

Annual Report

April 2010 – March 2011

Sama-Resource Group for Women and Health

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Introduction

April 2010 – March 2011 was a significant period for Sama; while some of the organization's ongoing initiatives were concluded, this period saw the consolidation of previous work and Sama's involvement in new and important areas of enquiry and advocacy.

Sama's capacity building initiatives and trainings reached out to diverse groups and constituencies – community based organizations, networks, health care providers, state health personnel, students, etc. We also received several requests for trainings on health from *sangathans*, community based organizations in urban as well as rural areas. While we were able to respond to some of these, others will be followed up in the following period. Sama's trainings enabled improved understanding on a range of issues and themes with regard to health, sexual violence, assisted reproductive technologies, etc.

During the last year, Sama also extended its area of engagement on various issues like Sexual and Reproductive labour, Universal Social Security Systems through exposure / study visits at the international level. These visits provided an opportunity to build the capacities of the Sama team with regard to debates and discussions in other parts of the world (for example, in countries like Nepal, Bangladesh, Brazil, etc.). They were also important for dissemination of Sama's work and initiating wider discussions.

Towards strengthening advocacy and other initiatives, Sama worked in collaboration with varied like minded organizations and networks. While collaborative initiatives are not without challenges, they were also crucial for wider mobilisation, advocacy and sustainability. Sama was part of collaborative initiatives for universal access to free OPD treatment, the National Bioethics Conference, strengthening response of the health system to sexual and domestic violence, etc. Sama was part of initiatives to inform policies. We participated in the consultation to provide inputs to the Twelfth Five Year Plan and well as deliberations on the legislation on sexual violence.

Sama's three year research on ARTs was completed this year. A report based on the findings and analysis of data has been the immediate outcome; however, the range of data provides opportunities for further dissemination and discussion and flagging of issues through contribution of articles and papers to journals, books, etc. Some possible areas for future research have also emerged from the findings as have several opportunities for collaborative research with academic institutions and universities.

This period also saw consolidation of its engagement with academic institutions specifically with regard to ARTs and Surrogacy. For example, Sama was invited by the Indira Gandhi National Open University to write a Unit on Surrogacy as a part of the curriculum for the Masters Programme. Sama members also presented on the issue of ARTs and surrogacy at different academic institutions in India and overseas, thus facilitating dissemination of knowledge, initiating debates among students, researchers and academics. Universities and institutes of higher education are important sites as they often direct research of different issues - interactions towards building perspectives on specific issues and informing future research.

Sama continued to be approached by students, film makers, media persons from India and abroad for discussion on health, ARTs, surrogacy, HPV, etc. We have attempted to interact with as diverse an audience as possible for wider dissemination of information and debate on issues.

Attempts to bring together diverse works on ARTs by scholars from across the globe to create knowledge resources have been fairly successful – two leading international publishing houses have shown interest in publication of contributed papers.

Although substantial amount of time was spent on ARTs and related issues, Sama's engagement with other issues have also gained momentum. These are presented in detail in the report. Sama, for example, has also been able to create much needed visibility on the ethical concerns vis-à-vis the HPV project in particular and clinical trials in general through the organization's work. The outcomes of Sama's report on the fact finding in Andhra Pradesh and sustained advocacy efforts along with others have been tremendous.

Sama continued to be actively involved with the people's health movement. During this period Sama took on the responsibility of coordinating the Jan Swasthya Abhiyan, Delhi (People's Health Movement). Sama's active involvement in the health movement, our work on diverse health issues, coordination capacities and commitment to right to health and health care prompted this. A member of Sama was also invited to be part of a global evaluation team to evaluate the global People's Health Movement.

Another member was asked on behalf of Sama and JSA to be part of a team to investigate maternal deaths in Madhya Pradesh.

Overview of Activities

I. Capacity Building through Trainings, Workshops and Orientations

I.A. Regional/ State Level Workshops with health activists, community based organizations, networks and young people

1.A.i. Regional level workshop, 'Towards Realizing the Right to Health: Lessons and Challenges'

A two-day regional workshop, 'Right to Health: Lessons and Challenges', was conducted in March 2011. The workshop sought to:

- Develop a broad understanding of the determinants of health
- Identify, analyze and reflect on complex challenges in public health encountered both locally as well as at the structural level and the need for multi-dimensional solutions
- Identify and reflect upon strategies used by the health movement as well as other people's movements and networks and develop a critical thinking towards realizing the right to health
- Develop a nuanced understanding on the different concepts/ discourse related to the right to health and emerging action

The workshop was attended by 40 participants (32 women and 8 men) from the five states of Uttar Pradesh, Uttarakhand, Madhya Pradesh, Rajasthan and Delhi. The workshop facilitated a strengthened understanding on the determinants of health and with the concepts of rights and equity.

The resource persons for the workshop were from the Right to Food movement, the Jan Swasthya Abhiyan and others. Presentations and sessions also focused on lessons learnt from these larger movements and were extremely useful in helping the participants envisage and identify strategies towards realizing the right to health. In this way, the workshop was specifically conceptualized and designed in such a manner so as to generate further discussions and reflections on health advocacy in their states and take up advocacy initiatives in this regard in their areas of work.

1.A.ii. Workshops / meetings to assess the training needs / requirements of a sangathan working in Jaunpur, Uttar Pradesh

Sama was invited to Khutahan Block of Jaunpur District in Uttar Pradesh to conduct capacity building workshops / trainings on health with members of the sangathan as well as with women and men from the community. The *sangathan* has been actively engaging against discrimination, exclusion and on other issues of human rights violations of the marginalized - *dalits*/adivasis in the area. Sama members visited the area during 23-26 August 2010 with the objectives of carrying out a needs assessment for future capacity building / training initiatives through interactions with members / leaders of the sangathan as well as with the community.

