Civil Society Meeting with UN Special Rapporteur on the Right to Health (1/12/07, Delhi)

30 NOV. PLANNING MEETING SUMMARY:

On Friday, 30 Nov., NGO partners and advocates from across India who are concerned about maternal health and maternal mortality met to pull together their ideas and finalize presentations for the 1 Dec. Civil Society Meeting with the UN Special Rapporteur on the Right to Health and his team. During the meeting, which was held at IPPF in New Delhi, 6 presentations were given, discussed, and consolidated into 3 presentations to allow for the key issues to be highlighted with less overlap. The 6 initial presentations were: Access to Safe Abortion (*Sharad Iyengar)*, Continuum of Care for Maternal Health (*Smita Bajpai*), Implementing Maternal Health Care Programs in India (*Jashodhara Dasgupta*), Social Determinants for Maternal Health (*Priya Nanda*), Equity Factors in Maternal Health (*Francis Raj & Dr. Prakasamma*), Operationalizing Rights-Based Approaches in Maternal Health (*Abhijit Das*). After much discussion and deliberation about what issues were most important to highlight in the presentations, and where there was too much overlap, these 6 presentations were consolidated into 3: Macro-Economic Issues & Social Determinants (*Abhijit Das-presenter*), Equity & Service Provision (*Asha Kilaru & Francis Raj-presenters*), Rights/Actor-Oriented Approach & Accountability (*Jashodhara-presenter*). After taking a break for lunch, the group had a discussion and compiled a long list of recommendations that they wanted to make to the UN Special Rapporteur. Then, a small subgroup edited this list for the recommendations presentation to be given on 1 Dec. After discussing recommendations, the state-level presenters broke up into 2 subgroups to discuss the 2 key points that each presenter would make during their brief presentations at the 1 Dec. meeting. After the meeting at IPPF ended, presenters continued their work on the 3 presentations at the CHSJ office.

1 DEC. CIVIL SOCIETY MEETING NOTES:

I. Attendees' Introductions:

1. Jashodhara Dasgupta– SAHAYOG (Lucknow)
2. Asha Kilaru – Belaku Trust (Bangalore)
3. Dr. Sebanti Ghosh – ASHA (West Bengal)
4. Dr. Mira Shiva – AIDAN (Delhi)
5. Dr. Jyoti Gupta – CHSJ (Delhi)
6. Biswajit Padhi – WRAI (Orissa)
7. Jameel Zamir – IPPF-SAR (Delhi)
8. Anjali Sen – IPPF-SAR (Delhi)
9. Jayeeta Chowdhury – CHSJ (Delhi)
10. Sharad Iyengar – ARTH (Rajasthan)
11. Rajat Kosla – Univ. of Essex HR Center (UN Team)
12. Lynn Freedman – Columbia Mailman School of Public Health, Director of "Averting Maternal Death & Disability" Program (UN Team)
13. Debabrata Bhuniya –PFI (Delhi)
14. Gitanjali Mishra – CREA (Delhi)
15. Patricia Jeffery – Sociology Dept. of Edinburgh University
16. Sunita Kujur – CREA (Delhi)
17. Dr. SR Patel – IIM, Ahmedabad (Gujurat)

18. Rakesh Kuman Sinha – BREAD (Bihar)
19. Dr. Prasanta Tripathy – EKJUT (Jharkhand)
20. Sangeeta Mourya – SAHAYOG (Lucknow)
21. Shakuntala Joshi – SAHAYOG (Lucknow)
22. Indu Capoor – CHETNA (Gujurat/Rajasthan)
23. Smita Bajpai – CHETNA & Dai Association of Gujurat & Rajasthan WRA (Rajasthan)
24. Francis Raj – ANS-WERS (Andhra Pradesh)
25. Rashmi Shetty – Action Aid (Delhi)
26. Sharmila Neogi – Population Foundation India (Delhi)
27. Dragan Accordlan – UN High Commission on HR
28. Elise Weiner – Researcher at Univ. of Essex in UK
29. Rachel Siemons – SAHAYOG (Lucknow)
30. Geetanjali Misra – CREA (Delhi)
31. Aparna – EIDHR
32. Bulu Sarin – EIDHR
33. Anuradha – AIDMAM
34. Bharat Kale – NCDHR
35. Louise Finer – Univ. of Essex HR Center (UN Team)
36. Dragana Korljan – Office of the High Commissioner for Human Rights (UN Team)
37. Vinod Bhanu, CLRA & IMPF, New Delhi
38. Namrata Jha – Packard Foundation, Delhi

II. Case Examples

1. Manju (AP)
2. Kamla (UP)

III. State-Based Presentations on Maternal Mortality

Group I: Uttar Pradesh, Orissa, Jharkhand, Bihar

1. Uttar Pradesh (Sangeeta Mourya)
    i. Uttar Pradesh is the state with the highest maternal mortality in India
    ii. The first main cause/factor in maternal mortality is the informal demand for money
        1. Out of 68 cases, only 7 women received JSY money, and 3 or 4 of these women were asked to pay Rs 500 of their JSY money to the providers.
        2. Out of 68 cases we documented, 32 were asked for informal payments.
        3. In the last month, 3 cases were documented in 2 districts, Kanpur and Banda, in which the 3 women died due to inability to pay the providers.
    iii. The second main cause/factor in maternal mortality is that there is no proper information or referral given to appropriate facilities for maternal health care.
        1. One example of this is the case of Salenta in Mirzapur district. During delivery, the hospital staff accidentally cut her bladder and then refused to take responsibility for the mistake. After the injuery, Salenta's husband took her to 9 hospitals in 3 different districts in an attempt to have her treated. However, after Salenta's husband spent Rs 50,000 that he borrowed from his boss at the brick factory where he works and sold all his brass kitchen utensils, Salenta was still left in the same poor condition.
    iv. There is also a lot of denial of care in health care facilities

