#### Whose Voice Really Counts? Experiences of Trying to Build 'Voice' for Health Accountability in Uttar Pradesh, India

#### Jashodhara Dasgupta

#### Background

This chapter reflects on a decade of working on maternal health issues in Uttar Pradesh (UP), the largest state in northern India. The state has a population of above 200 million, and would be the seventh largest country of the world; it is also the state with the most political clout, sending 15 percent of MPs to national parliament. Paradoxically, the state enjoys the dubious distinction of being sixth from the bottom of the Human Development Index in India and health related indices (NHDR 2001), a situation that has continued for the last few decades, despite having a woman leader of a *Dalit'*-focused party as Chief Minister three times. If we look at indicators around maternal health, UP has the highest number of maternal deaths in the country<sup>2</sup> (Government of India, 2011), and possibly contributes significantly to the global burden of maternal mortality. Unsurprisingly in the light of these figures, women's access to skilled care in pregnancy is also low in UP, and the state health system has not been able to make life-saving services available to all (NFHS 2005–06; IIPS and Macro International 2007).

I have been working on women's reproductive health and rights in UP since 1992, through a non-governmental organization (NGO) called SAHAYOG. SAHAYOG was set up as an NGO in 1992 by a group of social workers, including a medical doctor and myself. It began working on comprehensive women's health with rural communities in mountain villages of one district of UP<sup>3</sup> and gradually strengthened its role as a 'support organization' that conducted capacity building programmes for NGOs and government workers. Following the International

Conference on Population and Development (ICPD) in 1994, SAHAYOG sharpened its work to focus on women's human rights, including reproductive health and rights, and began anchoring a civil society advocacy platform called the Healthwatch UP-Bihar.<sup>4</sup> Currently, SAHAYOG works with the mission of promoting women's health and gender equality using human rights frameworks. In partnership with various civil society networks, community-based organizations and a few shared platforms with the government, SAHAYOG supports capacity building and generating evidence that is used for advocacy. The scope of SAHAYOG's work extends from the district level to the global arena.

This chapter is an examination of the efforts of SAHAYOG and its partner organizations over the last decade or so (2000-2012) during which there was an attempt to make a difference to the overall apathy towards preventable maternal mortality and morbidity in Uttar Pradesh. The chapter describes these attempts and, using a gender interpretation of Foucault's 'governmentalities', tries to unravel how the governmentalities of international development expertise, the state and civil society defined SAHAYOG's positions. The chapter draws on ideas about the nature of civil and political society (Chatterjee 2006) and how these relate to the decisions SAHAYOG and its allies made, the strategies they used, and how these played out in influencing responses to women's health rights claims. It analyses the significance of the role of 'civil' society, and its contribution to developing oppositional forums that may subsequently translate into forms of 'political society' that can negotiate rights claims.

#### The problem of maternal mortality reduction in India

Maternal mortality in India is a significant global issue since the country has a disproportionate share of global maternal deaths (WHO 2010), and this despite its international reputation for medical care and world-class health facilities. The former UN Special Rapporteur on the Right to Health in his 2007 Mission Report on India said that maternal mortality in India was comparably 'higher than in many other middle income and low income countries'. (Human Rights Council 2010)

In 1997, with international support,<sup>5</sup> the Government of India announced the ambitious Reproductive and Child Health Programme (RCH-Phase One 1997–2004) which promised, along with other reproductive health services, improved maternal health care via a comprehensive care package and a plan to train traditional birth attendants. But putting maternal care services in place effectively is easier said than done: data from recent national surveys in India indicate that the quality of services available for maternal health in rural health centres is not yet adequate for either routine or emergency maternal care (IIPS 2010). Despite overall progress in reducing the maternal death rates in several states of India,<sup>6</sup> slow progress in some states has stalled the graph for the country as a whole.<sup>7</sup> Lingam and Yelamanchili (2011) analyse national data to find that negative pregnancy and maternal outcomes are higher among women from the scheduled castes and tribes, poor and younger mothers, reiterating the multiple ways in which the disadvantaged women are at risk, and exposing social exclusion as a key determinant of maternal mortality (UNICEF 2008)

#### The global focus on maternal mortality and India's response

Globally the issue of maternal mortality was part of various international agreements and treaties that India was party to, such as the Alma Ata declaration (1978), the CEDAW treaty (1979), the ICPD Platform of Action (1994), and the Beijing Declaration (1995), among others. Global development goals in the decade preceding the new millennium were clearly aspirational, with a strong focus on the notion of 'rights', but these faced a crisis as we entered the new millennium. The final global consensus that emerged, the Millennium Development Goals (MDGs), was a disappointingly minimal set of pragmatic targets. Although the MDGs referred to women's development and empowerment, in practice they erased 'rights' talk and thereby eroded the identity of woman as subject-citizen with rights – the identity that feminists had long fought to

stabilize in international treatises, conventions and policy. Feminists have identified a strong role of the Bretton Woods institutions (as against the UN) in this eroding of rights: Ortega points out that it was not just that women's movement activists were left out. Instead 'the global agenda, covering issues that ranged from population and sustainable development to human rights and gender, was taken over by the World Bank and the International Monetary Fund... In the new scenario, public policy was transformed into services for 'consumers' or 'clients' as opposed to policies for citizens...' (Ortega 2011: 35–41)

Thus although maternal mortality reduction gained some prominence and was retained in the global agenda, it led to a new form of vertical programming in reproductive health, and was not articulated from the standpoint of the women's health movement that had earlier strongly influenced the inclusion of comprehensive reproductive and sexual health and rights at Cairo and Beijing.<sup>8</sup> Instead, the technical expertise of obstetricians and public health researchers was sought to define the problem of maternal mortality. The complex chain of causes leading to the death of women in maternity got narrowed down and defined by the technical experts as a problem of women not having trained health professionals to oversee the delivery and, therefore a simplified indicator was sought that would measure progress, which would be to track 'increased skilled attendance at childbirth'.<sup>9</sup>

The global emphasis was important for India, as the new Prime Minister attended the Millennium Review Summit in September 2005, and was embarrassed to see India at the bottom of the heap, so to speak. A major health sector reform was in progress called the National Rural Health Mission (the NRHM, launched in April 2005), within which the maternal mortality reduction programme was given great emphasis (called JSY for *Janani Suraksha Yojana*, meaning Mothers' Protection Scheme). The problem was diagnosed as that of poor women failing to access 'skilled attendance at childbirth' by reaching health facilities during labour. The policy

solution was to motivate poor women through a Conditional Cash Transfer programme towards a goal of '100 per cent institutional deliveries'. The assumptions here, drawing upon international public health expertise, were that it was only in health facilities that 'skilled attendance' could be made available, and that this 'skilled attendance' would definitely save the lives of any women who were at risk, thus reducing maternal mortality. Significant budget allocations were made, that drew again upon international expertise in development economics in designing a 'demandside stimulus'. The health impact of the intervention would now be measured simply by counting how many women were given the JSY cash transfer, equating these with institutional, and therefore safe, deliveries.

Somehow in the urge to measure up to the very narrow MDG indicator, policy attention was deflected away from the original goal of reducing maternal mortality, and what else was required to reach it. The inconvenient truths about the health system in most of India that had already emerged in recent large scale surveys were brushed under the carpet: that roughly 25 million births occur each year; that there are not enough doctors in rural health centres; that nurses are not skilled in childbirth care or in managing complications; there are not enough medicines and equipment; and that health centres are not accessible for a significant proportion of the population (IIPS 2010, Dasgupta et al, 2010). The inflexible policy solution also ignored the absence of the enabling conditions in many corners of the country where there are inadequate roads or public transportation facilities, where people live in remote coastal or riverine areas, or deep within forests, deserts or mountain ranges.