The lack of access to health and educational facilities and violation of health rights (including increasing privatization), misappropriation of funds/ money provided under NRHM and corruption at different levels clearly emerged from the discussions.

In addition to these, irregularities in the PDS, NREGA, etc. came up as important issues. The discussions at villages, *karyakartas* and other *sangathan* members highlighted the need for engaging with and mobilizing women in the areas around health issues. Given the situation of health and other social determinants of health, the need for strengthening of knowledge about the health system towards consolidating advocacy efforts clearly emerged from the interactions. Future workshops and trainings are being planned in the month of March 2011.

I.A.iii. Workshops on Infertility and Assisted Reproductive Technologies (ARTs) from a Gender Perspective

Regional/ State level Workshops were conducted for activists from community based organizations and networks towards initiating discussion on infertility and ARTs. These workshops were organised in different states / regions and sought to explore infertility and ARTs in diverse contexts while examining existing commonalities.

A three-day workshop was jointly organised by Sama and Jan Swasthya Abhiyan (JSA) Orissa during 15 – 17 December 2010 at Bhubaneswar, Orissa. It was attended by 30 participants from Orissa and Jharkhand. Participants were from eight different districts of Orissa and six districts from Jharkhand.

All participants were working on issues of health – the right to health care. The workshop discussed the gendered implications of infertility and ARTs; the response of the health system, to increase the understanding of participants about ARTs. One of the objectives of the workshop was to make participants understand the ethics and medicalization of new reproductive technologies.

I.A.iii. Regional Workshops on Infertility and Assisted Reproductive Technologies: A Gender Perspective, Chhattisgarh

Themes that were discussed / debated in the workshops

- Creation and essentialization of certain identities such as motherhood and questioning gender stereotypes.
- The issues and politics of infertility.
- Assisted reproductive technologies including surrogacy. The various Social, Ethical, Economic and Medical implications of these technologies, including the possibility of sex-selection using these technologies.
- Response of public health system to infertility.
- The growth, proliferation and Commercialization of ART industry.

A two-day workshop was jointly organised by Sama along with *Chaupal Gramin Vikas Prashikshan Evam Shodh Sansthan* and Public Health Resource Network in Raipur, Chhattisgarh, from 27-28 September 2010. The workshop was attended by 35 participants from 10 districts across the state. The participants of the workshop were engaged on diverse issues including women's health and rights, adivasi rights, children's health and rights, disability rights, *mitanin (health worker)* program, etc. and hence were able to raise and create linkages with different contexts and issues that they were involved with.

The workshop initiated discussion around the essentialization of motherhood, the devaluation of certain types of motherhood; and issues and politics of infertility. It also provided an opportunity to equip participants with technical information about Assisted Reproductive Technologies including Surrogacy; their social, ethical, economic and medical implications, including the possibility of sex-selection using these technologies. The workshop was also able to discuss the concerns regarding the draft ART Bill (2010).

The workshop provided the opportunity to examine motherhood, infertility, health care, adoption and other related issues particularly in the context of Chhattisgarh – situating these in the larger context particularly experienced by the adivasi communities in the state.

I.B. Seminar on Addressing Sex – Selection: Continued Challenges and Emerging Concerns, Delhi

Sama organised a Seminar on *Addressing Sex – Selection: Continued Challenges and Emerging Concerns* on **4 December, 2010** in Delhi. Sama has been involved over the years, in advocacy by the women's, health and other movements and networks against sex selection. For the past 5-6 years, Sama has been closely involved in research and advocacy on issues with regard to assisted reproductive technologies and in the course of this engagement with ARTs, Sama has come across the use of pre-implantation genetic diagnosis being used for sex selection and for the selection of other traits.

Foetal sex determination and consequently, sex-selective abortions is a thriving business for medical professionals and establishments, and has grown into a Rs 1,000 crore industry (US\$ 244 million).¹ Moreover, the misuse of high-tech pre-implantation genetic diagnosis (PGD) techniques raise grave concerns about exacerbating sexism, threatening the well being of children, and setting the stage for consumer eugenics in which parents are sold techniques to select not just their child's sex, but a range of other traits as well.

¹Alka Gupta (2007), 'Female Foeticide in India', UNICEF, available at http://www.unicef.org/india/media_3285.htm, accessed on 5 February 2010

Given the complex nature of the issue of sex-selection and emerging concerns, the seminar brought together individuals, organizations and networks, who have been working on different aspects linked to sex selection to reflect on past experiences and arrive at concrete strategies for future action. The Seminar facilitated the:

- Examination of the linkages between socio-cultural attitudes and behavior, including dowry, honour crimes, policies that control fertility; emerging debates on abortion; the economics and proliferation of new reproductive technologies and sex selection.
- Sharing and exchange of information and experiences emanating from activism and research on practices, policies, legal frameworks and regulatory mechanisms.

The seminar was attended by 25 participants from community based organizations as well as advocacy groups, working broadly on issues of women's health and rights, disability, marginalized sexualities and on addressing sex selection. Participants were from states in the northern region – Rajasthan, Haryana, Delhi, Orissa, Madhya Pradesh, Uttar Pradesh, and Jharkhand - with some of the worst sex ratios. Dr. Mary John, Prof Anita Ghai, Anjali from Sama made presentations that provided an overview, on disability and assisted reproductive technologies and their linkages / debates in the context of sex-selection. The seminar clearly highlighted the extremely poor implementation of the PC and PNDT Act, the lack of coordinated advocacy efforts at the national level and the need for discussion and formulation of an action plan to address these existing challenges and newer concerns associated with sex selection.

