

**Annual Report**  
**April 2013- March 2014**

***Sama-Resource Group for Women and Health***

B-45, 2nd Floor, Main Road Shivalik,

Malviya Nagar, New Delhi-110017

Ph: 011-65637632/26692730

This report provides an overview of the activities and initiatives undertaken by Sama during the period April 2013 to March 2014 across different organisational focus areas.

## **I. Advancing Right to Health and Health Care**

I.A. Strengthening capacities and perspectives of diverse groups, organisations, etc., through state and regional level workshops/ orientations

### ***I.A.i. Workshop on ‘Promoting patients’ rights and ensuring social accountability and rationalization of care in the private medical sector***

The northern regional workshop was organized by SATHI (Pune) in collaboration with Sama (Delhi) for northern states during 25-26 October 2013 in Delhi. The workshop was organized to deliberate on the Clinical Establishments Act (CEA) enacted by the central government in 2010 for private sector regulation and its adoption by some states, as well as the separate legislations formulated in other states, and existing legislation in others such as the ‘Delhi Nursing Home Registration Act’. About 40 participants from Delhi, Punjab, Haryana, and Uttar Pradesh participated. The workshop enabled a preliminary understanding of the nuances of regulation and monitoring of the private health care sector, including analysis of existing national and state level regulations and discussed possible ways of moving ahead in this situation.

### ***I.A. ii. Workshop on Gender, Health and Rights for Media and other Students, and Young Professionals***

The workshop used the illustrations of assisted reproductive technologies (ARTs), commercial surrogacy and gender based violence, to discuss health rights, health determinants, regulation, etc. This workshop, organized on 29 June 2013 in New Delhi and was attended by about 30 people, sought to build understanding on these issues amongst young people. Apart from Media students (journalism, mass communication, and cinema studies) and other young media professionals, students from varied academic institutions and backgrounds including Sociology, Gender Studies, Political Science, Math, Economics, History, Medicine, etc. participated in the workshop.

### ***I.A.iii. Seminar on Health Insurance: Current Trends and Challenges***

Sama organized a seminar on Health Insurance on 28 June 2013 in Delhi. This seminar brought together about 24 representatives from 20 Delhi based organizations and 4 key speakers (including one from Sama) to discuss, debate, and share experiences around current trends and challenges vis-à-vis the health insurance sector in India. Participants were from community based organizations, networks, organizations working on gender budgeting, research institutions, etc.

The seminar deliberated findings of different studies on social health insurance, community health insurance in India in the right to health frame – Sama’s review and analysis of literature

on health insurance, the RSBY from Chhattisgarh, the Comprehensive Health insurance Scheme (CHIS) in Kerala and the state initiated schemes in Tamil Nadu and Andhra Pradesh, the Family Planning Insurance Scheme (FPIS) were presented and discussed.

The emerging concerns with experiences from operationalisation of these schemes and the increasing foregrounding of corporatization and privatization where insurance and PPPs (Public-Private Partnerships) have become the new buzzwords, as pathways to universal health care, for improving access to health care, etc., were discussed.

#### I.B. National Consultation on Maternal Health

Following on the national level workshop, *Dead Women Talking*, in 2012, the need to draw a more focused political attention to maternal health was felt. The group of public health specialists and civil society activists from different networks and organizations including CommonHealth, NAMHHR and Jan Swasthya Abhiyan, Sama, CEHAT, SOCHARA and SAHAJ, co-organized a national consultation on 12-13 August in Delhi towards recommendations on maternal health policy and programmes and a policy dialogue to present the concerns and recommendations from the group. Dr. Syeda Hameed, Member, Planning Commission and Mr. Keshav Desiraju, Health Secretary, MoHFW, attended and responded to the issues flagged. Follow up initiatives and efforts through policy level interventions, informing of upcoming election manifestos, linking with other networks, etc. were deliberated. A follow up to this workshop is being planned in 26-28 February 2014.

#### I.C. Orientations, workshops on right to health and health care that Sama was invited to present / facilitate:

*I.C.i. Panel on Health and Development* organised by the Azim Premji University, Bangalore in May 2013, for students of the Masters programs in Development and Education (which includes Health as one of the areas of specialization). The panel focused on the issue of Public Health and its impact on development. Sarojini from Sama presented on the gender dimension of public health. The panel discussion was attended by around 50 academics and NGO representatives.