There was a deafening silence in the JSY scheme about the reality of millions of women undergoing childbirth at home. No role was assigned to the community based/traditional birth attendants (CB/TBAs) and there was no attempt to build their capacities in making childbirth safer for women who could not, for whatever reason, access a hospital. This was a turn-around

from earlier government training programmes for building skills among CB/TBAs, and was fuelled by the recent international disapproval of these community-based providers, who were now not considered fit to provide skilled attendance at birth. Thus for women in urban slums, poor hamlets, remote villages not connected by roads, there was no alternative: either they had to reach a hospital somehow, or give birth without a trained attendant.

The conditional cash transfer scheme for hospital childbirth did not anticipate that facilities would get over-crowded and the inadequate numbers of poorly skilled and equipped staff would send back home women perceived as coming 'too early' or refer them out if there was the slightest perceived complication.<sup>10</sup> This single-point intervention also ignored the fact that childbirth is not the only 'high-risk' stage in maternity; a miscarriage during pregnancy (or a botched abortion) could also develop complications, and many women die *after* childbirth of bleeding and infections. There was no consideration of widespread malnutrition and anaemia among women of reproductive age, or for high incidences of infectious diseases that contribute substantially to maternal mortality. The complex nature of the problem, deriving from the already fragile state of poor women's health where even the smallest health crisis could be the tipping point, was carefully ignored. (Subha Sri 2012, Banerjee et al 2013)

#### Evolving Strategies: SAHAYOG's Efforts on Maternal Mortality

SAHAYOG began working on maternal health right from the early days of community work in 1994, using a comprehensive approach to women's health. In addition to community-based awareness-raising, SAHAYOG also conducted small research studies, including one in 1999 on the local communities' vulnerability to HIV infections since the area had high male outmigration. In early 2000, SAHAYOG leaders and activists were suddenly arrested, denied bail and imprisoned, including being charged under a national security law, ostensibly because the

research report was obscene and offended local sentiments. Many human rights and sexual rights groups and feminist organizations protested against this, campaigning continuously for over a month, and appealed in the higher court, which led to the activists being released on bail six weeks later. This experience of having all our civil rights suspended shaped SAHAYOG's broader understanding of rights violations, and we clearly perceived state complicity with powerful forces in failing to uphold our constitutional guarantees. Concurrently, the support from feminist and sexual/human rights groups strengthened SAHAYOG's future engagement with gender and rights, sexual and reproductive rights, as well as the local application of human rights frameworks.

Between 2001 and 2012, SAHAYOG worked in close alliance with other civil society organizations, notably Healthwatch Forum UP (HF). Initially this alliance included women's rights organizations, but later changed to mostly community-based organizations working in different districts of Uttar Pradesh with the rural poor. During this time SAHAYOG built up a profile as a feminist organization, questioning state policies that violated women's rights and failed to translate into an improved quality of life for the poor: basically an 'oppositional' form of civil society. Despite being a formally registered organization that received funding to carry out development activities, SAHAYOG adapted several strategies of social movements and allied with them in order to realize its mission. In this way, SAHAYOG carved out an identity distinct from most development organizations working on health within the broader umbrella of 'civil society' – in India, 'civil society' can encompass grassroots community groups, faith-based groups, voluntary organizations headed by social activists or professionals, international organizations, providers' associations, quasi-government institutions and corporate social responsibility entities.

The following paragraphs trace the journey of SAHAYOG's comprehension of the problem of maternal mortality in Uttar Pradesh, as we tried to grapple with the possible causes of such monumental neglect of women's basic right to survive pregnancy. This journey included trying to identify 'duty bearers' accountable for the deaths of hundreds of thousands of women, as well as struggling to understand the gendered parameters of the rights claiming process of so-called 'rights holders'. In attempting to modify the relations between the duty bearers and rights holders, SAHAYOG applied the concept of 'voice and accountability' with limited success.

#### The first strand: understanding the gendered subject of rights

In December 2000, as part of a HF fact-finding team visiting a small town in eastern Uttar Pradesh, SAHAYOG first encountered the maternal death case that became an organizing principle and shaped the organization's understanding. The story was narrated by the devastated husband, who explained how at the onset of labour, his wife had gone to the district hospital in July 1999 for her third childbirth, and met the woman doctor on duty, who gave her an injection and then simply left her alone. As his wife developed rashes and went into distress, the husband made increasingly desperate efforts to get someone to attend to her, but in vain. The obstetric complication was neither detected nor managed on time, and despite having gone well in advance to the best-equipped hospital in her small town, the woman died before she gave birth. The hospital took no responsibility for what had happened.

This case raised several questions: the common refrain from senior medical doctors in hospitals and in policy making positions was always that 'women arrive too late in the hospital, usually after the traditional birth attendant (TBA) had messed up the case.' So who was at fault when a maternal death occurred even though the woman had reached a hospital well in time? Women have long clamoured for women providers to attend them in labour; but could a woman doctor in a district level hospital really neglect a labouring woman to the point when her complication

became fatal? These and other questions compelled SAHAYOG and its allies to re-examine the common assumptions around the 'Three Delays Model' which posited that maternal deaths were caused by delays in decision-making to seek care, delays in actually reaching care and delays at the point of providing care. The general assumption was that women's lives could be saved if women reached institutions in time during labour, and if institutions had skilled medical personnel (Thaddeus and Maine 1994). We were faced with the shocking possibility that even if the woman reached on time and skilled medical personnel were present and started her treatment, the providers may not always act in the best interests of the woman in labour.

Over the next few months, HF partners and allies working across several other districts of Uttar Pradesh unearthed an unending series of similar cases, in which health providers appeared to be wilfully neglecting women who attempted to reach institutions for childbirth or in obstetric emergencies. In some cases, providers had misdiagnosed the situation, or demanded sums of money that poor families had been unable to pay. Hoping to gather these stories together and highlight this issue, HF brought together survivors, their families, and families of victims to give testimonies of reproductive rights violations during a public hearing organized at the state capital, Lucknow, in April 2001.<sup>11</sup> We framed our articulation that such incidents of negligence were a violation of women's rights to reproductive health, as promised in the ICPD Programme of Action that India had committed to. We raised the question of accountability of the government and the key development partner, USAID, which was putting US \$325 million into the state for reproductive health. But there was no apparent impact of these efforts upon the government. Despite substantial media coverage, there was no discernible response from any officials of Uttar Pradesh.<sup>12</sup>

After the invocation of the ICPD failed to elicit a response, a dozen women's rights organizations of Uttar Pradesh came together in 2003 and took a decision to use the Convention

on the Elimination of all Forms of Discrimination Against Women (CEDAW) as an instrument to demand state accountability for the loss of women's lives, by preparing a shadow report about women's rights in Uttar Pradesh. We built our capacities and some of us began to systematically document these cases using the framework of 'state accountability for women's reproductive health and ensured maternal survival' as set out within the CEDAW treaty (SAHAYOG 2004 a). SAHAYOG and the partner women's organizations collated twelve cases of women's adverse experiences with maternal health services, several of which involved *Dalit* women. About half of the women had lost their lives due to preventable causes, including being denied maternal care in institutions, or being compelled to visit multiple providers in attempts to seek care, or dying in hospitals despite having sought skilled care. In addition, the women's groups also recorded many other cases of medical negligence during sterilization operations, cases of violence against Dalit women, communally-inspired violence against women and so on.

These cases were used in media briefs during a state-wide campaign by the women's organizations and partner NGOs of the HF, called the *Complete Citizens Total Rights-I* campaign in November-December 2003 that posited maternal deaths as tantamount to denial of equal citizenship rights for women. A roundtable was organized to brief all political parties in Uttar Pradesh on women's rights issues and state obligations. On 8 March 2004 (International Women's Day), the campaign demands were presented by women's activists to the Chief Minister of Uttar Pradesh (at that time a man). This was fortuitously followed by a government announcement to start maternal death reviews in the state, which fulfilled an important campaign demand. However, our elation was short-lived as no effective action followed this announcement, beyond a small pilot effort that elicited total denial of any maternal deaths in any district.<sup>13</sup>

The persistent lack of state response bewildered us: it became evident that global agreements on women's rights had limitations in enforcing local accountability. The state's disregard for this critical issue for poorer female citizens (at highest risk of maternal deaths) indicated that the subject of citizenship rights is clearly defined by class and gender. We were also struck with doubts about the style of our own campaigns, which appeared to have made no difference to the government; we wondered whether it was because we, as a handful of middle-class women, did not resemble their voters. Then suddenly in the middle of 2004, we got involved with another case of denial of maternal health services that enabled us to understand just how far poor rural women could hold the system accountable.