I.C. Training on Gender Mainstreaming for state personnel associated with Health and Nutrition Programmes

The main objectives of the training were to enable the participants to develop clear perspective about gender analysis and its importance in health and nutrition programmes; make them understand the interrelationship between biological, psychological and social factors that generate specific health and nutritional needs for women and men; develop the skills for conducting gender diagnosis of existing health and nutrition programmes; and provide skills for planning health and nutrition programmes/projects with gendered approach.

As part of the training on Gender Mainstreaming in Health and Nutrition Programmes, a training on *Reproductive Health and Reproductive Rights: Gender Issues Therein* was conducted by Sama on 22 September 2010. The training included 30 participants comprising of executives and middle level functionaries associated with health and nutrition programmes for women and children.

I.D.Capacity Building for Sama staff

Members of Sama staff participated in the following workshops, orientations and courses, towards strengthening the organization's understanding, perspectives and skills on diverse issues that Sama is working on.

I.D.i. Study Tour cum Exposure Visit to build perspectives and networks on Sexual and Reproductive Labour in South Asia

A study tour cum exposure visit to visit Nepal and Bangladesh, to build perspectives and networks on Sexual and Reproductive Labour in South Asia was undertaken by four of the younger women members of Sama.

These visits were undertaken in the context of emerging new markets for women's labour and body parts that have opened up under globalization - migrant domestic workers, sex workers and surrogates using their bodies as a resource in jobs that exploit their health and rights, while also presenting opportunities to enhance their autonomy.

These visits provided opportunities to build conversations and networks around these issues in South Asia, particularly to learn from the experiences of organizations and networks in Nepal and Bangladesh that work on trafficking, migration, livelihoods and violence, sexual and reproductive rights, etc., and the response of the feminist and other social movements to these concerns.

I.D.ii. World Conference on the Development of Universal Social Security Systems

As part of JSA, Sama (Susheela) participated in the first World Conference on the Development of Universal Social Security Systems, held during 1 - 5 December 2010, in Brasilia (DF), Brazil. This conference was organised by the Brazilian government, following the decision of the II World Social Forum on Health held in Nairobi, Kenya, in January 2007, and given the relevance of the theme for global policy. One of the objectives were to strengthen the existing universal systems through the exchange of experiences, achievements and common challenges

Participants from approximately 70 countries were part of the conference and presented on the health situation in their respective countries. Meetings of countries from diverse

regions facilitated discussions and recommendations specific to the health systems in those regions. The recommendations that emerged for different regions were presented at the conference.

The visit / participation in the conference provided the opportunity to understand the Brazilian as well as other health systems better – visits to Brazilian public health centres and hospitals, specific programmes to address HIV / AIDS provided insights into the functioning of the health system, thereby providing lessons for systems in other countries and regions, including India.

I.D.iii. Participation in the Indian Association of Women’s Studies (IAWS) Conference, Wardha

Two members of the Sama team participated in the IAWS conference on *Resisting Marginalisations, Challenging Hegemonies: Re-visioning Gender Politics* during 21-24 January 2011 organised by IAWS with the Department of Women’s Studies, Mahatma Gandhi Antarrashtriya Hindi Vishwavidyalaya. The discussions and presentations were extremely insightful and provided the opportunity for exchange of experiences and theories by young scholars and researchers on a range of themes – control of resources and the politics of exclusion, sites of justice, composite cultures and hegemonic ideologies. Sama members contributed to discussions on violence, technologies, etc. at the conference based on our work and experiences.

I.D.iv. Medico Friend Circle (MFC) Annual Meeting

The 38th Annual Meet of MFC was held during 7-9 January 2011 at Nagpur Maharashtra, to discuss the theme ‘Towards Universal Access to Health Care in India. Six members of the Sama team attended the meeting. A total of 120 persons attended the meeting.

Sama members were part of the discussions that spanned the diverse components of Universal access, different models and experiences, including experiences of Brazil. The meeting also raised many concerns about public private partnerships, health care financing, etc. which are being ‘pushed’ aggressively in the current context and their implications for universal access.

I.D.v. Workshop on Ethical Issues in Health Research, Delhi

Two members of Sama attended the workshop on *Ethical Issues in Health Research* conducted by the Indian Institute of Public Health, Delhi from 12 - 15 July 2010. The key facilitators were Dr Richard Cash (Harvard School of Public Health) and Dr Amar Jesani (Anusandhan Trust).

Ethics is an integral component of all health and biomedical research today, and ethical review has the potential to foreground and safeguard the rights of participants in research. This workshop afforded Sama members the opportunity to strengthen understanding of ethical principles of health research, as well as to share concerns regarding the ethics of the HPV vaccine projects in India.

II. Advocacy and Policy Monitoring

II.A. Advocacy around ARTs and Surrogacy

Sama has been addressing concerns around Assisted Reproductive Technologies (ARTs) through various strategies, including action research, advocacy, and information sharing.

Sama's advocacy efforts have been and continue to be situated within a larger framework that recognizes the inter-linkages of ill-health in general, and of infertility in particular, with social determinants (such as poverty, patriarchy, and hazardous occupations), and stresses the need for universal health coverage, thus mandating the strengthening of the public health system.

Advocacy was targeted at a range of actors simultaneously rather than in succession so as to maximize impact. Engaging at multiple levels together—the community, policy making, international, academia, the media, etc. — was useful for integrating varying perspectives into our work, as much as to involve multiple and diverse stakeholders in the ART discourse. Sama has been engaged in cross-sectoral movement building that has brought to the fore voices from organizations advancing women's rights, public health rights, legal rights, disability rights, and LGBTQ rights, to initiate discussions and debates around ARTs, especially with regard to their regulation. Although different strategies were adopted for different audiences, they were united by their common focus—securing of women's health and rights pertaining to the use of ARTs in India.