2. Orissa (Biswajit Padhi)
    i. 80% of population lives in rural areas and there is an urban bias in service provision
    ii. There are 900 vacant doctor posts in state, and many of these are in tribal areas
    iii. People living in tribal areas cannot get services
    iv. Non-functional FRUs are a big problem
    v. It is hard to get data on maternal deaths, and there have been inaccurate and under-representative counts of maternal deaths because targets affect reporting procedures
3. Jharkhand (Prasanta Tripathy)
    i. In Jharkhand, safe motherhood initiative has remained a poor cousin of global initiatives like childhood immunization. Childhood immunization figure has jumped from a mere 9% to 51% since the inception of Jharkhand because of political will but maternal mortality is not recognised as a major issue.
    ii. No official figures are currently available for MMR for Jharkhand (independent of Bihar). However, combined MMR for the two states for 2001-2003 through the Special survey of deaths puts the combined figure at **371** (ci-313-430). There is an urgent need to find out the state of maternal death rates in the districts as independent measurements have shown very high rates in rural areas. He cited a study involving 9021 live births with 81 maternal deaths from some of the underserved areas of West Singhbhum and Saraikela districts of Jharkhand at an mmr of **898**. When we look at this data in spite of the low sample size (number of live births) we definitely get an impression that there is a very high incidence of maternal deaths in remote rural areas in the two districts of the state.
    iii. JSY and institutional deliveries are being pushed vigorously without much improvement in quality of services in the public sector hospitals and with no regulation to curb unethical practices in the private sector.
    iv. Corporations and international agencies are giving inappropriate advice.
4. Bihar (Rakesh Kumar Sinha)
    i. In Bihar, people do not have information about any maternal health care services. Many people still do not know about their entitlements and are still not getting ANC.
    ii. Out of 17 documented cases, only a few received partial ANC which only consisted of one TT injection.
    iii. There is a lack of infrastructure and a lack of service providers, including no trained *Dai*s or ASHAs available. Health care facilities are also very spread out and are located far away from where people live. Thus, women often first seek care from quacks or untrained *Dais* who give irrational injections of Oxytocin and other drugs during labour that cause both maternal and infant deaths.

QUESTIONS & COMMENTS from UN Special Rapporteur Team:

Rajat: An earlier presentation mentioned the verbal autopsy work that's been done, could you please elaborate on that?

Rajat: When in Rajasthan, I learned that the State Women's Commission is organizing hearings for women to express the problems they have faced with getting their JSY entitlements. Is something similar happening in Uttar Pradesh?

Shakuntala: The women's commission is not very functional in UP, and because the government has changed again, we were unable to have a hearing about the health cases that were supposed to be tried. Many health care providers demand money for services and women don't get JSY, all this despite maternal health services being free according to NRHM.

Prasanta: The verbal autopsy cases given are not the worst, but belong to the poorer section of the rural, tribal section of 2 neighboring districts. Ekjut a voluntary organisation working in Jharkhand and Orissa has set up a surveillance system to record al births, new born deaths and still births. They are also recording all deaths of women and if these happen to be maternal deaths then maternal verbal autopsies are performed with the family members of the deceased to ascertain the possible cause of deaths and the circumstances leading to these deaths. For every 2 or 3 villages, we have a midwife who acts as an identifier and informs about any birth taking place in the villages. She is paid Rs 30 for each birth she reports. We did an interview after 42 days.

Group II: Andhra Pradesh, Karnataka, West Bengal, Delhi

1. Andhra Pradesh (Francis Raj)
    i. Primary health care centers are understaffed, with few providers available and many vacancies, especially relevant to MMR is the lack of ANMs and staff absenteeism also means that people trained to conduct deliveries at PHC level are often absent.
    ii. There is also a poor ratio of population to health care institutions
    iii. There is a problem with proper referrals, with referrals often going directly to speciality hospitals rather than FRUs.
    iv. Mothers who deliver at home are not receiving any JSY compensation
    v. Under-reporting of maternal deaths – very few deaths are being reported as "maternal deaths," and instead are being reported as accidents, etc. Many providers refuse to disclose maternal deaths and thus, we can't trust the information from health care providers.
    vi. Sterilization is 84% of contraception – women are getting sterilized rather than being offered alternative methods of contraception.
2. Karnataka (Asha Kilaru)
    i. We need to dispel the myth at Karnataka is one of the best performing states.
    ii. Bangalore has great services, but care is not available in many rural areas and there are wide regional disparities
    iii. Life-saving measures are not in place in many areas and 50% of births take place at home
    iv. There are high user fees, and increasing privatization of services
    v. There is also corruption in governance of the health care system
    vi. In Karnataka, the public health centers are not functional, and there is no referral available. While 260 crore rupees is given under NRHM, the state government does not know how to use this money. There is no political will to do anything about maternal mortality.
3. West Bengal (Sebanti Gosh)

i. Though considered to be a better performing state, West Bengal is characterized by inequities in maternal health service provision and uptake. The socio-economically and geographically vulnerable & marginalized populations remain unreached to a great extent.
ii. The major concerns are –lack of continuum of care from home to facility level , minimal micro birth planning, inadequate access to quality EmOC services, suboptimal level of referral chain functioning and inadequate postnatal care.
iii. The positive aspects of the scenario is gradually maternal death audits being institutionalized in the state and initiation of bottom up district planning starting from Gram Panchayat level (which provides scope to highlight maternal health concerns & priorities from grass root level)

4. Delhi (Gouri Chowdhury)
    i. There has been an overmedicalization of childbirth. The emphasis on obstetric care in institutions doesn't address the status of women, etc. and will not reduced maternal mortality.
    ii. Many women are victims of violence even during pregnancy.
    iii. We need a much more historical and feminist way of looking at birthing
    iv. Generations of Dais are dying out and the new generation of Dais don't have the same skills as the older generations.

QUESTIONS & COMMENTS from UN Special Rapporteur Team:

Lynn Freedman: Is there any impact of institutionalizing maternal death audits in West Bengal? Whether findings are being shared with public?

Sebanti Ghosh: Unless the deaths are reviewed through the system, we won't know exactly where the problems are and timely actions will not be generated. Initially UNICEf had supported the process of maternal death audit in selected district and NGOs were involved in the process. The interim findings have been shared in government and among civil society representatives. The findings of the government led maternal death reporting and auditing by Health Supervisor from GP level have not yet been shared. There are still gaps in the process. We are facing difficulties in undertaking facility based reviews of maternal deaths which is very important along with community based reviews.