In July 2004, a poor *Dalit* woman 'N', came to a Community Health Centre (CHC) during labour for her first childbirth. She was abused by the nurses and attendants as she couldn't pay the informal fees demanded, and thrown out of the hospital during advanced labour. She gave birth in the open outside the gate, and the baby died within a short while. This created an uproar that led to the incident being reported by the media. A departmental enquiry was constituted, and a team went to the woman's home in the village to examine her. After they left, SAHAYOG and HF activists and a journalist reached her to find that she had developed a large vaginal tear. We rushed her to the tertiary care hospital at Lucknow the same afternoon, but they refused to admit her until late night since we insisted that they do a medico-legal examination, which they would only do if the local police requested them. Persistent interventions by HF activists working with lawyers, the media and the local Member of the Legislative Assembly (MLA) enabled the woman to access medical care, as the severely infected tear required a month of hospitalization to heal; and we worked with her family to pursue justice for her case.

Yet despite petitions to all concerned officials, including the Principal Secretary of Health who was approached by the activists in person, the department refused to take any systemic action

beyond punishing a nurse in the CHC. In fact, HF's case-file notes (2004) indicate that senior government doctors colluded to conceal medical evidence on the case. The media remained a staunch ally: a year-long media campaign around this incident starkly highlighted the reality of poor *Dalit* women who are harassed for informal fees in hospitals; and this continued to be an issue which the print media covered constantly for the next few years (SAHAYOG 2009 c). Yet notwithstanding the media attention that helped keep N's case on the public radar, there was no formal response or declaration from any policy actor.

The media coverage enabled the Uttar Pradesh Commission for Prevention of Atrocities on Scheduled Castes and Tribes to take *suo motu* cognizance of the incident, and this Commission recommended that N be compensated for the death of her baby, and instituted criminal proceedings in court against the doctor on duty at the CHC. A lawyer from HF represented N, and we accompanied the family to every hearing in the court for months on end. But the criminal justice system is typically quite long-drawn out, and coming all the way from their village to attend the prolonged proceedings was too much for the impoverished family. In addition they had been under constant pressure from the local police and the hospital staff to 'withdraw' from the case. After a year they turned 'hostile' to the case and succumbed to the CHC doctor's offer of a small financial settlement in 2005.

Despite our initial shock and intense regret, we could not blame them, for N's family was fighting the case while simultaneously struggling with their own poverty. But it did raise the question of whether legal proceedings were the best option for such a vulnerable family to realize their rights, even when they had the constant support of NGOs and the media. Yet we wondered what else could have been done to claim justice? Until the legal case had been filed in court, none of the so-called 'duty bearers' within the government system (those with the formal authority to hold others to account) had responded to the petitions from N's family; they

12

appeared to have 'colluded instead of demanding explanations or enforcing penalties' (Newell and Bellour 2002). The case of N clearly brought home to us the elements of discrimination and social exclusion within the health and the justice system that prevent poor and marginalized women from seeking redress for their grievances.

#### The second strand: dilemmas of engagement

Several other things happened in 2005 that created a new strand in our response to the issue of maternal mortality. Following a new government in power at the centre, a National Rural Health Mission (NRHM) was announced in April 2005, and formally launched in Uttar Pradesh in September 2005. As mentioned earlier, a key focus of the NRHM was reduction of maternal mortality, through the JSY. This was meant to include several components of maternal care but the cynosure of attention was the Conditional Cash Transfer (CCT) of Rupees 1400 (approximately US \$22) paid if women attended health facilities during labour (Government of India 2005). In addition, to compensate for any ignorance or hesitation among poor pregnant women, a community-based link worker 'ASHA' - Accredited Social Health Activist - was paid a small cash incentive to ensure pregnant women were registered with the local health centres, as well as to accompany the women to a health facility during labour, and conduct post-partum home visits (NRHM undated). In addition, NRHM gave a space for decentralized planning and budgeting as well as citizen participation in programme monitoring which included communitybased monitoring that encouraged user participation.<sup>14</sup> Of course the reality was that this participatory aspect was not well implemented everywhere beyond a pilot in some states. The JSY Scheme, however, was implemented with great enthusiasm in all states of India, including Uttar Pradesh.

While the NRHM was a much-needed attempt to reform the health sector, many of its redeeming features were subsumed by the emphasis on the JSY conditional cash transfer. There

were different responses to NRHM by various civil society groups, some choosing to support in designing or implementation, some to engage in wary surveillance, some to ignore, and some to outright oppose. For example, a group of public health activists engaged with the government from the drafting stage of the NRHM document, and remained engaged throughout in the form of the Advisory Group on Community Action (AGCA) for NRHM. A number of international development organizations saw NRHM as a good opportunity to support the government through technical assistance. The People's Health Movement in India (called JSA for *Jan Swasthya Abhiyan*) groups participated in community-based monitoring of the implementation of the NRHM.

Even though many women headed organisations, especially those associated with the Medico Friend Circle (MFC) and the JSA were involved in community based monitoring of NRHM, the women's health movement as a whole did not get directly involved with NRHM. This is a noticeable gap as there was a large national mobilization of women's organizations between 2005-2006 around the 10th International Women's Health Meeting (IWHM) in India; in fact the closing session of the IWHM had an impassioned speech on maternal mortality as a human rights violation. While the global feminist movement has fought hard against the default association of women with just being 'mothers' and was disappointed with the MDG goal narrowing women's health to 'safe motherhood', it is also a reality that in the developing world the overwhelming majority of women do become mothers and are at very high risk of losing their lives because of this.<sup>15</sup> Although health policy was one of the key areas of concern of the IWHM, yet there was no organized response of the women's health movement to the way the maternal health programme was designed<sup>16</sup> or any strongly-voiced critique or campaign against the instrumentalist approach of the JSY (Indian Women's Health Charter 2007). The result was that the feminist Indian women's health movement remained quite dissociated from the NRHM in the first few years of its existence.

Within Uttar Pradesh we were faced with a dilemma: should we get involved with the NRHM or oppose it outright? Clearly the NRHM approach was quite technocratic; in its vertical programme design it ignored several social realities that poor women faced. Yet there was a strong feeling that SAHAYOG and HF might become irrelevant actors if we were to oppose or completely ignore these new policy announcements. As an advocacy group we felt we had to get involved, to continue with monitoring what was happening to women as a result of the NRHM and JSY. We were quite sure that the incentive of the JSY would exacerbate problems for poor pregnant women if health providers continued to deny services, or behaved in the abusive way they had done earlier. We knew the health systems in states like Uttar Pradesh were quite dilapidated to begin with, and might not be able to handle an increased demand for childbirth services; we worried that over-crowding in hospitals may deprive women who really needed it from life-saving skilled care. In fact if we looked beyond the JSY, the NRHM did plan for some positive changes and therefore could not be entirely opposed: support for creating more health infrastructure and upgrading all facilities, hiring more staff, as well as decentralized planning with local budgetary support, and community based monitoring.

