that would allow a user fee to turn her away at the hospital door. The principle is easy to state – indeed, the Economic and Social rights Committee has clearly stated it and even called for its application to international financial institutions¹⁰. But the implementation of social safety net policies, for example, has proved much harder. If such matters are treated as simply one more administrative task, there is little hope for change. If, on the other hand, they are seen as important questions of fundamental human rights for which facilities will be held accountable, then perhaps there is the possibility of change.

⁹ C. Ekwempu et al. (1990) "Structural Adjustment and Health in Africa," *The Lancet* 336(7):56-57.

¹⁰ General Comment 14 ¶64.

Moving Beyond EmOC

Our focus at this stage in AMDD is on ensuring the high quality EmOC services are available and accessible to all women who need them. As these services come into place and the programs move out beyond the facilities into communities and households and into the higher levels of policy, the human rights issues will take on additional layers of complexity and challenge.

When it comes to these arenas, we certainly are not alone as human rights advocates. In women's movements in every part of the world, these have long been the core issues. If AMDD projects, with their grounded understanding and powerful vision of health services, can ultimately link with advocacy groups, women's groups, and other community-based movements, then together we really can be a formidable force for change.