Biswajit Padhi: In Orissa, maternal death audits are also taken place, but we are not satisfied with the data being collected.

Rajat Khosla: The difference in governance structure came out prominently. If there is a strong governance structure and a sense of ownership as you go down to the village level, it has an effect. When you don't have that level of governance or village involvement in place, the situation changes. Is this something you were pointing towards?

Asha Kilaru: The grassroots government structures (ie. Panchayat Raj institutions) are really the only hope, and people are trying to build Panchayats' capacity to utilize laws put in place at the macro level, but it's been difficult. For example, many hospitals didn't have a lot of supplies, but had a lot of money from user fees. However, they couldn't use this money to get supplies because they couldn't get the necessary signatures from the Panchayat Raj, etc.

Rajat Khosla: In reference to the Andhra Pradesh presentation, I understand that even in cases of home deliveries, BPL cases were being given Rs 500, but you said that home deliveries didn't receive any money. Could you clarify this?

Francis Raj: Yes, this is because of state policy in Andhra Pradesh. In AP, there is no government order to give money to women who are delivering at home.

Shakuntala Joshi: In UP, women who deliver at home are entitled to Rs 500, but they don't get it most times.

Lynn Freedman: In a home delivery, what is the JSY incentive supposed to be for? Is it for home delivery in a particular way?

Jashodhara Dasgupta: It is part of the National Maternity Benefits Act in which all women undergoing childbirth were supposed to be given Rs 500. But JSY, while incentivizing Institutional Delivery, could not deprive women who give birth at home of the money. However, the government feels that women who are irresponsibly getting pregnant should not receive this money.

Biswajit Padhi & Sebanti Ghosh: In Orissa & West Bengal, women must receive 3 ANC checkups in order to get the JSY money.

Bulbul Sood: Since JSY was launched, many modifications have taken place in terms of who is eligible to receive money. Many states used this as an opportunity to say that the government was doing something, but after the big launch, not much has been done. The implementation of JSY was different for low-performing and high-performing states. Often, the JSY order does not trickle down to the community level. Also, even when you have the JSY payment, women have to make lots of payments to the health care system, and sometimes they even have to pay money to get the JSY money.

SR Patel: JSY was focused on institutional delivery, so the government has asked that only women who have institutional deliveries be paid the JSY money, but then the Supreme Court said that there shouldn't be discrimination against women who have home deliveries.

Sharad Iyengar: There are people, including ANMs and doctors, who are trying to suppress information about maternal deaths. Only in Tamil Nadu, it seems that people are reporting deaths. It's worth looking at how Tamil Nadu is reporting maternal deaths.

Smita Bajpai: The Rs 500 from JSY is only for BPL families who are delivering at home and are over 18 years of age.

Francis Raj: In Andhra Pradesh, the rural development scheme has established nutrition centers on a private basis in 100 villages. Pregnant women (from the 3rd month of pregnancy to end of 1 year of lactation) and their babies receive food which costs Rs 26/day per beneficiary. Out of this money, the woman pays Rs 6/day from her pocket, and the rest of the money is given as a loan by the rural development department that the woman has to pay back over a period of 3 years. Only 20-25% of women in villages are using these services, and they are mostly wealthy women, women who live nearby the nutrition center, and women of the higher castes. This marginalizes poorer/weaker/lower caste women who really need this service. Women feel that their basic self respect and dignity is being questioned by the entire system put in place by these nutrition centers, since no woman wants to leave

her family to come alone to the center. Women feel like the system is treating them as "worse than a beggar" by asking them to come get food alone at nutrition center.

Lynn Freedman: Is there a specific name for this scheme?

Francis Raj: It is called "Nutrition Centres" by the rural development department in Hyderabad

Jashodhara Dasgupta: I'd like to summarize what's been said. Lynn asked about the Right to Information Act in India and whether we find it is adequate for us to access any information we want on the issue of maternal health, or if anyone has any suggestions about it—can we respond?

Sharad Iyengar: I'll answer this question in the context of Rajasthan where we've been doing verbal autopsies. In Rajasthan, 45% of deaths take place in institutions, but it's hard to get death reports from the institutions because the norms of confidentiality come in and stop researchers from accessing this information. We can only get information about how many normal deliveries take place. I have had access to lots of good state information and statistics on maternal health, deliveries, etc. in Rajasthan, but a lot of this data doesn't get crunched. The latest family welfare handbook gives good information, but more research must be done.

Francis Raj: Accessing information about maternal death in Andhra Pradesh is not a problem, but there is no death register. The government says that 5,000 maternal deaths take place in the state each year, but only 1,000 are reported. We need to go to the village level to find out where the maternal deaths are occurring.

Abhijit Das: We recently tried to do a social audit of NRHM in 2 states. When our teams tried to get information from district and block officers using the Right to Information Act, they asked us to file our forms. The officers feel that their authority is being challenged. However, if we ask for this information at the state level, it's easier to get because there's more distance and people are more responsive and open to persuasion when faced with informal requests . So, in UP and Uttarakhand, the right to info. act is not very effective in getting information from people you know/want to build relationships with.

IV. Issue-Based Presentations

Jashodhara Dasgupta: I'd like to describe how these presentations came about. We had a planning meeting yesterday that was spent giving insights on 6 key issues. These 6 issues have been clumped together into the following 3 presentations.