#### I.D. Meetings on Universal Health Care with People's Health Movement (PHM) India (JSA) and PHM global

##### ***I.D.i. Coordination, participation in JSA national level initiatives***

Sama has been active in a range of initiatives by JSA at the national level:

- Sama was involved in coordination of press releases / memorandums by JSA (for e.g. concerns to the National Advisory Council (NAC) with regard to the recommendations regarding universal health coverage (May 2013); training on crisis management in clinical research for clinical trial professionals on 29-30 October 2013 by the government's Department of Biotechnology in collaboration with One World Health

(OWH), an affiliate of Program for Appropriate Technology in Health (PATH), with Clinical Development Service Agency (CDSA) and organized at Indian Institute of Mass Communication (October 2013), etc.

- Facilitating the study on health / health care status particularly of marginalized communities in Delhi and drafting of the Charter of Demands for the Delhi elections.
- Deepa from Sama is co-convening the JSA Delhi along with Joe Varghese.

### I.E. Study on the Impact of Health Insurance on Access to Health Care

A detailed review of the available literature on health insurance was carried out, which has resulted in a working paper *Health Insurance: Evaluating the Impact on Right to Health*. The study aimed to review the evidence base on SHI in India from a right to health perspective. The specific objectives were to (a) review literature on social health insurance (SHI) in India and to summarize the emerging conceptual debates and discourses underlying its potential to address the health care needs of poor populations; (b) critically review the evidence for community-based and SHI schemes and to assess the extent to which they address the various dimensions of the right to health care; (c) highlight the policy relevance of ongoing debates and to chart future directions for research and practice.

A total of seventy-four papers, articles, reports were initially identified that were linked to the theme. Of these about thirty-five papers have been identified as the most relevant in the Indian context. The analysis locates insurance in the frame of right to health and incorporates a substantive focus on equity, examines the evidence base for the ability of the insurance model / scheme to not only make quality health care accessible and affordable for the poor(est) but also provide adequate financial protection. Broadly, the findings of the study suggest the paucity of systematic reviews and comparative assessments undertaken to either test the assumptions underlying the expansion of health insurance across India or to examine the core contents of the right to health; they challenge claims of insurance as impacting equity, access, utilization, financial protection and quality.

Sama also published *The Rashtriya Swasthya Bima Yojana (RSBY) experience in Chhattisgarh: What does it mean for Health for All?* This paper based on six studies of RSBY in Chhattisgarh based on reviews on the ground of RSBY complements the Sama working paper which is based on study of existing research literature. The paper discusses how the reach of RSBY is unfulfilled as a large proportion of the vulnerable population still remains out of its ambit due to low enrolment rates even as evidence of experience among those enrolled points to high out-of-pocket expenditures. [authors: Dr. Madhurima Nundy (PHRN) et al.].

## **II. Strengthening Health System Response to Gender Based Violence**

### II.A. Capacity Building through Trainings, Workshops and Orientations

### ***II.A.i. Regional Workshop: The Way Ahead: Strengthening the Response of the Health Care System to Gender Based Violence***

Over the past two years Sama has been involved in initiatives for developing collective, strengthened understanding / perspectives of gender based violence as a health issue and strengthening health sector response to survivors of violence, through workshops with community based organisations, networks, health workers in the states of Bihar, Uttar Pradesh, Jharkhand, Orissa, Chhattisgarh, Rajasthan, Madhya Pradesh, Delhi, Assam and others. Towards taking forward the discussions and outcomes of these workshops, and consolidating understanding and capacities of organizations from the different states.

The workshop from 27-30 November 2013 in Delhi was envisaged as an “advanced” workshop for organizations and networks that had been part of previous state level capacity building initiatives by Sama. The workshop sought to specifically (a) enable an understanding and analysis of the health system in which response to gender based violence (sexual violence as well as ‘domestic’ violence) is located; (b) build capacities in engaging with the health system to initiate / or strengthen response; (c) strengthen understanding and analysis of the law, policy, recent amendments, standard protocols and proformas; (d) learn from existing strategies amongst participants to initiate responses at different levels of the health system.