At present, there is no legislation for the regulation of ART clinics in India. At the onset of the study, the only document guiding the conduct of ART clinics in India was the National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India (2005), by the ICMR, which was not, however, legally binding. As part of its preliminary advocacy efforts, Sama had, in 2006 critiqued the guidelines from the perspective of women's health and rights, and had highlighted the need for comprehensive legislation formulated through a wider, participatory and transparent process.

Some concerns regarding the Draft ART (Regulation) Bill and Rules, 2010

- The Draft Bill restricts itself to regulating only ART clinics and ART Banks, without taking cognizance of other players like travel agents, surrogacy agents, surrogacy law firms, or even public hospitals providing ARTs that form the diverse components of this growing industry.
- While minimum age for undergoing ARTs is 21, no maximum age is prescribed.
- Though the Draft recommends that not more than three oocytes be transferred (for GIFT) and not more than three embryos (for IVF-ET), it also makes allowance for 'exceptional circumstances', thus leaving scope for exploitation.
- The Draft discriminates on the basis of sexual orientation and declares that ARTs can only be accessed by couples who have a sexual relationship that is legal in India.
- The health risks and adverse outcomes of ARTs, especially for children, are not adequately listed.
- The Draft allows a woman to donate oocytes up to 6 times in her lifetime with a minimum interval of 3 months between the cycles. Not only is the stipulated interval inadequate, the maximum number of cycles that a woman can undergo has not been specified. This is a significant omission, as every cycle may not result in oocytes viable for donation. Also, no system has been suggested to monitor and record the number of times a woman donates oocytes. Further, the maximum number of oocytes to be retrieved needs to be prescribed not only in case of donors, but also for women undergoing IVF or in egg-sharing programmes.
- The number of live births a surrogate is permitted has been raised from three to five, including her own children. Not only is this on the higher side, thus risking the surrogate's health, but the maximum number of cycles that a surrogate can undergo has not been specified. This is significant because repeated cycles may be required for a live birth.
- Though the Draft outlines that commissioning parent/s should ensure that the surrogate mother and child are 'appropriately' insured, the nature and kind of insurance are not specified. Further, responsibilities of the commissioning parent/s with regard to post-delivery and follow-up care are not clarified.
- There is no provision for legal aid for the surrogate.
- The appointment of a local guardian to keep a close watch on the surrogate is an impingement on her autonomy, freedom and rights. In case the commissioning parent/s give up custody of the child, the local guardian is responsible for either bringing up the child or giving the child to an adoption agency. Herein, the welfare of the child has been left to the discretion of an individual.
- The proposed mode of payment to the surrogate is highly imbalanced and unfavourable to her. The Draft stipulates that the payment will be made in five installments, with 75% to be given in the fifth and last installment, after the delivery of the child. This entirely reduces the labour and risks (emotional physical, social, ethical, etc) undergone by the surrogate to a measurable output, i.e. the baby.

In 2010, the Draft ART (Regulation) Bill and Rules, 2010, prepared by ICMR, incorporating revisions to the previous draft bill, was made available. While the ICMR and the MoHFW had taken into consideration some of the concerns raised by Sama with regard to the Draft Bill (2008), the present draft (2010) is far from comprehensive and falls short of addressing many concerns vis-à-vis women's health and rights. Although changes have been made in different clauses, and significant modifications have been introduced in clauses specific to surrogacy, earlier concerns regarding the nature of Operationalization of the provisions of the bill, the functional relationship between the ART Bank [referred to as Semen Bank in the Draft Bill (2008)] and the ART clinics, etc., still remain. A critique of the ART Draft Bill was developed by Sama and advocacy with policy makers, media advocacy strategies are being followed up to reiterate continuing concerns.

II.B. HPV Vaccination 'Projects' In India

Thousands of young girls have been vaccinated against HPV in India (in the two states of Gujarat and Andhra Pradesh) over the last year, under an ambiguously termed 'demonstration project' led by the American NGO 'PATH', and funded by the Bill and Melinda Gates foundation. The extremely unethical nature of administration (lacking basic health infrastructure, adequate consent, follow-up care etc) of a vaccine surrounded by controversies over its safety and efficacy, raises some serious questions. While seven girls have sadly died post-vaccination, many are suffering from adverse impacts.

Two members of Sama along with other activists had conducted a field visit from March 27-30th to the Bhadrachalam mandal of Andhra Pradesh, one of the vaccination sites. The findings from this visit were then compiled to a report. Following this, the main findings from the fact finding were presented at a Press Conference organized in Delhi on 7 April 2010, on World Health Day. Sarojini from Sama was one of the Panel members at the Press Conference along with Rajya Sabha MP, Brinda Karat, Amit Sen Gupta from Jan Swasthya Abhiyaan, Sudha Sundararaman from AIDWA and Kalpana Mehta from Saheli. Following this press conference the 'project' was suspended by the Ministry of Health and Family Welfare, and a committee was set up to look into the entire process. However, the composition of the committee was far from representative and was also cause for concern to which an immediate memorandum was dispatched, albeit with no response from the Ministry.

Most recently, on 8 February, 2011, an article in the Hindu newspaper stated that the Committee set up by the Ministry to investigate into the trials had submitted their interim report. Although the report highlights several inconsistencies and violations it fails to hold those involved liable or accountable. Following efforts to get a copy of the report, a detailed study and critique of the report was carried out by Sama, along with JSA and other groups. Although the Committee has identified several deficiencies in the planning and implementation of the project, the report, submitted to the MOHFW has failed to fix responsibility on any individual or agency. Rather than suggesting any punitive or disciplinary measures, it merely marks out certain minor deficiencies as lessons for strengthening clinical research in the future.