1. Equity and quality in maternal health services (Francis Raj & Asha Kilaru)
    i. Clustering of maternal deaths among women who are:
        1. Illiterate
        2. Low educational status
        3. Poor
        4. Conceive early
        5. From SC & ST communities
        6. Daily wage laborers
        7. Other marginalized groups (tribals, migrants, rural, young/unmarried, HIV +, religious minorities)
    v. Maternal deaths are under-reported by the civil registration system, even hospital deaths are not inquired into.

vi. Socioceconomic inequities persist in service provision and uptake
    1. Inefficient and uncaring hospitals perpetuate caste and class and cultural biases
    2. Unregulated and harmful medical practice exacerbated by weak community capacity to negotiate care and weakened or often non-existent primary health care system
vii. Social exclusion & ANC
    1. NFHS-3: Proportion of women from SC/ST women who have two or more TT injections is lower than other groups
viii. Weak primary health care system
    1. Women from marginal groups are most affected by a weak primary health care system that lacks staff, equipment, etc.
    2. Corruption at all levels
    3. Lack of sensitivity to poor women and their rights
    4. User charges for poor women (many are not considered BPL because they lack a certificate)
    5. Unregulated and harmful private medical practice
ix. Ineffective and uncaring service provision
    1. No continuum of care for maternal health from pre-pregnancy, through pregnancy and postpartum, including linkages from home to referral facilities
    2. Persisting vertical program priorities and emphasis on single technical solutions
x. Are institutional deliveries safe/safer?
    1. If facilities are open and have providers available
    2. If action is taken immediately
    3. If all women are treated equally
    4. If quality is maintained
    5. If continuity of care is ensured
    6. Childbirth should be safe at home and in institutions. Services at home must be linked to emergency care in institutions
xi. Successful examples of reduced MMR for rural/tribal areas
    1. Building capacity and skills of Dais (as done in Gujurat, Rajasthan, etc.), supported by a continuum of care, rather thanfocusing on 100% ID
        a. Technical skills on her core role during labour and childbirth,
        b. Her expanded role in post-childbirth and newborn care, linking with the health services for ANC/ referrals, Primary Health Care, Reproductive health issues, health issues.
        c. Leadership/coordination skills to establish linkages between community and public health systems
        d. Attitudinal aspects to deal with class, caste, gender issues
        e. Social aspects to act as a social change facilitator

2. Macroeconomic Issues & Social Determinants (Abhijit Das)

xii. Socioeconomic determinants include:
    1. Poverty
    2. Social Exclusion/Marginalization (Clustering of Dalit MM cases)
    3. Women's literacy
    4. Access to food & nutrition (precluded by Indian women's social status)

5. Young age at marriage (before 18 yrs.) - Over 15% of pregnancies take place before age (?????????)
6. Access to health care services: Access to contraceptive services in India is focused on sterilization, and abortion services are under threat because of issues related to sex-selective abortion

xiii. Maternal mortality's factors
1. MM is caused by a complex web of factors, including: Socioeconomic status, level-policy regime, women's status, governance and accountability, health services.
2. Levels affecting maternal health: Family/community/health services/laws & policies/trade, IPR, International law
    a. These linkages must be established to make sure the larger context is considered

xiv. Government programs
1. JSY – to encourage institutional delivery
2. NREGA – to increase rural employment
3. NRHM – to provide universal access to HC services

xv. Government programs don't consider macroeconomic policy environment which includes:
1. Jobless growth
2. Agriculture policies
3. Pharma policies
4. Private medical colleges – high costs create doctors who do not want to work in rural areas
5. Private services
6. PPP (public private partnerships FOR PROFIT)
7. No social security – no social security nets in place
8. Increased economic inequality

xvi. Health issues
1. High level of anemia and vitamin A deficiency among mothers
2. Availability of food won't necessarily deal with anemia

xvii. Issues that are not considered in policy planning that affect women's health and nutrition status include:
1. Migration/displacement
2. Poverty
3. Agriculture policy
4. Farmer Suicides
5. Food Availability

xviii. A rights-based approach needs to understand and work to change the larger context in which maternal mortality takes place.

3. Rights and Accountability (Jashodhara Dasgupta)

xix. For health care and all underlying determinants of health (ie. Sanitation, nutrition, shelter, safety), we must determine:
1. Are services available? Where? (RCH Facility data provides some of this information)
2. Are services accessible? To whom, which social groups? On what payment and with what result? Is information accessible?

3. Are services acceptable? By all? Are they gender sensitive?
4. Are services of the highest quality? Who determines what "quality" means and who monitors quality?

xx. States have an obligation to:
1. Fulfil the right to health - facilitate, provide and promote - through legislative, budgetary, administrative, judicial, promotional and other measures
2. Respect the right to health - refrain from interference
3. Protect the right to health - take measures to prevent third parties from interfering with the right to health

xxi. Normative level vs. Actor-oriented perspectives
1. Normative level: laws/policies
    a. There is a flawed assumption that the system will implement whatever is passed by policymakers.
2. Actor-oriented level: lived experience in claiming right to health which is different based on one's class, caste, gender, location, level of political influence, etc.
    a. Rights-claiming is fraught with contestation
3. At normative level, there are laws on: abortion, right to food, quality of care, right to information, age at marriage, etc. There are also participatory monitoring mechanisms, including RKS, community monitoring, Patients' Charters, and public hearings. There is also ID with JSY, PPP and IPHS to ensure quality in institutions
4. Gaps at normative level:
    a. Maternal mortality isn't as high a priority as polio eradication and HIV/AIDS eradication.
    b. Women are not seen as agents having preference/choice, but seen more as objects
    c. Women's irresponsible breeding is often the focus, instead of maternity services and benefits
    d. Monitoring systems are not in place to ensure quality compliance, or are not well-resourced
5. Factors weakening the state health sector:
    a. Indian is marketing tertiary care globally, but neglecting local primary level care
    b. Vertical programs continue, drawing attention away from regular health services
    c. Strong involvement/influence of international organizations (and their priorities) as opposed to local health experts
    d. Decimation and deskilling of staff, lack of resources for preventive and promotive health
    e. Privatization of the medical system without regulations in place, including privatization of medical education (affirms profit motives)
    f. Little dialogue with traditional medicine system.
6. Actor-oriented perspectives
    a. Doctors, as a professional class, have considerable local power and influence, and may have protection of local political forces and enjoy impunity

   b. Power/class/education differential between providers and marginalized patients (ie. Poor, rural women)
   c. Poor are seen as unimportant for the system and providers because they are often unable to pay and thus, are a "financial liability"
   d. Faulty assumption that health providers are interested in providing care at state health facilities, when they actually have a vested interest in denying care at state facilities in order to refer patients to their private practices where they make more money
   e. Large profit motive and corruption at every level (not just at ANM/doctor level…there are also scams going on in the Ministry, etc.)
   f. There has been no state practice of increasing women's/ community's participation in getting their health care needs
7. To move towards accountability, must look at what cases from states show:
   a. No documentation of deaths and near-misses
   b. No grievance redressal, compensation, legal protection of the victims, or liability at any level
   c. There must be an articulation of women's right to health and to life (freedom from morbidity and mortality)
   d. Proactive measures to ensure services from an equity framework
   e. Ensuring liability in cases of denial of care, negligence or malpractice
   f. Women/men must participate in demanding services and monitoring services
8. Good practices:
   a. Documentation of maternal deaths taking place in Andhra Pradesh, Uttar Pradesh, Bihar, Jharkhand, Rajasthan, Karnataka
   b. Maternal health social audits conducted in Uttar Pradesh and Uttarakhand
   c. Women's Health Rights Forum in Uttar Pradesh
   d. Public hearings on maternal health with State Women's Commission as done by Orissa WRAI
   e. Civil society networks around maternal health in Uttar Pradesh, Andhra Pradesh, and Jharkhand
   f. TBA Union/Organization as in Gujurat
   g. Citizen's watch reports