### **II.B. Initiatives with health care providers in the public and private health sectors**

***II.B.i. Meetings and Orientations at public sector hospitals:*** (i) Sama continued to engage with the doctors at the Safdarjung hospital in Delhi towards improved response to GBV. The doctors from the hospital were also involved in orientations at other hospitals for health care providers. (b) Orientation at the Guru Tegh Bahadur Hospital (GTB) with doctors and nurses An orientation on health care response to sexual assault, medico legal role of health care providers, updates with regard to the law, counseling, etc. for healthcare providers was organized by the hospital along with Sama in October 2013. The orientation was attended by around 60 participants including Faculty members, Senior Residents, Nurses, mainly from Gynaecology and Obstetrics Department who are involved in the management of cases of Sexual Assault. The Medical Superintendent and the HOD of Gynaecology Department were also present for some sessions. Similar orientations have been requested by different hospitals in Delhi to strengthen the capacities of health care providers which are being planned in the forthcoming period.

***II.B.ii. Orientations for private sector health care providers: Panel on Violence against Women- Responses and Challenges at the Annual Conference of the Association of Obstetricians and Gynecologists***

Sama has been engaging with the Association of Obstetricians and Gynaecologists of Delhi (AOGD) through interactions, conducting workshops, etc. The AOGD comprises of about 1600 members, including a number of doctors from the private but also from the public health sectors in Delhi. The AOGD organises annual conferences and for the 35<sup>th</sup> Annual Conference this year,

Samawas invited to organize a panel in the conference. The panel was moderated by Sama and included panelists - Adv. Vrinda Grover (a senior lawyer and activist); Dr. Jagadeesh (a forensic specialist engaged on ethical issues in this regard); Dr. Surveen (a practicing infertility specialist in the private sector and member of AOGD) and Dr. Renu Arora (associate professor and consultant at Safdarjung Hospital). The panel following a question and answer format, clarified doubts and issues with regard to law, ethics in response to sexual assault by health care providers and institutions. Concerns were also raised by participants with regard to the law on mandatory reporting, role of health care providers in private institutions, the finger test, and provision of opinion by doctors.

***II.B.iii. Sama was invited as resource persons for other capacity building/advocacy initiatives:***

- Presentation on *GBV as a public health issue* for students of law at a seminar on “Critical Overview of the Legislative Advances on Gender Based Violence and Child Abuse in the Year 2012-13” on 8<sup>th</sup> October 2013. The seminar was organized by Jindal Global Law School, O.P.Jindal Global University, Sonapat, National Capital Region New Delhi, Haryana.
- On 10 December 2013, on the occasion of World Human Rights Day, Sama was invited by Bharat Gyan Vigyan Samiti, to speak at the Concluding session of the 16 Days of Activism in Bhopal.

**II.C. Assessment of the public sector hospitals’ practices and responses in Delhi towards survivors of Sexual Assault**

In 2009, the Delhi High Court issued guidelines describing the role of different authorities including hospitals/doctors/health departments to respond to sexual assault. On 28 January 2013, the Department of Health & Family Welfare, Govt. of NCT of Delhi issued *Guidelines for Rapid Response by Hospitals of Govt. of NCT of Delhi in case of MLC examination of victims of Sexual Assault*, on 28<sup>th</sup> January, 2013.

Given these developments, an assessment was initiated by Sama in public health hospitals in Delhi. The assessment seeks to explore and understand the preparedness, current practices and perceptions of healthcare providers in responding to sexual assault. This process has also brought to the fore the gaps in knowledge and the need for strengthening of capacities. Interviews have been conducted till now with nine public hospitals including seven tertiary hospitals, one mother and child hospital and one district level hospital. Apart from infrastructural and resource constraints, gaps in knowledge and skills also emerged as major issues in responding to sexual assault.

**II.D. Policy Monitoring and Advocacy**

- i. Review and recommendations on the proforma developed by the Department of Health Research (DHR), Ministry of Health and Family Welfare with regard to and

- manual for medical examination and treatment of sexual assault survivors as well as toolkit for psychological support to survivors of sexual assault and domestic violence were sent (May 2013).
- ii. The 6<sup>th</sup> Monitoring and Evaluation Report- Staying Alive: Evaluating Court Order was released which analyzes the extent of protection against violence for women within the framework of marriage and other domestic relationships. The participants also signed a petition requesting the Finance Ministry to increase the budgetary allocation for effective implementation of the PWDVA Act.
  - iii. Sama also participated in protests through the year on the issues of violence against women and marginalized.