A memorandum has been submitted to the MOHFW, highlighting these inadequacies and that all involved be considered culpable, and appropriate punitive action be taken. A press conference by JSA took place on the 17 February 2011 to highlight concerns regarding the Interim Report of the Committee; Sama was part of organizing it. Speakers at the conference were Brinda Karat, Member of Parliament, Amit Sen Gupta, AIPSN / JSA and Sarojini, Sama / JSA.

II.C. Advocacy towards strengthening of the Health System towards strengthening Maternal Care and Prevention of Maternal Deaths

Sarojini from Sama along with others - Dr Subha Sri and Renu Khanna on behalf of the Jan Swasthya Abhiyan, CommonHealth and Sama - carried out a fact-finding visit to Barwani to investigate into the maternal deaths and the situation of maternal care in Barwani district, Madhya Pradesh. The visit was undertaken following recent reports of large numbers of maternal deaths, especially in the district hospital. This issue was initially raised through protests by organizations / sangathans working in the area.

A report, *Maternal Deaths and Denial of Maternal Care in Barwani District, Madhya Pradesh: Issues and Concerns* based on interactions with families of women who had died, and with health providers was completed and disseminated during this period. Meetings were held in Bhopal, Madhya Pradesh with health officials, media, *sangathans*, and organizations, networks for dissemination of the findings and to plan future strategies. Similar actions are also being planned in Delhi in the month of March 2011. The investigation reflected the abysmal and disturbing status of health of women, particularly from the adivasi communities; the extremely poor condition of the health system, despite five years of the implementation of the National Rural Health Mission. This raises the need for urgent and ongoing collective advocacy efforts in the forthcoming months around issues of strengthening of health systems, violations and complete lack of accountability.

II.D. Universal Access to Free OPD Treatment

II.D.i. National Consultation on 'Meeting Health Rights by Free Treatment to All Indians - Requirements and Challenges', Delhi

A day long consultation on *Meeting Health Rights by Free Treatment to All Indians - Requirements and Challenges* was jointly organized by Prayas, Jan Swasthya Abhiyan, Centre for Budget and Governance Accountability (CBGA), Oxfam India, Centre for Legislative Research & Advocacy (CLRA) and Sama on 4 May 2010 in Delhi.

The consultation was organized taking into consideration the urgent need to mobilize different stakeholders, policy makers to discuss and deliberate on different issues related to access to treatment and medicines as well as identify systems and mechanisms which can be put into place to make public health services more accessible and affordable to everyone in the country.

More than 60 people from different civil society organizations, people's networks, members of Parliament, experts on pharma and medicines, academia, etc., participated in the consultation. A poster related to the issue was also released on the same day.

The consultation provided an orientation towards sensitization of members of parliament and policy planners about this very vital issue towards evolving an economic and social model to ensure free treatment to all citizens of India.

II.D.ii. Study on the existing situation of Free OPD drugs in Delhi Government Hospitals, Jan Swasthya Abhiyan Delhi

The *Universal Access to Free OPD Treatment*, was launched by JSA in 2010. The action for universal access was identified as the focus action point by the Jan Swasthya Abhiyan

Delhi and as part of this, members of JSAD concluded the need for a study / situation analysis of the existing situation vis-à-vis OPD treatment / drugs. The study aims to examine the existing situation vis-à-vis availability, accessibility and quality of drugs in government facilities in Delhi. The study is expected to reflect the realistic situation of the functioning public health system in Delhi and to use the findings that emerge to strengthen it.

Sama has taken on the responsibility of secretariat for JSAD, and coordinating the JSAD from April 2010, and was actively involved in designing the study along with other member organizations and in coordinating the study. However, the study is yet to begin due to the inability of organizations who had initially volunteered to be part of the study to continue with it. This situation is being reviewed towards developing a plan / strategy to carry out the study and the follow up action.

II.E. Advocacy on Bioethics

Sama has been active in the national bioethics movement and was a member of the organizing committees of the first and second National Bioethics Conferences in 2005 and 2007 respectively. Both these conferences enabled substantial strengthening of the ethics movement in the country and discussion on pertinent ethical issues in the context of health care.

II.E.i. The Third IJME National Bioethics Conference (NBC3) 2010, Delhi

The NBC 3 whose theme was ***Governance in Healthcare, Ethics, Equity and Justice***, was held at All India Institute of Medical Sciences, New Delhi from 17 -20 November, 2010. The objectives of the conference were:

- To bring together key institutions within the healthcare sector to engage with the issue of governance with a view to ensuring equity and justice for all.
- To enable emerging research in bioethics in India to be presented in a public forum and encouraging this research to be published in national and international journals so that it reaches a wider audience.
- To create a forum for organising skill-building and resource sharing in bioethics among different organizations and to enable dialogue between key stakeholders from India and abroad on a range of issues and from a range of perspectives with a view to enlighten healthcare practice, policy making and management from a bioethics perspective.

In NBC3, Sama continued to be part of the national organising committee as well as hosted the local secretariat in Delhi for the conference. Sarojini from Sama was part of the Conference Co-ordination Committee that oversaw the entire organization process for the

NBC3. As a member of the organizing committee, Sama was involved in planning the content, structure and mobilizing financial resources for the Conference. Over 350 participants attended from 7 countries participated in the NBC3. In all, 58 papers in 25 parallel sessions and 44 contributions to 12 workshops sessions that were spread over the four days of the conference.

Four presentations (three paper and one poster presentation) were made by members of Sama at NBC3 that looked at ethical issues with regard to:

- HPV vaccine trials in India and the collapse of governance, law and ethics
- stem cell research
- regulation of assisted reproductive technologies
- Janani Suraksha Yojana in the NRHM

The NBC 3 resulted in:

- Participation by over 350 participants from 7 countries.
- Presentation of 58 papers in 25 parallel sessions and 44 contributions to 12 workshop sessions over four days.
- Involvement of 38 organizations in the National Organising Committee towards organising NBC3.
- Reiteration of the concern for equity in health and health care.
- Demand for a legal framework rooted in social justice and a monitoring mechanism for ethics that respects both of these concerns.