But the decision to be involved in the NRHM process, and the ensuing work of HF using the NRHM framework, led to a change in the composition of the civil society alliance. After having campaigned together on maternal mortality and seeking justice in the case of N's violation of the right to maternal health, other leading women's rights organizations of Uttar Pradesh slowly drifted away from HF.<sup>17</sup> We continued to work together on violence against women as a key issue of women's rights violation, since it was so unambiguously about 'women's rights as gendered citizens'. But there was increasing dissociation of activist women's rights organizations with the work of the HF on critiquing and monitoring the NRHM. Perhaps the efforts to make health systems more responsive to women's needs appeared more like a 'health sector

development' concern than a women's rights-claiming process. However, the grassroots NGOs working in different districts with rural women's issues continued to work together with SAHAYOG, and they remained part of HF.

As part of civil society engagement with the NRHM frameworks, SAHAYOG and HF partners continued to document cases of maternal mortality, and collated another 23 post-NRHM cases of maternal deaths and near-miss situations from 2005–2007 in six districts of UP. The findings remained depressingly similar to the pre-NRHM scenario: despite fulfilling the government's requirements, women attending hospitals during labour continued to face humiliation and disempowerment, poor quality services, petty corruption and in some cases outright denial of care. The cases raised once again the basic questions of institutional capacity and willingness to respond to poor women's increased demand for maternal health services, and the absence of any mechanism to ensure some degree of accountability for this. The findings from these cases were published in July 2007 and presented as feedback on the implementation of the NRHM from civil society to the Government of India, which was funding the NRHM in UP (Dasgupta 2007). But the national government's standard response was that 'health was a State subject' and they could not do much;<sup>18</sup> therefore we had to, somehow, make our state governments more accountable in implementing the NRHM.

Nonetheless SAHAYOG went ahead with raising questions for the Indian government on the presumptions of the JSY programme design. Although SAHAYOG did not possess the 'technical' or bio-medical expertise on health, we allied with a group of equally concerned activists from other states to conduct an investigation into the JSY. This group drew upon the expertise of an advisory panel of medical doctors and public health researchers to carry out a voluntary block-level study in six states in 2008 on poor women's post-JSY experiences with accessing institutional care during labour. SAHAYOG anchored the entire process and the draft

findings of the study (SAHAYOG 2009 a) were formally presented in 2009 to national policy actors, including newly elected parliamentarians and a Health Minister; later presenting them again before researchers at the Global Maternal Health Conference 2010. The activist group used quality of care frameworks as well as equity and cost analyses to build a case for re-examining the assumptions behind the JSY. Partly as a result of the processes around the study and its dissemination, SAHAYOG joined a group of women and health activists to form the National Alliance on Maternal Health and Human Rights (NAMHHR) in India. This group continues to use a critical lens on maternal health policies and budgets.

The national government usually presents a more liberal front than the local, and the regime at the time provided spaces for civil society engagement in policy discussions, for example the long-term National Advisory Council<sup>19</sup> and the AGCA (NRHM), or various committees during the drafting of the 12<sup>th</sup> Five Year Plan. When a high-level expert group on 'Universal Health Coverage' was set up by the Planning Commission in October 2010, SAHAYOG was among the civil society representatives who constituted half among the fifteen members. The next year, a Technical Resource Group on Maternal Health was set up by the health ministry (July 2011) and once again SAHAYOG was included. Yet the promises of the liberal state always remained unfulfilled when it came down to implementation at the local level.

#### The third strand: user voice and accountability

Recognizing that we needed to simultaneously address policy implementation within the state of Uttar Pradesh, SAHAYOG worked from 2006 with a strong partnership of district NGOs who were concerned with the issues of maternal mortality. These NGOs were largely involved with organizing the rural poor, including daily wage workers, and reached out to *Dalit,* tribal and Muslim<sup>20</sup> women. In early 2006, a state-wide campaign was planned where these women could directly address the political actors in UP, and demand accountability as the constituents who

voted them to power, and as those 'users' who directly depended on functioning government health services. The NGOs collected tens of thousands of women's signatures and organized demonstrations. Some of the more articulate women directly presented their experiences to the Director General (DG) of Family Welfare in UP, as well as before members of the State Women's Commission. A delegation of women handed over a memorandum with 35,000 signatures to the Minister of Health; they even spoke before their elected representatives in the Uttar Pradesh State Assembly.<sup>21</sup>

But the apathy of the political class continued: despite the rural women leaders presenting themselves as the citizen constituency that votes elected leaders into power, the MLAs were dismissive and did not pay much attention to the women's issues and recommendations; in fact the health minister was most reluctant to even receive the memorandum with women's signatures. The rural women leaders were frustrated and annoyed, while our campaign partners wondered why the reminder by their constituents had failed to have any impact on the politicians.

By now we had tried addressing many state actors to awaken them to their responsibilities towards the women at risk of losing their lives: the federal government, the UP Chief Minister, the MLAs, MPs and political parties, the health ministers, the Principal Secretary Health, the Director General, Health and Family Welfare Department. None of our efforts, despite great support from a sympathetic media in Uttar Pradesh, appeared to have led to changed political intent, or any perceptible improvements on the ground. Meanwhile cases of maternal death and denial of care by health providers continued to surface with sickening regularity.

SAHAYOG and its allies were challenged by the basic question: who is the appropriate 'duty bearer'? Who is responsible for access to quality health services that could actually save the

women's lives? Here there was an assumption that the state could be awakened, like a sort of sleeping giant, and slay the demon of maternal mortality with one strong statement of political will. When the earlier invocation of obligations under constitutional responsibilities and international law had failed, we had tried the instrumental logic of pressure from the voting constituency in return for more political attention to the issue of maternal deaths. But the fact of the matter was that poor, rural, non-literate women were not perceived as an independent political constituency at all (Kabeer 2002). Neither could any health official tackle maternal mortality single-handedly: the health system was in a complete shambles and the problem was complicated by many social determinants.

A new strategy was adopted on 28 May 2006,<sup>22</sup> in an assembly of 200 women leaders and NGOs from fifteen districts, to set up a grassroots women's organization in Uttar Pradesh for long term campaigning and action, called the Women's Health Rights Forum (MSAM for *Mahila Swasthya Adhikar Manch*). Since our attempts to get the policy actors of Uttar Pradesh to respond did not yield effective results, SAHAYOG also decided to increase the engagement with the programme managers, health providers and frontline workers within the districts. Both of these strategies were shaped by the opportunities provided by the NRHM that encouraged decentralization of planning and budgeting, as well as provided spaces for citizen engagement. Besides this, we hoped that being part of a large grassroots organization like MSAM that claimed accountability from the state would build a sense of agency among the rural poor, who were usually treated as passive 'beneficiaries'.<sup>23</sup> The organization was in a sense the 'political' response of the beneficiary group (i.e. women users of maternal health services) to the 'state-provided entitlements' within the National Rural Health Mission (Chatterjee 2004). We felt the organization had the potential to empower the women, and counteract the humiliations they routinely experienced in their interactions with the health providers (Bloom et al 2008).

19

We had also learned from the struggles with trying to seek justice for N and others, that working on single cases of rights violation took a heavy toll on the family as well as the supporting activists. The individual 'claims process' itself required resources that poor women lack; as such, the liberal subject envisioned by human rights, who can contest in a court of law and be awarded the claim or compensated, did not hold true for rural, non-literate women facing death or illness. SAHAYOG and allies decided to move away from conventional human rights work that often engages in litigation for individual cases, and attempted to foster a 'collective claims process'. We continued our earlier documentation of cases of the violation of women's right to health services, but tried as far as possible to bring women together in public hearings where collective solidarity was also assured.

SAHAYOG began investing its energy over the next few years in building capacities of the women leaders of the MSAM<sup>24</sup> and providing information on the entitlements available to them. Women indicated early on that merely knowing about the NRHM was not enough; they needed to know about livelihoods guarantees<sup>25</sup>, food security and nutrition programmes and provisions for social security as well. Each year the women learned about one aspect of their entitlements and then engaged in a local monitoring exercise.<sup>26</sup> Armed with some facts, they faced the officials in an annual 'district dialogue' which was meant to enable the health managers, providers, users (the MSAM) and NGOs to discuss the problems related to provision of maternal health services without expressing mutual antagonism.