#### II.E. Knowledge Creation and Dissemination

- Booklets in English and Hindi on *Gender Based Violence as a Health Issue*, information resources for organisations, activists as well as health care providers towards building a better understanding on gender based violence and health, were widely disseminated.
- A Hindi-English poster that complements the booklet was also developed during this period for wider mobilisation and dissemination on this issue.
- Reports on prior workshops, consultations were compiled and finalised for dissemination.

### **III. Enhancing Adolescent SRHR through Health Systems Engagement**

This initiative attempts to assess the needs, concerns and experiences vis-à-vis adolescent SRHR; particularly in the context of health system engagement and response. During this period, the following were some of the main activities that were carried out:

#### III.A. Assessment of Needs Vis-À-Vis Adolescent Sexual and Reproductive Health and Rights (SRHR)

*State Level Deliberations* with regard to adolescent SRHR were conducted across the selected states of Madhya Pradesh, Rajasthan, Orissa, Chhattisgarh and Jharkhand, with approximately 45 organizations, networks, *sangathans* which included (a) members of the people's health movement / Jan Swasthya Abhiyan (JSA), (b) organizations, networks that are engaged on adolescent SRHR issues, (c) youth led groups and organizations, (d) health planners, community health workers such as Accredited Social Health Activists (ASHAs), their supervisors and coordinators, mental health professionals including some involved in running a hospital based adolescent centres. These interactions have flagged several common concerns and issues for adolescent SRHR across the five states particularly with regard to the political economy, the heterogeneity of the locations (geographical, economic and social) of adolescents and its implications for their sexual and reproductive health. The need for collective action was articulated in all states, with most of those who were part of the initial assessment process expressing interest in being involved in the initiative towards strengthening health system response to ASRHR. The gaps in knowledge and understanding of organizations and networks

were also shared and the need for ongoing engagements for building capacities and perspectives was stated. These will be consolidated in forthcoming workshops in the states.

This process also enabled discussions with relevant state level officials involved with the ARSH initiatives in Chhattisgarh, Madhya Pradesh, Jharkhand, Rajasthan and Delhi and also visits to clinics in some of the states.

*Review of Policy Documents, Literature on ASRHR* has been an ongoing process has also enabled a close and critical examination of the ARSH strategy, the design, the objectives, implementation strategies. Existing literature on the status of adolescents' SRHR issues has also contributed to the overall analysis. This is in the process of finalization.

### III.B. Capacity Building and Orientations

- Workshops for community based organizations, networks, *sangathans* were conducted in Jharkhand and are being planned in Orissa (March 2014) and in the other states in the following months.
- Workshops with health workers, etc are also being discussed in the states.
- (*For Sama Project Team*) Orientation on Monitoring and Evaluation of the team working on this initiative was conducted in April 2013.
- Sama members attended the TRIOS Consultation on ARSH- Mapping and Developing an Operational Framework for Enhanced Access on 4-5 June, 2012 with regard to the status of implementation of the ARSH strategy based on research by TRIOS.

### III.C. Policy Monitoring and Advocacy

- *Prioritizing of Adolescent SRHR within JSA (National) And Global People's Health Movement (PHM) - The Right To Health And Health Care*: through the circle on gender, health and reproductive justice and the listserv that brings together organizations and networks that are as part of the global people's health movement.
- Incorporation of concerns regarding adolescent SRHR in the Charter of Demands by Jan Swasthya Abhiyan (Delhi) towards influencing political manifestos for the Delhi elections (November-December 2013).
- As part of the Gender, Equity and Social Inclusion Working Group, Sama provided feedback / inputs for the ARSH module for training of doctors in the public health system. The gaps and limitations in design as well as content and information, the perspectives and linkages with population, poverty, lack of gender analysis, absence of sexual health / sexuality were flagged for revision.

### III.D. Knowledge Resource

Briefs based on the assessment process will provide summary information about the ARSH strategy, a critical comment on it, recommendations for strengthened health response to ASRHR and will be printed in English and Hindi in the forthcoming period.