QUESTIONS & COMMENTS from UN Special Rapporteur Team:

Lynn Freedman: What is being discussed in terms of amending the abortion law?

Sharad Iyengar: The movement to reduce sex selection in India has decided that easy access to abortion encourages sex selection tests. Surveillance measures have been proposed when a woman goes for an abortion. Another option is to make eligibility for abortion difficult. Another option is that the sex of the fetus should be recorded after the abortion. Easy access to 2nd trimester abortions is encouraging women to go in for sex-selective abortion. There are moves to increase access to 1st trimester abortions, since it's more difficult to select for sex in the 1st trimester.

Lynn Freedman: Have new proposals gotten to a written stage yet?

Sharad Iyengar: Not yet, although there have been proposals that have not yet reached the ministry.

Lynn Freedman: I haven't heard a lot about the posting/transfer of policies at work in the field. Are there any specific ideas of things that this report might recommend to address that? Jashodhara, are there any specific ideas about proactive measures that could be taken at the facility level to find out who is and is not being treated. Also, you point out the large and unregulated private sector. We know that a huge proportion of services are obtained in the private sector, and it's clear that the state has an obligation to regulate this. Do you have thoughts on concrete recommendations of first steps towards regulating the private sector that this group could suggest? There was also a comment in Jashodhara's presentation that said "since Alma Ata, there's been a decimation and deskilling of staff." Could you elaborate on what you mean by that?

Rajat Khosla: How, in Tamil Nadu, have the audits been done as part of the system, and how have they been used to inform the system in terms of maternal mortality?

Paul Hunt: In the NRHM, there are several references to the right to health and a Human Rights-based approach. I'd like to know whether or not that is rhetoric, or whether there is any evidence that a Human Rights approach has been used in policy formulation and project work, or is this really only a label? Also, the issue of the private sector…as Lynn said, we're keen to go beyond a couple of sentences emphasizing how important it is to regulate the private sector, since it is an internationally-binding obligation of the government to regulate the private sector. How could the government of India begin to roll out an appropriate process of regulating the private health sector?

Abhijit Das: I'd like to respond to the issue of Human Rights in NRHM. The NRHM is a product of the UPA government which has a pro-poor rhetoric and commitments to a common minimum programme, but it comes on the back of RCH-2, which was planned through a longer period of time during which the government fell and a new government came in. The new government made commitments to improve livelihood, health and education. The health commitment was articulated as NRHM. NRHM has been conceptualized in 2 ministries: 1) PMO and 2) Ministry of Health and Family Welfare (MoHFW). This provided a space for civil society to intervene in the planning process. The MoHFW was envisioning NRHM as a population planning program, but the PMO was conceptualizing NRHM as a health care program with rural health providers. These 2 ministries had 2 completely different drafts that could nor be merged (this was around October 2004), so 8 task forces were set up to merge the 2 drafts, and there was huge civil society participation in these 8 groups. It's through civil society participation in these groups that words like "rights-based approach" were incorporated. At this point, international organizations were absent. However, the NRHM task group reports were consolidated in the NRHM Implementation Framework by the Ministry, not civil society. The Ministry didn't know how to implement community monitoring or decentralized planning, so these parts came back to civil society to write up. Where it falls apart is that there is no accountability mechanism. Basically, there was no conceptual unity in the Ministry, so the weaving together of this into a consistent whole is missing.

Jashodhara Dasgupta: At the village level, there used to be a 2-person team of Male Multipurpose Worker (MMW) and the ANM, but because the Male Multipurpose Worker was paid by the state, his role was taken away and the ANM was left with too many responsibilities. So, the ASHA became the new "assistant" to the ANM, but the ASHA is not a direct substitute for the Male Multipurpose Worker because the MMW was a link to male community members and brought in the sense of male responsibility. Many ANMs faced deskilling and lost childbirth skills, but there has been no reskilling of

ANMs in the changed paradigm. The ANM is supposed to fill up 18 registers in month for the care she provides. The ANMS are also expected to work with Panchayats and communities, but they don't have the skills for this. They are being pushed into jobs for which they are not prepared. We have to take proactive measures for equity. We cannot rely on the health system and the providers to provide information and data about what is happening and what is not happening, because maternal deaths, abortions, etc. are not picked up as they have an interest in concealment. If we wish to measure the pro-equity measures in the maternal health care system, it must be done from outside by neutral 3rd parties, but cannot be done within the health system.

Shruti Pandey: There's a proposed bill for registration and regulation of clinical establishments that we've looked at, and we have some issues with it. Though the name is "regulation," there are no features for regulation. It postpones the regulation features. It says the standards will be set later by the parliament, which is a very prolonged process, so regulation might not happen. There are also no core standards that have been laid down and there is nothing on patient rights. . We feel that these core standards should be laid down and subsequently evolved. Also, there is no implementation strategy (no timelines, strategies, responsibilities). There is no provision for renewal or revalidation, which should be done, and no provision for liability or accountability, especially financial. There is also possibility for corruption. There is a medical council that exists that is supposed to regulate providers, but it does not function.

Sharad Iyengar: In Tamil Nadu, essentially the government has brought in a system by which all maternal deaths are notifiable and personnel of the health system are meant to convey news of a maternal death within 24 hours, or else they will face a penalty. A district review committee meets monthly and reviews maternal deaths. The committee includes community members and draws certain conclusions about maternal deaths to allow people to move forward. This has contributed to a lot of other policy measures to focus on maternal death. The measure is system-driven, there aren't NGOs participating in it.