II.E.ii. The 10th World Congress on Bioethics, Singapore

The 10th World Congress on Bioethics was held in Singapore from 28-31 July 2010 and was attended by 3 members from Sama. Two presentations were made at the Congress - *HPV vaccination in India: A public health 'experiment'* and *Assisted Reproductive Technologies and stem cell research at crossroads* to highlight the lack of ethics of the HPV vaccination projects, particularly focusing on their public health implications and ethical issues related to ARTs and Stem Cells in India respectively.

The presentations enabled facilitated discussion on these issues with a wider, international audience and engaging with the ethics discourse.

II.F. Strengthening the Public Health System Response to gender based violence – domestic and sexual violence

Given that gender based violence has serious and pervading implications for health, health care institutions have a critical role to play in addressing the health consequences of violence. Further, since the health care system is the first-- and often only-- point of contact that women survivors of domestic violence access when they seek treatment, it is the obligation of health care systems to provide referral services for other support systems. Health care providers such as doctors, nurses, medical and psychiatric social workers, psychologists, physiotherapists, etc. assume a critical role in screening patients for assault as well as referring them to appropriate agencies for help. The health sector also has a fundamental role to play in violence prevention. As such, the need to begin viewing violence against women as a public health issue cannot be overstressed. A proactive and sensitive health system could well make the difference between survival and death for women in situations of violence.

Sama in collaboration with CEHAT (Mumbai) has been involved in an important initiative with the Safdarjung Hospital and the Association of Obstetricians and Gynaecologists, Delhi (AOGD), a professional body comprising health providers from public as well as private facilities, towards understanding the role of the health system and health care providers in addressing the health consequences of violence against women.

Examining the protocol for examination of sexual assault and recommendations strengthening examination and evidence collection

As part of this initiative, meetings were organised with the Director General of Health Services, Delhi and with Heads of Departments of ObGyn, faculty, senior specialists, senior residents, nurses, etc. from hospitals (Safdarjung, Ram ManoharLohia, Lady Hardinge, Hindu Rao, Lok Nayak Jai Prakash Narayan and Guru Teg Bahadur) in Delhi, on 28 and 29 May 2010 respectively to discuss the protocol for examination and evidence collection in sexual assault cases and to arrive at a consensus on the protocol and recommendation for Examination and Evidence Collection in cases of Sexual Assault, towards strengthening examination and evidence collection in cases of sexual assault.

Needs Assessment of Health System Response to Sexual Assault

Towards working with health care providers in the hospital to develop a comprehensive health care response for survivors of sexual assault, there was need to understand the existing systems - procedures and practices in the hospital prior to initiating activities in the hospital. Such an assessment, it was felt, would facilitate the planning and designing

of the intervention based on the needs of the hospital. It would inform the nature of the collaboration and components that need to be put in place so that a comprehensive response to sexual assault can be implemented. Thus a needs assessment was initiated with the following objectives:

- To understand the existing procedures followed and services provided in cases of sexual assault.
- To understand the role of varied players in responding to cases of sexual assault and problems faced while performing the role.
- To understand the nature of documentation that is maintained and gaps in documentation.
- To identify perceived training needs of health professionals and recommendations to improve the response.

The needs assessment took place during June – August 2010 using in-depth interviews with key informants. The key informants included health care providers who come in contact with a survivor of sexual assault or were involved in handling of forensic evidence. Fifteen interviews were conducted in all from the department of ObGyn. In addition to this, an Assistant Sub-Inspector (ASI) of one of the police stations from where sexual assault cases were brought to hospital was also interviewed.

A report *A Study of Response to Sexual Assault at Large Tertiary Care Hospital* based on the needs assessment was completed during this period and is undergoing a process of review and reorganization prior to it being published.

Dissemination of the report as well as interventions in the hospital based on the emerging findings are being planned in the forthcoming months.

II.H. Other Advocacy Efforts

II.H.i. Presentations and participation at conferences, seminars, meetings

➤ Sama participated in the **National Consultation on Issues Impacting on Women for Inputs into the 12th Plan document** on 11 December 2011 at Chennai. The Planning Commission had opened up a process for broader consultation and inputs, particularly with the civil society towards the preparation of 12th Five Year Plan. The Planning Commission sought engagement with civil society to get inputs for the approach paper of the 12th. The consultation was presided over by member, Planning Commission, Syeda Hameed and provided the opportunity for Sama to raise critical issues pertaining to the proliferation of the ART industry and surrogacy and the need for their regulation in the context of growing medical tourism, etc.

➤ Presentation on ARTs and Sex Selection, at a Consultation on the Implementation of the PC&PNDT Act, 26th September, organized by the Human Rights Law Network, to

brainstorm on the list of direction to be sought at the upcoming hearing of the VHAI vs Union of India PIL filed in the Supreme Court regarding the implementation of the PCPNDT ACT

- Intervention on the linkages between ARTs and sex selection and other draconian policies, at a brainstorming meeting on Complexities and Challenges in Addressing Sex Selection in India. 8th September 2010
- Sama made a presentation on 'Issues in Women's Health' at the AIPSN workshop held at Shimla, Himachal Pradesh, from 2nd to 5th July, 2010. The presentation, followed by a discussion, covered contemporary issues in women's health in India today, locating these within the framework of a gender and rights based perspective, and also within a global neo-liberal shift in governance. Maternal mortality, medicalisation of women's bodies, violence against women, and the relationship between gender and development, and gender and queer rights, were some of the key areas of discussion. The session was attended by approximately 50 participants from across the country.