#### **IV. Advocacy on Sex-selection**

##### IV.A. Seminar on Gender and Technologies: Examining Intersections, Expanding Discourse

The seminar in April 2013 in Chandigarh, Punjab facilitated exchange of information, experiences and concerns emanating from activism and research on practice and policy on sex selection. The discussions pointed to the need to examine sex selection in a larger political economic context that includes honor killings, property rights, and state policies like the two child norm. Furthermore, the workshop sought to examine the scenario vis-à-vis legislation with regard to ARTs and sex selection. The transnational nature of these industries represents a medicalised and market driven ‘solution’ for infertility. The seminar was attended by approximately 30 participants - representatives from community based organizations, students from Punjab University, faculty members from Punjab University, researchers, lawyers, activists.

##### IV.B. Interrogating Trends and Challenges: Sex Selection in Punjab

A review was conducted to examine possible factors that may have facilitated the slight improvement in the 2011 census sex ratio figures for Punjab. Towards this, interviews were conducted with key informants – academics, activists, lawyers with a long engagement on the issue in Punjab and analysis of data from available literature, media sources was carried out. A paper based on this process was developed. The paper and the workshop in Chandigarh in April 2013 enabled deliberations and reflection around sex selection in the State and continued areas of concerns and challenges.

##### IV.C. Participation in Advocacy efforts: Sama participated in the following advocacy initiatives to strengthen advocacy against sex selection:

- i. *National Consultation on Declining Child Sex Ratio - Civil Society Campaign* organized in June 2013 by the National Foundation for India (NFI) in partnership with civil society organizations towards building a coalition among civil society organizations and networks to broad base the ownership and dialogue around the issue of gender biased sex selection.
- ii. Consultation to evolve compliance mechanism in the light of the Supreme Court order (4 March 2013) vis-à-vis implementation of the PC-PNDT Act organized by Voluntary Health Association of Punjab in May 2013. Sama contributed to the discussions on sex-selection in the context of ARTs and provided suggestions, revisions to the prayers to strengthen them. Additional and revised prayers were to be submitted to the court in July 2013.

- iii. Sarojini from Sama was invited as a visiting scholar to University of Massachusetts Amherst, USA. She presented at various events in Boston and New York on ARTs, surrogacy during which issues of sex selection were also flagged.
- iv. *Committee for Regulation of Refurbished Ultrasound Machines set up by the Ministry of Health and Family Welfare (MoHFW)*: Sarojini from Sama continued to be a part of the committee to devise suitable regulatory mechanism for effectively monitoring of the sale of imported/ second hand/ refurbished ultrasound machines, including use of technology for effective tracking of ultrasound machines.

## **V. Action Research, Advocacy on Clinical Trials**

### V.A. Research on clinical trials

During this period Sama completed two research studies pertaining to clinical trials in India – (i) Exploratory study on Clinical Trials Conducted by Swiss Pharmaceutical Companies in India with Berne Declaration (ii) A multisite study on the Participants’ Perspectives on Clinical Trials in India.

### V.B. Building Capacities and Advocacy

Two two-day capacity building workshop on *Ethics and Regulation of Clinical Trials in India*, was organized in Bhopal (19-20 December 2013) towards informing and initiating dialogue and building capacities of students, fellow activists, media persons and others in the regulatory and ethical aspects related to the conduct of clinical trials in India. The workshop sought to develop an understanding and enhance capacities about different aspects of clinical trials, particularly participants’ rights and regulatory mechanisms, towards creating local resources for strengthening advocacy and policy advocacy for participant rights and ethical practice in clinical trials in India.- Dr. Amar Jesani (Indian Journal of Medical Ethics (IJME)], Mr. S. Srinivasan (LOCOST Baroda), Dr. SunitaBandewar (independent researcher and ethicist), Adv. VeenaJohari, Adv. VishwasDevaiah, Dr Shree Mulay, Dr. AnantBhan, along with Sama.

### V.C. Policy Monitoring and Advocacy

Initiatives for monitoring of law, guidelines and policies with regard to clinical trials and advocacy towards ensuring safeguards for clinical trial participants, were substantive and critical during this period.

- i. Comments on the report of the Prof. Ranjit Roy Chaudhury Expert Committee to formulate policy and guidelines for Approval of new drugs, clinical trials and banning of drugs, July 2013 were sent in November 2013 to the Union Minister for Health (MoHFW), Dr Ghulam Nabi Azad,
- ii. Participation and presentation in a meeting (10 September 2013) at Nirman Bhavan called by the Health Secretary (MoHFW), on regulation and monitoring of clinical trials.