Asha Kilaru: NRHM says that nearly 260 indicators should be collected at the district level. This needs to be built in incrementally.

Biswajit Padhi: In reference to the question about posting and transfers – In Orissa, there are very deprived areas (mainly tribal areas). We have been working for a policy in which every doctor/health worker has to complete some years of rural posting. We advocated having an ANM posted in the far off hill areas.

Shakuntala Joshi: Local providers are powerful and can ensure that complaints against them are diverted. There are no incentives for people to go and live/work in rural areas because there are no facilities for them there (ie. Vehicle, etc.)

Prasanta Tripathy: Rural posting should be encouraged as a form of reward to the best medical graduates to be rewarded after with postings to their choice later on.

Sebanti Ghosh: In rural areas, it is difficult to get specialists posted and retained particularly at FRU level. There are frequent out-transfers of providers. But government does not provide figures on this.

Bulbul Sood: We should start with pre-service education for nursing and medicine. Medical schools in India are also a mess right now, as they are understaffed, have poor training, etc. Medical school costs a

lot of money (including donations to obtain admission , so when students come out of school, they want to start making money. The transfer policy needs to be looked at, since once doctors are posted in a rural/poor place, they're often forgotten. Also many doctors work in both private and government sector simultaneously.

Mira Shiva: The National Human Rights Commission has asked the Medical Council of India to initiate a 3 year course for medical personnel for rural areas and also initiate a nurse practitioners course. The IMA and pharma comprise a strong lobby and lower-level training is restricted which additionally marginalizes poor women. Dehumanization of the poor makes poor women be seen as a liability. If medical education is going to be more privatized, equity is out, sensitivity to the poor is out. The Health Minister wants to start a medical college in each district as a public-private partnership, but who will benefit from this?

Bharat Kale (Speaking for the National Campaign on Dalit Human Rights): There are three main reasons for lack of access to maternal health care:

1) Poverty forces Dalit women to work until the last period of pregnancy, putting them at risk and they are often in dangerous jobs
2) Services do not reach Dalits because of caste-based discrimination. Services are located in main areas, not Dalit villages.
3) Service providers are not sensitive to issues that concern Dalits, and Dalits aren't consulted. Service providers discriminate against Dalits.

We have some recommendations to change this situation: Caste must be recognized and named as a main cause of discrimination. We also need more data on this issue. We need a mechanism to bring more equality to society to improve the standard of Dalits' health status.

Priya Nanda: It's the responsibility of facilities to collect data, but there is a resistance to collecting data for socially-vulnerable groups. We need to reinforce the need to collect data about who is really accessing care, and the data needs to be linked to the kind of social audit data being collected at the community level in order to see the disconnect between these 2 types of data.

Geetanjali Misra: I want to respond to the question about the use of a Rights-Based Approach – Currently in India there's a crisis about pushing to institute sex education in schools. Eleven states have opposed having sex education in schools, but the national government supports it. Lack of coordination exists at the government level and in civil society.

Sharad Iyengar: Equity is an important part of the Human Rights framework, but there are important differences. The government will like hearing about equity more than Human Rights

V. Recommendations (Shruti Pandey)

1. RIGHTS
    i. The government must recognize the right to safe and legal abortion
    ii. Articulation of right to maternal health (including abortion) should be linked with surrounding vital rights, including the right to:
        a. Dignity
        b. Self-determination/Choice
        c. Privacy/Confidentiality
        d. Integrity – physical, mental, emotional
        e. Information/Education

iii. The government must enforce the right to food and nutrition, and must take all measures necessary to reduce rural indebtedness and eliminate hunger, malnutrition and starvation in India.
    a. Regulation of health services should extend to both the public and private sector, with comparable norms
    b. Rights based approach should be woven into NRHM through documentation, reporting, enquiry into adverse outcomes/denial of rights. Accountability must lead to liability.
    c. Strong strategic information campaigns should be initiated in communities to inform women of their entitlements
    d. Providers and managers should be trained in a gender sensitive and rights-based perspective so that they plan, deliver and monitor programmes that do not discriminate on the basis of caste, class, gender and sexual orientation

2. SERVICES
    i. Maternal health services must be free for the entire population and must be universal.
    ii. Ensure continuum of care which includes institutional delivery and home based care. Maternal care must include prenatal, delivery and post natal care to ensure safety of mother and new born**.**
    iii. Increase base of skilled providers for delivery and abortion (non- doctors/nurse practitioners /midwives) in the country**.**
    iv. Essential drugs for pregnancy and childbirth must be available and must include drugs for illnesses that affect maternal mortality (e.g. Falciparum Malaria)
    v. Participation of Traditional System of Medicine/AYUSH systems
    vi. Anemia should be addressed within a nutritional support program
    vii. Affirmative action for marginalised/ vulnerable populations (young, rural, tribal, Dalits, HIV+)
    viii. Safe delivery should not be equated with JSY and delivery services should be integrated beyond delivery to ensure a continuum of care from prenatal to postnatal.
    ix. Incentivization of institutional delivery should be stopped, as it is leading to a coercive approach and neglect of quality services.
    x. The government should concentrate on ensuring 100 percent availability of critical infrastructure, staff, equipment and supply inputs at all levels of public health facilities for delivery and emergency care, especially in remote areas, with priority given to provision of health care access to poor underserved and marginalized communities.
    xi. Appropriate transport facilities must also be ensured for continuum of the referral chains

3. RESEARCH
    i. Further research must be into existing values, beliefs and practices surrounding maternity and the interventions during childbirth in homes and institutions (including ethnography)
    ii. Assessment of long-term morbidity due to pregnancy or delivery/abortion needs to be done and appropriately addressed

iii. Tracking the equity factors through disaggregated data gathering on maternal deaths and near-misses: by caste, religion, age, income and location (Urban/Rural)