In addition, the women continued identifying cases of maternal death resulting from denial of care, and brought testimonies to public hearings in 2009, after which they presented the cases and recommendations to the health minister of UP the following year.<sup>27</sup> When the Panchayat (local council) elections came around in UP (2010) the NGOs and women campaigned on a 'women's manifesto for Panchayats' and put up nearly 500 candidates across ten districts.<sup>28</sup> In

December 2011, the political parties contesting the upcoming state assembly elections in Uttar Pradesh were visited by MSAM women leaders to hand over copies of their 'Women's Manifesto'; after which they told the media, '*We know our rights, and are now going to vote for those who really keep their promises and bring about change. We will not be fooled into voting along caste lines*'.<sup>29</sup>

The iterative annual cycle of learning, monitoring and feedback to officials has had multiple outcomes. At a pragmatic level, it did lead to local improvements in service provision: more doctors and nurses are now posted in the areas where the women have raised issues of lack of services; some local health facilities have been strengthened in the villages where the MSAM is active; corruption in health facilities has been acknowledged as an issue that impedes access to care. In some districts, the district health officials responded to the women's feedback by providing the MSAM leaders with their personal cell-phone numbers as a sort of hotline in case of an emergency. Thus in various ways, MSAM has been strengthened as a 'grassroots voice' claiming health accountability. The regular dialogue at district level has also led to some recognition of the MSAM and the supporting NGOs as a credible source of feedback, and towards more opportunities for involvement within the NRHM implementation committees.

At another level, women leaders have gained considerable confidence; which is partly due to awareness of being part of an organization that has over 10,000 members, but also through their experiences of repeatedly negotiating improved quality of services with health providers and officials at various levels. The knowledge of entitlements itself is empowering in a state where the government machinery delivering benefits to the poor remains clogged by corruption and fraud. Now that the MSAM women know what services they are entitled to free of cost, they challenge the providers who ask for bribes.<sup>30</sup> The MSAM women also garnered approval of their male family members when some women leaders raised questions with their village *pradhan* 

21

(elected council head) about the 'job-cards' they should be entitled to, and insisted on fair wages for all under the NREGA law.

The unrelenting media coverage of corruption in hospitals, maternal and infant deaths and the dysfunctional aspects of the health system over the last eight years, has occasionally spurred the health department to take some action, though usually against the lowest cadre of staff. The various health ministers addressed also appear to have instituted some enquiries.<sup>31</sup> A positive development however is that the current health minister (of the government that came into power in February 2012) has taken up accountability within the health department as a focus of his work and instituted a toll-free complaint helpline.<sup>32</sup>

However the cases of preventable deaths, denial of care, and demands for money have continued with almost total impunity for several years. Many have occurred repeatedly in the same health facilities despite media coverage (such as one close to Lucknow where the case of N occurred) and regardless of whether they have staff in place or not. Maternal death audits have been made mandatory on paper but the state committee to review the reports appears missing; community-based monitoring of NRHM has not yet been instituted in UP although the NRHM mandated them in 2007.

The dramatic shifts towards institutionalized accountability that we had envisioned in conventional human rights frameworks have clearly not taken place. But the small local changes in power relations and negotiations between the MSAM women as users of public health services and their providers and health managers are also significant markers. We are hopeful that these indicate the slow movement towards greater agency among poor, non-literate women, who were only meant to be the passive 'beneficiaries' of the JSY programme.

#### **Governing Maternal Mortality**

In the course of the different phases of SAHAYOG's story as represented here, various actors have engaged with the problem of maternal mortality and tried to solve it through their specific interpretations of the issues involved. Each constituency constructed a language to represent what was to be governed and in doing so represented the reality of maternal mortality and the subject of maternal mortality, poor rural women, in different ways. For example, the JSY represented maternal mortality as an issue of reluctance to seek skilled care for childbirth. But since governing is not only about representation but about intervention – i.e. something has to be done to solve the problem – each constituency attempted to make their particular version of reality operable by using 'technologies' (Chatterjee 2004) such as mechanisms for categorization, standardization, professional specializations and vocabularies, mechanisms that reify expertise. In this case, for the government implementing health reforms, this involved re-defining what counted as 'skilled care'; introducing a cash incentive for hospital births; and producing and legitimizing the ASHAs who were to accompany the care-seeking process.

#### Global and national governmentalities

An analysis of the governmentalizing principles at work here in this local maternal mortality story also produces other insights on the global picture of maternal mortality: for example, that an issue which affects only women, and disproportionately affects poor women or marginalized groups, has been entirely constructed by 'expert' voices. These define the 'pregnant woman' as the problem category needing intervention at the point when she gives birth, because that is when most deaths occur. An alternative option, such as defining the problem as inadequate health facilities which urgently need to improve, is not given priority. The established knowledge around the issue has described it as a problem of the women who have been giving birth at

23

home, being too poor or too ignorant or too slow to access the modern services such as skilled attendants that are available at health facilities.

Since the deaths appeared to be obviously caused by obstetric complications, the 'evidence-based assumption' was that if all women put themselves in the hands of an obstetrician in time, none of them would need to die. There is an element of truth in this that makes it sound rational (some women have died because they did not reach hospitals – but certainly not *all*) and women could be persuaded to see themselves at fault for being 'irrational' and not reaching hospitals at all, or not in time. The invocation of medical expertise lent weight to this narrative, making it even more difficult to put the locus of the problem elsewhere – such as in poor treatment and abusive behaviour of health facility staff towards poor clients. Other forms of knowing or thinking or doing became virtually impossible. The emphasis on medical expertise also completely sidelined the role of those community women who had been supporting labour and childbirth at home, as being ignorant, dirty and ineffective in handling any complications.

The national government further perpetuated this global health perspective, and the expertise that produced it, by agreeing to locate the problem with 'poor, pregnant women' rather than with its own crumbling health system, plagued by under-investment and poor management. As the person who needed to be 'governed', the benevolent state offered the poor, pregnant, uninformed woman a potentially life-saving option if she could meet a rigid standard of 'good behaviour,' which was reaching the hospital '*on time*' during labour. The state provided her a person to support her to make the correct decision (the ASHA volunteer) and gave her a cash reward for doing this, which was seen as the best incentive for the impoverished.

However, if she failed to conform to this carefully-defined governmental standard of behaviour for any reason, the state did not take responsibility to ensure her safety: she then deserved to be

at risk of maternal death. If she *chose* to not go, or if she was not *able* to go, for any reason – in fact, even if there are no roads from her village, or if she was turned away from the health centre, or denied care because she could not pay bribes; if she ricocheted around from one health centre to another in desperate search for the 'skilled attendant' that could manage her obstetric complications, and finally reached the tertiary centre after a long-drawn struggle for transportation and resources – it was clearly her own fault for coming '*too late*'. Thus the government was not making itself answerable in any way for the safe outcome of the pregnancy; it limited the entitlement to the cash reward. In this the state has erased the language of rights and accountability and undermined its own constitutional obligation.

In this way, development authorities including specialist development agencies and the governments they work with, have through organized practices successfully governed the discourse around maternal mortality and produced the gendered citizen best suited to fulfil their policies. The technical expertise of international organizations dominated by obstetricians, economists and public health researchers has dictated the policy solution to the problem in India by locating responsibility with the individual woman who has to 'govern' her own conduct and get to the health facility on time.

This construction is entirely blind to the fact that deaths also occur *after* women choose to go, and do reach institutions on time, yet are mistreated by an inept system; therefore SAHAYOG's attempts to raise examples of these were met with virtually no response. The 'represented' version of the problem here has been carefully selective: it deflects attention from other systemic issues such as ever-lower health budgets or the dilapidated state of health services, the unethical and often abusive attitudes of health providers, the costs incurred in seeking skilled care, lack of roads and regular public transportation, and the unregulated, profit-seeking private sector. The fact that many deaths occur during unsafe abortions or in the periods before or after childbirth

(when no care may be provided) is omitted from this 'evidence-based policy'. The apparently rational 'expert' logic also made invisible the many inconvenient and messy aspects of women's gendered reality which contribute to their vulnerability via long-term denial of their rights as gendered subjects – such as the abysmal level of fulfillment of rights to services and information on contraception and abortion; women's lack of control over their own sexuality and endemic domestic violence; their lack of education, economic decision-making and mobility.