The submission was made by Sarojini (Sama) with regard to compensation, placebo trials, new chemical entities (NCEs), BA& BE studies, and other issues along with the recent changes in the Drugs and Cosmetics (Amendment) Bill 2013

- iii. (International) At the UNESCO Chair in Bioethics 9<sup>th</sup> World Conference at Naples in Italy November 19-21,2013, Sarojini from Sama presented on “*Ethical and Legal Issues in the context of clinical research using vulnerable populations in India*”.

#### V.D. Knowledge Creation and Dissemination

- Research Report: *Trials and Travails: Perceptions and experiences of clinical trial participants in India.*
- Paper based on the research findings titled, *The Means or the End? Experiences of Clinical Trial "Subjects" in India* .in the peer reviewed Asian Bioethics Review, Vol. 5, Issue 4 (an academic journal providing a forum to express and exchange original ideas on all aspects of bioethics, especially those relevant to the region)<sup>1</sup>.
- Research report by Sama and Berne Declaration: *Exploratory study on Clinical Trials Conducted by Swiss Pharmaceutical Companies in India: Issues, Concerns and Challenges*
- An editorial in the Indian Journal of Medical Ethics (IJME) (Vol X No 4, October-December 2013) - *Trials and tribulations: an expose of the HPV vaccine trials by the 72<sup>nd</sup> Parliamentary Standing Committee Report* – was contributed by Sama members towards strengthening advocacy and mobilising public opinion towards strengthening accountability in conduct of clinical trials.
- Dissemination of the toolkit on Clinical Trial (in English and Hindi) was also disseminated widely during this period, including the Infosheet on *Clinical Trials: What Information Participants Must Know.*

#### **VI. Action Research, Advocacy on ARTs and Commercial Surrogacy**

##### VI.A. Civil Society Window on ARTs and Commercial Surrogacy by the Planning Commission

Sama was invited by the Planning Commission in July 2013 to present on ARTs and commercial surrogacy in India. The meeting was attended by representatives from the Planning Commission, Ministry of Health and Family Welfare, Department of Health Research / ICMR, Ministry of Law and Justice, the National Commission for Protection of Child Rights (NCPCR), Office of the Registrar General of India, amongst others. The film, ‘Can we see the baby bump, please?’ produced by Sama was followed by a brief presentation. The

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<sup>1</sup> Available at

[[http://www.asianbioethicsreview.com/journal/index.php?journal=abr\\_sbc1&page=about&op=editorialPolicies#focusAndScope](http://www.asianbioethicsreview.com/journal/index.php?journal=abr_sbc1&page=about&op=editorialPolicies#focusAndScope)] accessed on 26 December 2013.

ensuing discussion fore-grounded various facets, nuances, issues and concerns about ARTs and commercial surrogacy.

The discussion flagged concerns with regard to the unregulated industry, unethical practices, especially lack of protection of the surrogate women's health and rights, sex selection, lack of employment opportunities, unethical practices, and other health and rights issues of children born through surrogacy arrangements, citizenship, etc. The deliberations also focused on the content / provisions of the Draft ART Bill 2010; their short sightedness, the absence of sufficient protection for surrogate women and in general the lack of transparency, consultative processes involving domain experts including organisations in the drafting of the Bill, lack of clarity on nodal authority, were challenged.

The discussion concluded with the urgent need to initiate a consultative process through the setting up of a (small) committee of domain experts with key ministerial representatives to deliberate these very grave and critical concerns and explore possible ways in which to address them including through legislation.

Members, advisors from the Planning Commission reinforced the need for substantive changes in the legislation and advised the ICMR against moving forward with the Draft Bill 2010, till such a process was satisfactorily concluded.

## VI.B. Other Advocacy Initiatives

### **i. Screening of film, *Can We See The Baby Bump Please***

- At the Delhi School of Economics for students in August 2013.
- At United Nations, the University of Massachusetts Amherst, Johns Hopkins University Baltimore, Boston University, School of Public Health MIT, Boston
- The film, 'Can we see the baby bump, please?' produced by Sama won an award at the Jeevika film festival

### **ii. Lecture at Brocher Foundation**

Sama was invited to deliver a lecture, followed by a discussion, within the panel on "Wombs for rent" on "Commercial Surrogacy in India at **Brocher Foundation** organised by Fondation Brocher, Geneva (Switzerland), the CECID, Université Libre de Bruxelles (Belgium) and the UIHMPH, University of Lausanne (Switzerland), the Institute of Global Studies of the Fondation Maison des Sciences de l'Homme

Sama was invited to present on ARTs and surrogacy by Miranda House in May 2013, Delhi University for students; the presentation also drew attention to the potential for sex selection, issues regarding consonance between varied regulatory provisions vis-a-vis ARTs and sex selection (PC&PNDT), etc.