II.A.ii. Presentations at Universities and Institutions of Higher Education

Universities and other institutions of higher education were tapped, both nationally and internationally. Lectures and seminars where ARTs could be discussed provided opportunities not only for the dissemination of the research findings, but also for influencing future research on a range of issues:

Lectures at American Universities, September 2010

➤ *Hampshire College, Amherst*

This session was organized by the Reproductive Politics group of five colleges situated in Amherst valley (Smith, Hampshire, Amherst, U-Mass, and Mount Holyoke). The audience comprised of over 30 professors and research students, several of whom were working on similar issues.

➤ *Tufts University, Boston*

This session was organized by professor and researcher Kevin Irwin, for an undergraduate class on Community Health. Over 60 students and one professor of Women's Studies (also working on surrogacy) were in attendance.

➤ *Harvard School of Public Health, Boston*

This session was organized as a Guest Seminar by the Women, Gender and Health group, in collaboration with the South Asian Student Organization, with over 50 students and professors from Harvard University in attendance

Assisted Reproductive Technologies and Globalization: Conceptual and Methodological Challenges, presented at the Symposium on Health Systems, Health Economies and Globalization: Social Science Perspectives organized by the Centre of Social Medicine and Community Health, Jawaharlal Nehru University (JNU), 3 November 2010.

Globalisation of Birth Markets: A Case Study of Assisted Reproductive Technologies in India, presented at a Symposium in London, on Health systems, Health Economies and Globalisation: Social Science Perspectives organized by Kings College, London and the London School of Economics and Political Science in July, 2010.

The Business of Making Babies for Profit at Home and Abroad, presented at the International Conference on Ethical Issues in Medical Tourism, Canada, *organized by Simon Fraser University and the Canadian Institutes of Health Research* in June, 2010.

Presentation on **Biomedical Research** in India at National Workshop on “Challenges to Clinical Legal Education in Contemporary India” organized by the Chityala Ailamma Centre for Interdisciplinary Research, Secunderabad in collaboration with the A.P. University of Law, Vishakapatnam, at Centre for Economic and Social Studies in Hyderabad on the 27-28 June 2010.

II.A.iii. Media Advocacy

Sama engaged the media as a significant tool to mobilize public opinion. This was done through contributions to newspapers and journals (including peer-reviewed journals), TV interviews, etc. Sama contributed articles and papers to the following journals and newspapers:

➤ ***Surrogacy: Law’s Labour Lost?, The Hindu, 25 July 2010***

The article presents the inconsistencies in the revised Draft ART Bill of 2010, particularly with regard to provisions about surrogacy and citizenship.

➤ ***The HPV Vaccine: Science, Ethics and Regulation, Economic and Political Weekly, 27 November 2010.***

Two members of Sama (Sarojini and Anjali) were co-authors of the paper that highlights the various inconsistencies and ethical violations that have occurred during the licensing of the HPV vaccines in India as well as during the demonstration projects conducted post licensing.

➤ ***At What Price? Gardasil Research Targets Girls from Vulnerable Communities, Different Takes, No.65, Summer 2010***

The article outlines some of the main findings from the Fact Finding visit to Bhadrachalam, one of the sites of the HPV vaccination projects in Andhra Pradesh.

Some of the contributions to visual media- television and documentary films by Sama:

➤ Sama was part of television talk shows and documentaries on the issue of surrogacy on *Lok Sabha TV, Doordarshan, etc.* Other channels such as NDTV, 9x, Reuters Television, etc. also approached Sama for inputs in the issue. Radio Canada approached Sama in November 2010 as part of a radio documentary about the growth of the surrogacy industry with focus on Canada, USA and India.

➤ Sama provided critical inputs to the co-directors of the film, 'Made in India' which looks at cross border commercial surrogacy, especially on the issue of regulation.

➤ Sama members were also approached by B&B Films, a documentary production company based in Rome, Italy for their recent project on ARTs in India with a special focus on Surrogacy.

III. Action Research

III.A. Action Research on Assisted Reproductive Technologies

Sama successfully completed the action research on Assisted Reproductive Technologies in the three states of Tamil Nadu, Uttar Pradesh and Orissa. The period (April 2010 – December 2010) was the final phase of the research, requiring a substantial amount of time in analysis, conceptualizing, structuring and the writing of the research report. The preliminary drafts of the report went through several rounds of internal review, along with external reviews and comments from members of the advisory as well as other experts.

The research highlighted both inter and intra state variations and commonalities regarding the practice and the experiences of accessing these technologies. Some of the main findings of the research are:

- While the definition and the understanding of infertility was fluid and varied across different communities, an increased medicalisation of the condition and the causes was a significant observation.
- Stigmatisation and ostracism as a result of infertility was commonly found, and not surprisingly the disproportionate burden of this was experienced by women.

- Socio-cultural and economic factors as well as institutions such as family and ties of kinship significantly influence the decision making process during infertility treatment (including accessing ARTs).
- Couples from different economic strata accessed ARTs, many a times also pushing their financial capacities in the pursuit of a biological child. Couples from varied caste and religion were accessing ARTs, and seemed particularly important in the context of donor gametes and surrogacy arrangements.
- More often than not infertility treatment was found to be multidirectional and multifaceted, with the couples also going for alternative systems of medicines (such as unani, siddha, ayurveda, homeopathy, and home remedies). ARTs as technological intervention were seen as part of the larger infertility treatment, and many a times were not the culmination of the treatment.
- Infertility treatment in general and ARTs in particular has a significant bearing on the economic condition of the couples, and was most evident in the couples from low economic background.
- The practice of ARTs continues to proliferate even in smaller towns in the absence of any regulatory mechanism. Services for infertility care, including basic screening facilities are conspicuous by their absence in the public health system. This also raises the larger question of access, equity and affordability.
- While the health consequences of infertility treatment in general and ARTs in particular was noticeable, the movement of users from one health facility to another, across towns, cities, districts was also seen. The geographical relocation for accessing ARTs also influenced the social worlds and realities of the users in a significant way.
- The extent of the growth of the ART industry has not been uniform across cities, districts or states. While in Tamil Nadu it seems to be most proliferated, the industry in Orissa is still at a nascent stage, but at the same time growing.
- Other stakeholders and players such as the tourism agencies, private health care establishments, consultancy agencies, law firms, and state and central governments also play significant part in the growth and proliferation of the ART industry.