Against this larger backdrop of governmental technologies, SAHAYOG and her allies grappled with the endless question of who is the appropriate duty bearer to be held accountable for the tens of thousands of maternal deaths, the omnipotent one who can change the policy approach to respond to the realities of the 'gendered subject of citizen rights'. It is not surprising that the question remains always unanswered, even as the women and health organizations campaigned with the media and demonstrated on the streets, remonstrated with ministers and legislators, documented evidence of what is going horribly wrong, and organized testimonies or published the findings. (Dasgupta 2011)

#### Governmentalities of civil society

SAHAYOG and allies, including the media, were also a key set of actors that engaged with the problem of maternal mortality, trying to define it in terms of a counter discourse to the official definitions. Situating themselves in an oppositional politics of development, they refuse to provide welfare or services directly; and instead raised the question: why can the state not provide services to the poor?

At every stage described, the positions taken by SAHAYOG are attempts to respond to development governmentalities; in doing so, SAHAYOG's own positions became defined by those categories. In the first stage of engagement, they attempted to re-define the problem of

maternal deaths in India as 'an issue of women's human rights', and drew the meaning of this from the UN and international civil society working on global treaties and agreements. In a bid to push for translating international commitments into local action, SAHAYOG and her allies invoked the frameworks of reproductive health and rights of the Cairo Platform of Action, and then women's rights as defined by the CEDAW treaty. But it became evident that global agreements on women's rights had their limitations in terms of enforcing local accountability; the government was not moved by this narrative. The NGOs hunted for the elusive 'duty bearer' always invoked by international human rights language. But clearly they fell prey to another set of governmentalities, for things don't work this way where there are high levels of poverty and inequality, such as in post-colonial societies like India. While democracies may declare formal political equality, it is not supported by substantive socio-economic equality; therefore the class divide clearly demarcates whose rights will be the priority of the state, and whose rights will not concern those in power.

There was a similar lack of fit with conventional human rights work engaging in litigation for individual rights-claiming, in which the courts are considered a means of realizing rights for the poor. This strategy presumed that the claimant would have the social, financial and other resources necessary to pursue the long-drawn processes in court, while simultaneously holding out against the pressure tactics of those more powerful. This strategy also often presumes that poor and disempowered rights claimants will have the assistance of human rights activists to negotiate the complexities of the judicial system. None of these proved applicable or sufficient when elements of discrimination and social exclusion within the health and legal system prevented impoverished and marginalized women from continuing their claims for justice. The non-literate woman from rural Uttar Pradesh, burdened by her struggles for livelihoods and police harassment, was not quite the liberal subject of rights conceived by human rights frameworks; she was too vulnerable and succumbed to a miniscule cash settlement instead.

27

SAHAYOG learned a lesson about the human rights definitions of individual 'rights holders' and moved away from this towards 'collective rights claiming'.

One feature of this move was a search for the 'real users' of health services, those who could genuinely present their own experiences, reflecting earlier feminist anxiety about 'who speaks for whom' by seeking to build an essentialized 'authentic voice'.<sup>33</sup> Predictably, the 'authentic voice' of poor rural women led to no perceptible response from the local state government. On the other hand, SAHAYOG's research built its credibility as an 'authentic voice of the grassroots' and it gained space in the national policy arena. This inclusion in more liberal policy discussions, however, failed to impact upon practice at the local level.

Nonetheless, the self-doubt of the women activists of UP was productive, in that it mobilized the MSAM organization and fostered rural women's discursive claims, such as the claim to have a voice, to be heard and to participate in decisions that affect one's life. (Gaventa 2002)The mobilization of 'user voice' created a constituency around the governmental 'beneficiary group' category of women users of maternal health services and in doing so subverted the assumption of a passive beneficiary. As these constituencies grew in awareness of what was at stake, they intervened at local levels to question the status quo. Operating closest to the site where accountability failures occur, the MSAM women could negotiate local changes. They were able to get some responses from the service providers and local officials, and this counteracted the humiliations they routinely experienced as *Dalits* and tribals, as the illiterate poor. Being part of a large organization that claimed accountability from the state certainly built a sense of agency among the rural women, although it did not yet create them into a political constituency. The organization became, in a sense, a response of the 'beneficiary group' to the 'state-provided entitlements' within the National Rural Health Mission. (Chatterjee, 2004)

But here too one can discern a governmentality associated with international development discourse that tries to get global agreements operationalized: that in order for state services to deliver there must be the 'voice' of user constituencies who could demand accountability. This kind of 'user engagement' has also been promoted by the neo-liberal good governance agenda However even NGOs working on rights have taken this up enthusiastically, as they educate 'rights-holders' and enable them to identify 'duty-bearers' and hold them to account. Building up a sense of entitlement as citizens among poor rural women is seen as an exercise in 'democratization' (Gaventa 2002). But SAHAYOG's experience suggests that in a context like UP, merely eliciting a broader expression of the voices of poor women will not produce changed policies or change the behaviour of bureaucrats, the police, or politicians, without concurrent changes in the norms and procedures of accountability institutions. (Dasgupta, 2011)

In fact this brings into question the linearity of the standard NGO strategies for policy change, which is to create awareness, empowerment and 'voice' of those affected, as a means of creating pressure for policy change. For SAHAYOG it seemed that democratic voices really have no effect on making bureaucracies accountable. It was only at the very local level that collective voices of the user community were able to create some pressure for answerability, moving some local officials to respond.

The informed interrogation of the modern state by 'civil society organizations' (presumably representing a voiceless community) is yet another technology promoted in development governmentalities and part of the vocabulary of human rights. The actions of NGOs as 'informed interlocutors' of state health services are meant, somehow, to result in reformed state practices towards the 'fulfilment of rights', even though NGOs have absolutely no formal means to demand answerability. When this predictably did not happen, SAHAYOG and its partners worried about and were disappointed by the lack of policy response to their invocations.

Nonetheless the questions they raised based on their grounded experiences earned SAHAYOG a place in the liberal national policy arenas. This may have had some discursive influence but did not lead to any transformation at the local level.

#### Conclusion

These reflections on SAHAYOG's experiences over the last decade suggest possible future directions for those civil society formations that have perhaps started off being funded for developmental activities but have moved on to becoming voluntary associations that strengthen oppositional movements clamouring for change. There is a need to challenge the concept of civil society as the handmaiden of development governmentalities, both of the state and international development organizations.

On the one hand, it is important to engage with policies and their implementation by providing a different kind of expertise; merely opposing is not enough. Thus feminist activists do need to take up liberal spaces in policy forums or get into accountability functions. On the other hand, there is a need to retain the critical approach of social movements: to examine the ground realities where law and policies operate through the experiences of the actual users; and to feed that research back into policy forums so that we can prevent governmental technologies from defining the problems in other ways. In fact the presence of SAHAYOG in certain policy spaces provided an opportunity to represent the experiences of the gendered subject which questioned the definition of the problem.

The ways in which global development discourse defines the relation between 'voice' and 'accountability' do not work in the post-colonial context: enhanced voice of the poor, female user community does not lead to bureaucratic accountability. Merely using the standard NGO

strategy of awareness-raising and organizing may therefore not be adequate; other kinds of mobilization will have to be intensified so that we can democratize and influence local political responses to the denial of women's entitlements, and feminist activists have a role to play here. However, the distinction made by Chatterjee (2006) between 'civil' and 'political' society is important to remember: we should not completely 'civilize' outrage, for outrage fuels the efforts of the dispossessed. It may foster the organic growth of local forums for those who do not fall into 'civil society', and cannot operate within the assumptions of modern state-citizen relations, to build their voice in negotiating their entitlements with the state. Within the modern state, putative citizens have the freedom of association and can engage with state actors as 'civil society' while remaining within the democratic state-citizen contract. Those who belong to the arena outside, who are targeted in the government's development interventions, have to negotiate in other ways (Chatterjee 2004).