4. GOVERNANCE & ACCOUNTABILITY
   i. Ensure participation of local communities and women in planning, social audit monitoring of services, and evaluation through multiple strategies like public hearings. Enhance government's capacity with effective participation of PRIs.
   ii. Rational allocation of resources with transparency and accountability safeguards at all levels.
   iii. Strengthening of public health systems in all respects:
      a. Skill building and career development of health personnel
      b. Transfer policy
      c. Supplies of equipment/drugs
      d. Policies to fill gaps in underserved areas
   iv. Develop a comprehensive health MIS system that is well integrated with the social/maternal death audit as part of the government system. This should be used at both the facility and community level, and action on findings should be legally binding.
   v. Strengthen monitoring mechanisms for all deliverables and integrated services with accountability indicators for all the concerned departments.
   vi. Stringent measures for financial accountability and against corruption, especially against demands for informal payments for delivery of health services.
   vii. Make mandatory the ongoing and end line evaluation for all programs on well defined indicators, and fix accountability for ensuring compliance with recommendations .
   viii. Stop project based data collection like registration of pregnancies for detecting sex-selective abortions.
   ix. Initiate measures for effective access to justice like waiver of court fee, effective remedies

5. POLICY
   i. The government must resist international pressures for institutional delivery and target-driven programs
   ii. The government must enact the Public Health Acts at central and state levels
   iii. Increased, equitable and rational allocation of resources for health; with increased managerial capacity for complete utilization of the funds.
   iv. Provide comprehensive integrated health services, also with complete integration of all vertical programmes like STI, HIV/AIDS programs.
   v. Review public private partnerships to ensure that they strengthen public health services, not sabotage them by leading to privatization.
   vi. JSY must be submitted to re-examination – quality services must be ensured rather than incentives. Policies of providing incentives and disincentives for achieving indicator goals should be scrapped.
   vii. All laws and policies on the issues of maternal health, abortion, 2-child norm, pre-birth sex-selection, child marriages, etc. must converge, not oppose each other.

QUESTIONS & COMMENTS from UN Special Rapporteur Team:

Paul Hunt: I'd like to give a brief background on the mission – I recognize that research is important, and I haven't yet captured that in my present thinking. First, some background remarks to understand why my report looks as it does. My reports go to the UN general assembly and the UN Human Rights Council. I've written 2 different sorts of country reports as I've learned over the years. At first, I would go to a country and look at the right to the highest attainable standard of health in all its aspects. But there's a second type of country report I've written that much more specifically looks at one issue through the prism of the right to health. My reports are restricted to 25 pages. I have taken the view that it's much more effective to have a specific country report rather than a generic one. I feel that a country report that looks specifically is able to drill down into the issues in a way that I couldn't do if I was looking at all the issues in the country. I asked the government of India if I could visit to look at maternal mortality, even though I know that there are many other hugely important issues. I made the judgment that I couldn't look at all issues in a constructive, specific manner, especially only if I was focusing on 2 states.

Why did I choose maternal mortality? Because it's a global catastrophe and I wanted to draw attention to it because in the UN system it wasn't getting the attention it deserved, and it also was mentioned in the MDGs and MDG 5. Secondly, I wanted to frame maternal mortality as a Human Rights issue since it's not seen as a Human Rights issue broadly speaking, and we know that it is and should be. I wanted this to be a challenge to the traditional Human Rights community that has a preoccupation with death penalty cases, etc. There was another reason for choosing maternal mortality. The right to health is extremely complicated and large. To try to make it more manageable is to talk about the right to health being understood as the right to a particular type of health system that includes health care, is accessible to all, and reflects national and local priorities. If we are to address maternal mortality, we need better health systems, and by looking at maternal mortality, it's a way of strengthening health systems from which all will benefit. Part of my thinking was instrumental.

What's the aim of my mission and of the report? A key aim is to figure out what is a human-rights-based approach to maternal mortality. In all my work I'm trying to operationalize the right to health. I don't want it to be just rhetorical, important though rhetoric is. By focusing on 1 issue in 1 country in 2 states, I think it will be possible to figure out a Human Rights-based tool to deal with maternal mortality in an operational, practical way. This report will also be written for people beyond India to help others figure out a Human Rights-based approach to maternal mortality.

The report will include some of the following information: Maternal mortality is an enormous problem in India and it's a Human Rights problem. At least some states aren't going to meet their state targets for MDG 5 and India could be doing much better on maternal mortality, especially when compared to states in the region such as Sri Lanka and China. And for a middle-income country like India, this maternal mortality rate is unacceptable. I then need to recognize that some of the Government of India's policies are in the right direction, that the NRHM is flawed, but is in the right direction. Of course, there's a big gap between the policy and the practice. I think I should commend the Government of India for some of its policies and programs because they represent a significant advance on what came before. There is a huge increase in financial commitment to the public health sector. JSY is flawed, but it seems that it can contribute to equity issues. The ASHA program is flawed, but has some positive elements. Negatives: Some services are very thin, some infrastructure is grossly inadequate. There is an excessive focus on institutional delivery without ensuring that the institutions are good and properly equipped. I have to talk about the issue of sex education, life skills training, talking about healthy gender relations, the issue of contraception and the need to ensure access to a

wide range of contraceptive services, not just terminal contraceptive services. One needs an integrated and coordinated set of medical services, including ANC, essential obstetric care, critical access to EMOC, postnatal care, and there must be an effective, functioning referral system. I also have to mention unsafe abortion, and any changes in the law that might restrict access to abortion are likely to help increase unsafe abortion figures. The issue of health information and health data is important – we don't know who's dying, so more work must be done on this (ie. birth registration, death registration). Human resources in the health sector, from RMPs to large private hospitals, are critically needed. Regulation of the private sector is important, and I want to make some positive recommendations to deal with this issue.

A key reason for this mission is because it's a way of teasing through a Human Rights-based approach to maternal mortality. Part of this approach is a basket of services, facilities that are needed. Even if these services are available, that basket isn't enough from a Human Rights point of view. There also has to be a formal legal recognition of the right to health, including the right to maternal health. There has to be a proper needs assessment in relation to maternal health and maternal death . There have to be appropriate plans with proper sequencing based on reliable and disaggregated data. Part of the plan must be around human resources. There must be standards without which there's a dramatic deficit. There must be proper inter-sectoral coordination. There must be bottom-up participation, not just participation in implementation, but also participation in policy making and accountability. Accountability and monitoring and redress are vital. I want to explore maternal death audits and reviews as a means of accountability. Another element is the issue of financial access, affordability. I recall that CEDAW talks about free access, I'll have to check. Another aspect is outreach to marginal groups. Another element is respectful treatment, and I've heard a lot about disrespectful, unprofessional treatment. Another issue is respect of culture, which does not cost anything. If this means that women want to be treated by a woman, this must be respected. There also must be transparency around data and policy making. Another issue is international assistance and cooperation. High income countries must provide assistance, and countries of the global South can learn from each other. Another crucial issue specific to resource poor settings is delegated authority so that people without full training can perform services and provide care.