- i. *I.C.ii. Research Seminar organised by the Public Health Foundation of India (PHFI) for faculty. Sama presented on Assisted Reproductive Technologies (ARTs) and Commercial Surrogacy: Assistance in Reproduction or Subjugation, focused on ARTs and commercial surrogacy, drawing on Sama's research and advocacy initiatives. The discussion fore-grounded a macro picture and analysis of this transnational ART / fertility industry, while locating it within the political economy framework of women's health, rights and social justice. Key issues around regulation of private sector were also discussed.*
- ii. Press release on concerns related to the recent Draft Assisted Reproductive Technologies Bill, 2013, by the Indian Council of Medical Research (ICMR).
- iii. Sama was approached by French Government for an orientation on ARTs including Surrogacy;
- iv. Maharashtra Government approached Sama for inputs on ART Regulation Bill (2010). Sama was approached by the National Commission for Protection of Child Rights (NCPCR), National Mission for Empowerment of Women (NMEW) to give inputs on the ART Bill 2013.

#### VI.C. Knowledge Creation and Dissemination

- 'Sourcing Surrogates' based on the pilot study by Sama, Jawaharlal Nehru University and Kings College London published by Zubaan.
- Sama's Anthology 'Reconfiguring Reproduction' is also expected to be published by Zubaan in the forthcoming period.
- Critique of the *Assisted Reproductive Technology (Regulation) Draft Bill-2013*.

### **VII. Other Key Activities**

#### VII.A. Mission Steering Group member

Sarojini (Sama) has been invited as a member of the Mission Steering Group of the National Health Mission, a high level policy-making group, which provides an important opportunity to deliberate and flag key issues and concerns regarding health / health care issues.

#### VII.B. Medico Friend Circle meeting

The MFC annual meet and 40<sup>th</sup> year celebrations are taking place in Delhi during February 13-15, 2014. Sama team members have been actively involved in organising, coordination of logistics and other aspects of the upcoming meet.

### **VIII. Knowledge Resources from this period**

#### VIII.A. Research Reports

- *Trials and Travails: Perceptions and experiences of clinical trial participants in India.*

- *Exploratory study on Clinical Trials Conducted by Swiss Pharmaceutical Companies in India: Issues, Concerns and Challenges.*
- *Sourcing Surrogates* based on the pilot study by Sama, Jawaharlal Nehru University and Kings College London published by Zubaan.
- *Health Insurance: Evaluating the Impact on the Right to Health (Working paper)* by Sama based on a review of CHI / SHI schemes in India.
- *The RashtriyaSwasthyaBimaYojana (RSBY) experience in Chhattisgarh: What does it mean for Health for All?* published by Sama. This paper is based on six studies of RSBY in Chhattisgarh [authors: Dr. Madhurima Nundy (PHRN) et al.].

#### VIII.B. Papers/Editorials

- *The Means or the End? Experiences of Clinical Trial "Subjects" in India*: Paper based on the research findings in the peer reviewed Asian Bioethics Review, Vol. 5, Issue.
- *Interrogating Trends and Challenges: Sex Selection in Punjab* based on an assessment of sex selection in Punjab.
- *Trials and tribulations: an expose of the HPV vaccine trials by the 72<sup>nd</sup> Parliamentary Standing Committee Report: an editorial in the Indian Journal of Medical Ethics (IJME) (Vol X No 4, October-December 2013).*

#### VIII.C. Information Booklets

- Booklets in English and Hindi on *Gender Based Violence as a Health Issue: towards building a better understanding on gender based violence and health.*

#### VIII.D. Posters/Infosheets

- A Hindi-English poster that complements the booklet was also developed during this period for wider mobilisation and dissemination on this issue.
- *Toolkit on Clinical Trial and the Infosheet on Clinical Trials: What Information Participants Must Know (in English and Hindi).*