Through this analysis of the events and attempts that constitute a decade of SAHAYOG's history, we can conclude that civil society organizations can indeed challenge the project of government – which is never complete – but this does not necessarily happen in expected ways. In this case, it was not through the central effort to get poor women recognised as the subjects of health rights, but rather through the 'offshoots' of that effort, including the work of the MSAM and the space to contest the definitions of problems at policy level. By gaining an understanding of the relation between problem diagnosis and development of policy solutions, these experiences of an oppositional civil society group provide insights into how this narrative can be re-constructed by subversive feminist voices.

#### References

- Banerjee S., P. John and S. Singh (2013) 'Stairway to Death: Maternal Mortality beyond Numbers', *Economic & Political Weekly* XLVIII, (31), August 3.
- Bloom G., H. Standing and R. Lloyd (2008) 'Markets, Information Asymmetry and Health Care: Towards New Social Contracts', *Social Science and Medicine* 66, (10), pp. 2076-87.
- Centre for Health and Social Justice (with support from SAHAYOG) (2007) 'Reviewing Two Years of NRHM: Citizens Report', New Delhi, October.
- Chatterjee P. (2004) The Politics of the Governed: Reflections on Popular Politics in Most of the World, Columbia University Press.
- Dasgupta J., (2007) 'Experiences with Janani Suraksha Yojana in Uttar Pradesh: Analysis of Case Studies by SAHAYOG and Partners', in 'Citizens' Report: Reviewing Two Years of NRHM', Centre for Health and Social Justice, New Delhi. Available online at <u>http://www.chsj.org/reports.html</u>, accessed on 8 June 2015.
- Dasgupta J., C. Sharma and S. M. Khan (2010) 'Assessing the Readiness of the Health System to address Maternal Mortality: A Study in Uttar Pradesh', in A. Hagopian, P. House and A. Das (eds), 'Reaching the Unreached: Rapid Assessment Studies of Health Programmes Implementation in India', Centre for Health and Social Justice. Available online at <a href="http://www.chsj.org/pages/publications.php">http://www.chsj.org/pages/publications.php</a>, accessed 28 August 2011.
- Dasgupta, J. (2011) "Ten Years of Negotiating Rights around Maternal Health in Uttar Pradesh, India', in H. Standing (ed). Contextualizing Rights: The Lived Experience of Sexual and Reproductive Rights', Volume 11 Supplement 3, BioMedCentral International Health and Human Rights 2011. Available online at

http://www.biomedcentral.com/bmcinthealthhumrights/supplements/11/S3, accessed 8 June 2015.

Freire, P. (1970) Pedagogy of the Oppressed, Continuum, New York.

Gaventa J. (2002) Introduction: Exploring citizenship, Participation and Accountability in

Gaventa J., A. Shankland and J. Howard (eds) 'Making Rights Real', IDS Bulleting

Volume 33 No 2, Institute of Development Studies 2002

Global Maternal Health Conference (2010) 'Glimpses of Institutional Maternal Care: User

Experience from Six States', details at

http://maternalhealthtaskforce.org/gmhc2010/index.php/conference/session/viewsessi

on/session\_of/70, accessed 24 March 2013.

Government of India (2005) 'National Rural Health Mission: Meeting People's Health Needs in

Rural Areas, Framework for Implementation 2005–2012', Ministry of Health and Family

Welfare, New Delhi. Available at

http://www.mohfw.nic.in/NRHM/Documents/NRHM Framework Latest.pdf, accessed 28 August 2011.

Government of India (2011) Provisional Population Tables and Annexures, Provisional

Population Totals Paper 1: Census', Ministry of Home Affairs, Office of the Registrar

General and Census Commissioner India. Available at

http://www.censusindia.gov.in/2011-prov-results/prov\_data\_products\_up.html,

accessed 29 August 2011.

- Government of India (2013) 'Special Bulletin on Maternal Mortality in India 2010-12', Sample Registration System, Office of Registrar General, India, December.
- Healthwatch UP-Bihar (2002) Priorities of the People: People, Population Policy and Women's Health in Uttar Pradesh, Lucknow, March.

Human Rights Council (2010) 'Agenda Item 3, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Health', General Assembly, Fourteenth Session, Paul Hunt, Addendum Mission to India A/HRC/14/20, United Nations; 15 April. International Institute for Population Sciences (IIPS) and Macro International (2007) 'National

Family Health Survey (NFHS) 2005-06: India: Volume 1', Mumbai.

International Institute for Population Sciences (IIPS) (2010) District Level Household and Facility Survey (DLHS) 2007-2008: India. Ministry of Health and Family Welfare,

Government of India, Mumbai, April.

- International Institute for Population Sciences (IIPS), 2010. District Level Household and Facility Survey (DLHS-3), 2007- 08: India.Uttar Pradesh: Mumbai: IIPS.
- Kabeer N, 2002 Citizenship and the boundaries of the acknowledged community: identity, affiliation and exclusion. IDS Working paper 171 Institute of Development Studies Sussex England October.
- Lingam, L. and V. Yelamanchili (2011), 'Reproductive Rights and Exclusionary Wrongs: Maternity Benefits', Economic and Political Weekly, Vol. XLVI, No 43.
- National Health Assembly (2007) Indian Women's Health Charter, 8 March, unpublished document released at *Jan Swasthya Abhiyan*, Bhopal.
- NRHM, (undated) 'About "ASHA", Government of India. Available at <a href="http://www.mohfw.nic.in/NRHM/asha.htm#abt">http://www.mohfw.nic.in/NRHM/asha.htm#abt</a>, accessed 28 August 2011.
- National Human Development Report (NHDR) (2001) Planning Commission, Government of India.
- NFHS (2001-2003, 2004-06, 2005-6, 2007-09) Live Births, Maternal Deaths, Maternal Mortality Ratio in India by State from Special Survey of Deaths, SRS Estimate, Registrar General of India, Ministry of Home Affairs. Available at <u>http://nrhm-mis.nic.in/</u>, accessed 29 August 2011.
- Newell, P. and S. Bellour (2002) 'Mapping Accountability: Origins, Contexts and Implications for Development', IDS Working paper 168, Institute of Development Studies, Sussex, October.

Ortega, Adriana Ortiz (2011) 'Perpetuating Power - A Response (to Berit Austveg)'

Reproductive Health Matters, Vol 19, No 38, pp. 35-41.

- SAHAYOG (2004a) 'An Evaluation: Women's Voices Monitoring Women's Rights under CEDAW in India', by S. Misra S and P. Parbha, Lucknow, October. Available online at <u>http://new.sahayogindia.org/gender-equality/complete-citizen-total-rights-2003/</u> and <u>http://new.sahayogindia.org/wp-content/uploads/2012/08/Monitoring-CEDAW-2003.pdf</u>, accessed 24 March 2013.
- SAHAYOG, SARC, AALI, Sangatin, DISHA, Vanagana, Shikhar Prashikshan Sansthan, & Healthwatch Uttar Pradesh (2004b) 'Women's Voices: Monitoring State Implementation of the CEDAW: An Alternative Report of Uttar Pradesh State on Women's Health and Violence Against Women', Lucknow.
- SAHAYOG (2009 a) 'Glimpses of Institutional Maternity Care: Some Food for Thought', New Delhi, April. Available online at <a href="http://new.sahayogindia.org/maternal-health-and-rights/national-2/quality-and-accountability-within-the-maternal-health-programme/">http://new.sahayogindia.org/maternal-health-and-rights/national-2/quality-and-accountability-within-the-maternal-health-programme/</a>, accessed 24 March 2013.
- SAHAYOG (2009 b) 'Mahila Swasthya Adhikar Manch An Evaluation of Three years' Experience 2006-2009', Sri S., Lucknow, December.
- Solanki, P. (2009 c) 'Report of the Evaluation of Media Advocacy on Maternal Health by SAHAYOG (2006-2009). SAHAYOG Lucknow September
- Subha Sri, B., N. Sarojini and R. Khanna (2012) 'An investigation of maternal deaths following public protests in a tribal district of Madhya Pradesh, central India', *Reproductive Health Matters* 20 (39), pp.11–20.
- Thaddeus, S., and D. Maine (1994) 'Too Far To Walk: Maternal Mortality in Context', *Social Science and Medicine*, 38, pp. 1091–110.
- UNICEF (2008) Maternal and Perinatal Death Enquiry and Response: Empowering Communities to Avert Maternal Deaths in India, New Delhi.