The research on ARTs and advocacy initiatives have contributed to:

- The global debate on ARTs and surrogacy; consolidation of existing knowledge, understanding and analysis of ARTs, surrogacy, the fertility industry, tourism, role of caste and class vis-à-vis ARTs and surrogacy.
- Initiation of discussion among activists, community based organizations, networks, academics, researchers, media towards wider dissemination and mobilization; discussion across social – women’s, disability, sexual rights, ethics, health – movements has facilitated flagging of issues around these technologies in their work; and their perspectives informing the discourse on ARTs.

- Filling the existing gap in the lack of literature and providing for a nuanced, evidence-based understanding of the operationalization of ARTs in the Indian context. Several of Sama's published articles and reports mentioned above on the issue of ARTs are being used as reference material by researchers and academics working on allied issues.
- Creation and strengthening of linkages with researchers, activists, academics, organizations, and networks engaging on issues of biotechnology, ARTs, surrogacy, etc., nationally as well as globally, especially around the advocacy on ARTs, surrogacy.
- Informing / influencing policy and legislation - evidence from the research has strengthened advocacy efforts towards ensuring that the legislation - the draft bill- is more comprehensive from the perspective of health and human rights.
- Recognition of Sama as a key knowledge resource working on the issue. Sama has come to be recognised as the key/prime group working on issues of ARTs and surrogacy, and has been approached by activists, students, researchers, film makers, journalists, and policy makers who seek inputs on various aspects of ARTs and surrogacy.
- The research study contributed to strengthened knowledge and understanding of infertility, the nature and functioning of the ART industry, etc.

III.B. Research to study the *Impact of Health Insurance on Access to Health Care*

Insurance has been one mechanism through which the issue of access has been addressed in other countries, but health insurance is at a nascent stage in India, where about three percent of the population are insured in any form. Most of the insured are people in the formal sector (especially civil servants and industrial workers). The issue of health insurance has become extremely important in the current context of liberalization of the insurance sector in India. Few prior systematic attempts have been made to examine health insurance from a right to health framework. The research is an essential step to situate the issue in the current context of liberalization and attempts to examine whether health insurance improves access to health services and ensures Right to Health for All.

During this period, systematic search of published literature, organizational reports, thesis on insurance in India was begun. Preliminary meetings with experts who have been looking at health financing and insurance were very useful in focusing the research. The research is extremely pertinent and has several implications for policy and is expected to facilitate the development of pertinent policy recommendations with regard to health insurance.

III.C. Proposed future initiatives in research

➤ Sama and the Centre of Social Medicine and Community Health, Jawaharlal Nehru University, are in the process of formulating a research proposal ‘Ethics, Commercialization and Care: Globalisation of Reproductive Technologies’ that will be a multi-site ethnography, mapping the supply chain of reproductive technologies between India, UK and USA. In this project, Sama seeks to investigate in particular third party reproduction, involving the use of reproductive technologies with donors and/or surrogates, and the ways in which these are imagined and negotiated, thus taking forward Sama’s past research on ARTs in India.

IV. Knowledge Creation and Dissemination

IV.A. Constructing Conceptions: The Mapping of Assisted Reproductive Technologies in India

The detailed analysis of the research findings has been published in the report-Constructing Conceptions. The report documents the premium placed on motherhood, social stigma associated with infertility and the cross cutting desire of having a biological child, which have led to the escalation of birth technologies into a ‘fertility industry’. The report also highlights unethical practices in provision of these technologies due to the lack/absence of regulation, with grave implications on the health and rights of women availing these technologies. That the state has been promoting these technologies, without addressing the issue of infertility and its root causes and that these ‘birth technologies’ or assisted reproductive technologies (ARTs) have, using a language of choice and rights, not only created a market for donors and surrogates, but have also commercialized and fragmented human reproductive body parts like ova and uteri is discussed in the report.

The report documents the lived experiences of women of different class and caste backgrounds accessing reproductive technologies. It critically addresses the impact of ART on women, moving beyond the economics or commercial aspects. It examines the wider set of issues in which ideas about market, science, culture, nature and kinship are intertwined in complex ways.

IV.B. Unravelling the Fertility Industry: Challenges and Strategies for Movement Building

A report based on the discussions, major challenges and strategies that emerged during the international consultation organised by Sama on the commercial, economic and

ethical aspects of assisted reproductive technologies during 22-24 January 2010 in Delhi was published and disseminated widely during this period.

Some highlights of the last year:

- Trainings with community based organizations has facilitated and strengthened advocacy efforts at the local level, in particular, with regard to ARTs and surrogacy.
- As part of JSA, Delhi, Sama is involved in designing and coordination of a study to understand the availability, accessibility and quality of drugs in the public health system.
- Following the fact finding by Sama and consistent advocacy efforts by groups and organizations in which Sama was actively involved to highlight the inadequacies and unethical implementation of the HPV vaccination projects in Andhra Pradesh and Gujarat, the projects were suspended on 8 April 2010.
- The findings from Sama's research on Assisted Reproductive Technologies: Implications for Women's Reproductive Rights and Social Citizenship were compiled in the form of a detailed research report - *Constructing Conceptions: The Mapping of Assisted Reproductive Technologies in India*.