I will hold a Press Conference at 4:00pm on Monday (3 Dec.) to give some preliminary observations and conclusions.

Indu Capoor: I agree about regulation of the private sector, but even the public sector needs regulation and accountability. Also, you need to put very carefully this culture thing as it can be double-edged. For example, sex education is being banned for "not being culturally sensitive."

Smita Bajpai: I think you've missed out on food, so if you can link the right to food to all women, that would be excellent. There is a pressure to go to institutions, so you should look at that issue.

Mira Shiva: Please link maternal mortality with what's happening with food security. Also, when we talk about education in schools, children need to learn essential health skills (ie. making of ORS, hygiene and sex education). She also talked about hanky-panky in the pharmaceutical industry –but she did not elaborate

Prasanta Tripathy: You did mention JSY in absence of good infrastructure, but you didn't mention that many women would like to have safe home delivery.

Tej Ram: There is an intentional denial of health care and state-sponsored violence (I think this latter was in the context of special economic zones such as Nandigram and the threats they pose to farming and thus food security).

Jyoti Gupta: It's good that you acknowledge the government, but we need to identify the bottlenecks in implementation (ie. Medical education), and participation should be ensured.

Bulbul Sood: One more issue that must be addressed is political interference and dominance of parties that make this into a political issue. Within India, sharing is not there, but is needed too.

Sharad Iyengar: Not just the private sector, but the public sector must be regulated. There's a conflict of interest when the provider of services is also the regulator of services. There needs to be a separate regulating authority.

Francis Raj: The government programs are implemented in a very campaign mode, but they are not regular, long-term programs and that must be redressed. Also, liquor plays an important role in India, especially in rural areas

Jayeeta Chowdhury: I think you missed out on the TBA point and emphasis on AYUSH.

Geetanjali Misra: We need to do ethnographic resource and evaluation of health personnel. In terms of standards, the issue of consent must be linked to choice and respect.

Kamayni Mahabal: Look into the ICMR guidelines and the issue of medical ethics.

Priya Nanda: There needs to be articulation of what kind of resources need to be committed, and this should be linked to the idea of removing incentive-based schemes and diverting the resources elswhere

Abhijit Das: Civil liability is a life and death issue in this case.

Paul Hunt: Is AYUSH a good policy? Is it working? In district plans, will there be any references to Human Rights?

Smita Bajpai: Very little effort has gone into straddling the systems. The mainstream system doesn't integrate the traditional system. NRHM was the first time integration was mentioned in terms of placing the doctor, who got a degree from AYUSH, in the system, but there's no clarity on the role of this person. There's huge emphasis on increasing Ayurvedic tourism and marketing/cultivating ayurvedic plants. There's little dialogue around maternal mortality because people don't see a role for AYUSH in reducing maternal mortality. This is an inequity issue because we are ignoring a whole knowledge system in India.

Sebanti Ghosh: The West Bengal Government last year went into extensive district planning starting from the bottom up (ie. gram panchayat and block level up to district level) involving multiple stakeholders from Government (other departments beyond Health & Family welfare), Panchayat, NGOs, CBOs and community representatives. Participation of stakeholders including NGOs and community was not uniform across all districts and was even minimal in several places. This helped capture voices of different stakeholders including community members about how Sub-Centres/Anganwadi Centres are functioning and what are the local health needs & concerns to some extent. We are trying to bring in

more grassroots participation this year and address the issues of equity, access & demand and gender through the planning processes. More examples could be shared from district plans, but need a bit of time.

Biswajit Padhi: It is basically the state government's agenda that's being pushed through district plans because if it's not in district plans, you can't spend the money. There's no local-specific plan in district Project Implementation Plan.

Francis Raj: District plans take last year's budget and upscale it and resubmit it. They're not consulting people in the community about the plans although there is some intention to do so.

Indu Capoor: When the plans are made at the district level (I can speak on Gujurat/Raj.), there's hardly ever consultation of NGOs. It's mostly the technical officers in these districts who make these plans with very little understanding and involvement of even steering groups.

Paul Hunt: Are you aware of any district plan that mentions human rights?

GROUP RESPONSE: "No."
Paul Hunt: Secondly, the right to health is about the right to health care and underlying determinants of health, including social determinants of health (ie. Women's empowerment, access to water, sanitation). Are there any comments on that part of the puzzle in the context of maternal mortality? Also, what's the relationship between maternal mortality and HIV?

Mira Shiva: There are supposed to be sanitation committees, but much water is poisoned with chemicals and pesticides. The access to water is limited even though there is a committee.

Jashodhara Dasgupta: Lack of water and sanitation is linked to increased diseases.

Lynn Freedman: We've focused a lot on rural areas, but in many parts of the world urban areas are suffering from maternal mortality and it's not a question of proximity. Are there any things to mention with respect to urban areas?

Sharad Iyengar: In the context of sex selection and safe abortion, there's a lot of talk of the right to be born. Paul should comment on this using Human Rights language. He commented that this is a minefield.

Prasanta Tripathy: A large number of maternal deaths in urban areas come from migrant women who have no safety net.

Bulbul Sood: In urban areas, NRHM and RCH-2 had an urban health policy too. Even in Delhi, for example, there are tertiary care hospitals where women end up going if they don't have their delivery at home.

Gouri Chowdhury: Birthing centres should be created in urban areas. We've also left out the women themselves in this exercise. There are women who are trying themselves to develop ways to have healthy births.

Paul Hunt: I feel very humble. I come here as an outsider and you are willing to share all this information with me. I am extremely grateful that you organized this meeting, and we will try the best we can to reflect what you've said in our report.