World Health Organization (WHO)(2010) Trends in Maternal Mortality: 1990-2008. Estimates

developed by WHO, UNICEF, UNFPA and The World Bank', Geneva.

<sup>9</sup> Earlier it was Target 5.A 'Reduce by three-quarters, between 1990 and 2015, the maternal mortality ratio' (indicators MMR and skilled birth attendance). This was later expanded to include an additional indicator on reproductive health: Target 5.B 'Achieve, by 2015, universal access to reproductive health' (indicators: contraceptive prevalence rate and adolescent birth rate, ante-natal coverage and unmet need for family planning) (GoI 2013).
<sup>10</sup> The darker connotation of private sector vested interests in creating a huge health market through changing maternal health-seeking behaviour is never alluded to.

<sup>11</sup> Based on data from the unpublished event report: Healthwatch UP-Bihar (2002).

<sup>12</sup> The state health department and the USAID-led unit continued to focus on population control as a key reproductive issue. However, HF initiated a Writ Petition in the Supreme Court against the unacceptable quality of care in the thousands of female sterilization operations and got the Government of India to promise better standards and provide insurance coverage for all of these.

<sup>13</sup> Within a year, the government orders for maternal death reviews died an unnoticed death since district medical officers sent in reports of zero maternal mortality each month. It appears also that the health department never got round to constituting the State Committee that would study these reports.

<sup>14</sup> This was taken up by civil society organizations to develop a pilot model of Community Based Monitoring in nine states of India, through the Advisory Group on Community Action; details in

http://nrhm.gov.in/communitisation/community-action.html

accessed 8 June 2015.

<sup>15</sup> The UN Special Rapporteur on the Right to Health, Paul Hunt, spoke eloquently about maternal mortality as a major human rights violation of women. My personal observation was that this was not very well received, as women's health activists may have felt he was being too minimal in agenda-setting (reducing women to wombs) or perhaps interpreted that, as a white male speaking to Southern women, he was invoking some kind of *'mother-ism'* which was unacceptable.

<sup>16</sup> The author was invited by the IWHM organizers to write a background overview paper on maternal mortality in India, which was done in September 2005. The background papers were not published by the IWHM; and the author's national overview presentation was slotted into a session along with others describing some very local studies on maternal health.

<sup>17</sup> From the original CEDAW campaign that had brought together seven women's organizations and several independent activists, only SAHAYOG and one more remained.

<sup>18</sup> In India, various subjects of government are either on the National list, the State list or the Concurrent list.
<sup>19</sup> The National Advisory Council (NAC), comprising mostly civil society activists and researchers, was set up to advise the head of the then ruling coalition on social policies.

<sup>20</sup> In India, Muslims are a religious minority and often face subtle forms of discrimination, as well as sporadic violent attacks in communal riots.

<sup>21</sup> Details of campaign are available at <u>http://new.sahayogindia.org/maternal-health-and-rights/local/campaigns/complete-citizen-total-rights-2006/</u> accessed 24 March 2013.

<sup>&</sup>lt;sup>1</sup> *Dalit* refers to the marginalized social groups considered 'untouchable' by other castes, usually termed in government literature as the 'Scheduled Castes'.

<sup>&</sup>lt;sup>2</sup> The maternal mortality ratio (MMR) for Uttar Pradesh has remained disproportionately high, at 292 per 100,000 live births (SRS 2010–12), which is 1.64 times the MMR of 178 for India as a whole.

<sup>&</sup>lt;sup>3</sup> This area since then separated out into another state called Uttarakhand.

<sup>&</sup>lt;sup>4</sup> Now known as Healthwatch Forum UP and Healthwatch Forum Bihar

<sup>&</sup>lt;sup>5</sup> Partly also in response to global shifts in the post-ICPD era.

<sup>&</sup>lt;sup>6</sup> Kerala, Tamil Nadu, Maharashtra and West Bengal are below 150 MMR.

<sup>&</sup>lt;sup>7</sup> Assam, Orissa, Rajasthan and undivided Uttar Pradesh, Bihar and Madhya Pradesh.

<sup>&</sup>lt;sup>8</sup> The global UN conferences on Population and Development (at Cairo, 1994) and on Women (at Beijing, 1995) were seen as groundbreaking in that their declarations recognized women's rights, notably rights to reproductive autonomy and choice, as well as to the services that would ensure reproductive and sexual health.

<sup>22</sup> May 28 was declared the International Day of Action for Women's Health in 1987 during the 5<sup>th</sup> International Women and Health Meeting, with a call to women to take action against maternal mortality.

<sup>23</sup> The organization was in a sense the post-colonial political response of the 'beneficiary group' (i.e. women users of maternal health services) to the 'state-provided entitlements' within the National Rural Health Mission (Chatterjee 2006).

<sup>24</sup> The methodology used to understand maternal mortality as a rights violation was an adaptation of the 'conscientization' approach developed by Paolo Freire (1970).

<sup>25</sup> The National Rural Employment Guarantee Act (NREGA 2005) had been passed recently that assured 'job-card holders' of 100 days of employment in a year.

<sup>26</sup> First they pointed out rampant corruption in the appointment of the ASHA workers (2006), then they investigated the payment of the conditional cash transfer under the JSY (2007); they examined how 'untied' health budgets are spent locally and how much poor families are spending on maternal health services (2008); they audited the compliance of health sub-centres with the Indian Public Health Standards (2010); and they surveyed women's access to the promised 'free maternal health services' (2012) they investigated access to post-partum care (2013) and village based ante-natal services (2014). Details of the approach are available at

http://www.mhtf.org/2015/05/20/right-holders-to-rights-claimants-promoting-social-accountability-though-theuse-of-picture-materials-for-non-literate-women-in-uttar-pradesh-india/ as seen on 8 June 2015

<sup>27</sup> Two public hearings were organized in 2009, one bringing cases of maternal deaths and the other looking at denial of quality of care in hospitals. An earlier set of cases was also presented to the health minister of UP in 2008 by women leaders.

<sup>28</sup> Out of 477 MSAM candidates, 162 women managed to win as Pradhans (Village Council Leaders), or Members in the village and block councils.

<sup>29</sup> Speech by Tetra Bano (MSAM Chandauli District), at a press conference in Lucknow Press Club, 27 December 2011.

<sup>30</sup> But the same service providers still demand money from women who are not MSAM members, unfortunately. <sup>31</sup> However, following murders of three senior health officials in 2011, a monumental financial scam was unearthed within the NRHM in UP and required all health ministers in the earlier regime to resign, while the Principal Secretary, Health was arrested and imprisoned.

<sup>32</sup> See Dainik Jagran newspaper, 20 April 2012, p. 11, Lucknow edition (Hindi).

<sup>33</sup> Later we realized that not all other voices are suspect: our representations of the experiences of the gendered subject could also be considered valid. In fact the presence of SAHAYOG in certain policy spaces provides an opportunity to bring in the experiences of poor rural women and learning we have gained from working with them.