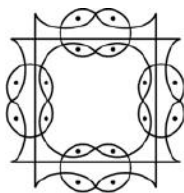


# Annual Narrative Report

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April 2015 to March 2016



## Sama Resource Group for Women and Health

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This report provides an overview of the activities and initiatives undertaken by Sama during the period April 2015 to March 2016 across different organisational focus areas. The last one year has been very significant in terms of enabling the organisation to strengthen areas of work and ways of functioning. This period saw the consolidation of Sama's previous work and involvement in new and important areas of research and advocacy as well.

Sama's work over the past year has been critical to influencing policy, deepening evidence, strengthening capacities for a range of stakeholders, expanding outreach and dissemination on the range of issues that Sama is engaged with currently. This period witnessed significant progress and consolidation of activities initiated previously with regard to right to health and health care, in the areas of, health system response to gender based violence, young people's sexual and reproductive health and rights, access to medicines in the context of clinical trials, Assisted Reproductive Technologies (ARTs) and Surrogacy etc.

Sama's capacity building initiatives and trainings reached out to diverse groups and constituencies – community based organisations, networks, health care providers, ethics committee members, students, etc. Sama's trainings enabled improved understanding on a range of issues and themes with regard to health, gender based violence, assisted reproductive technologies, etc.

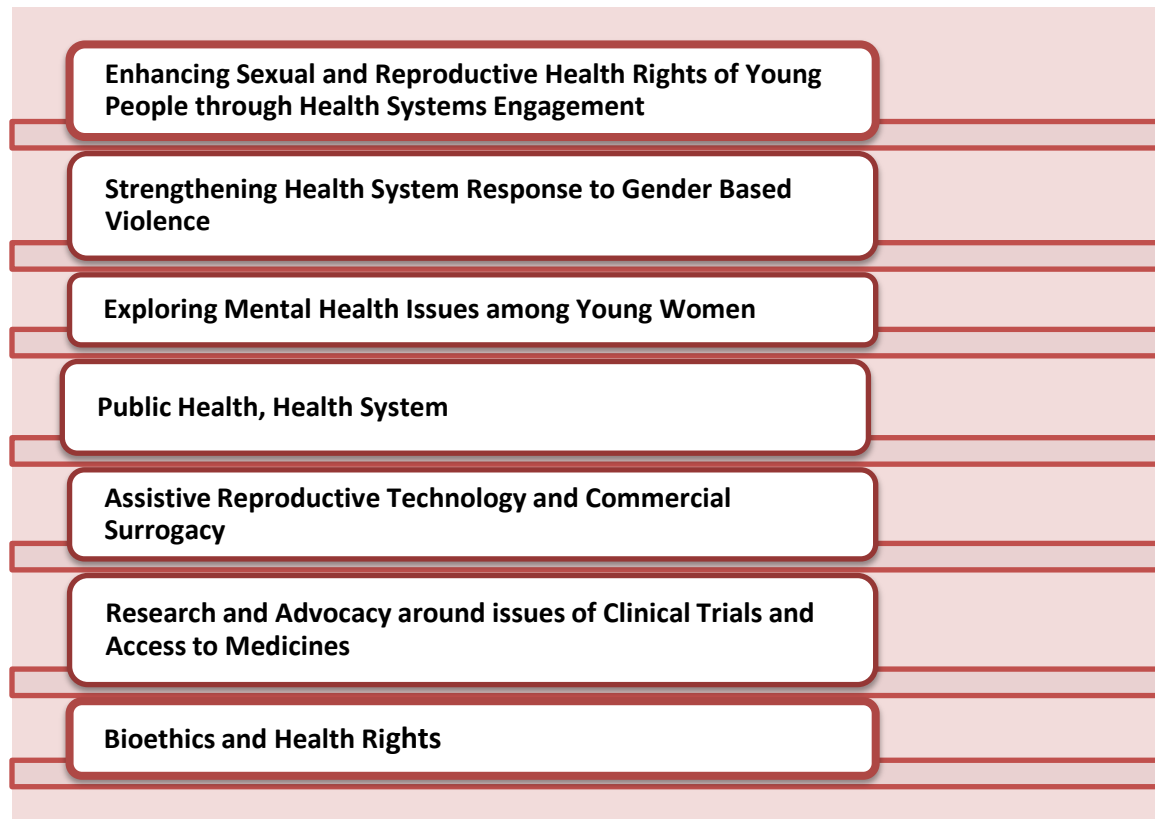
In recognition of the organisation's contribution and expertise, newer opportunities have emerged for participation in high level government committees as well as in collaborative initiatives with the state.

Sama was invited to be part of consultations and committees to deliberate the regulation of ARTs and commercial surrogacy in India; of review and accountability processes (Common Review Mission) of the health system of Delhi.

Sama was invited as a member of the reconstituted Central Ethics Committee on Human Research of the Indian Council of Medical Research (ICMR), to advise on research of national relevance, policy matters, ethical guidelines, with regard to biomedical/ health research in India.

## Thematic Areas of Work

Sama's thematic areas of work during this period were the following:



## Highlights and Milestones

Some of the highlights and milestones from this year:

- Sama was invited by the National Human Rights Commission (the highest body in the country for the protection and promotion of human rights in the country), to carry out a Country Assessment/National Inquiry on Human Rights in the Context of Sexual and Reproductive Rights, along with another organisation. This onerous task is expected to assess the sexual and reproductive rights status in the country towards holding duty bearers to account.
- Sama's work on ethics and rights with its focus on women, children and those socially and economically marginalised, has gained immense recognition; Sarojini from Sama was invited by the Indian Council of Medical Research (ICMR) to be a member of the Central Ethics Committee on Human Research of the Indian Council of Medical Research (ICMR), to advise on

research of national relevance, policy matters, ethical guidelines, with regard to biomedical/ health research in India.

- Sarojini from Sama is part of the Subcommittee on Vulnerability that is examining the section on vulnerability in the document and has been instrumental in drafting sections on research on women, tribal population and on sexual minority groups. The section on vulnerability is especially significant considering the extra safeguards that are to be in place for the safe and ethical conduct of trials in groups that are already vulnerable. These guidelines are one of the most significant policy documents that influence the ethical conduct of clinical trials in the country and is referred to widely for guidance.

- Sama contributed to the section-wise critique and comments for submission by the Forum for Medical Ethics Society (FMES) to the Council for International Organisations of Medical Sciences (CIOMS) 2002 Working Group towards the 'International Ethical Guidelines for Biomedical Research Involving Human Subjects'.

- Sarojini from Sama who is a member of a high level expert group for health policy planning, Mission Steering Group (MSG) of the National Health Mission (NHM) of the Government of India was able to raise critical concerns on a range of issues related to health systems, Health budgets along with other key health issues.

- As a member of Mission Steering Group of the National Health Mission and Sama, the Executive Director was invited to be a part of the ninth Common Review Mission (CRM) for Delhi State by the Ministry of Health and Family Welfare. The CRM is a state led process of monitoring and accountability of the quality of health system functioning including its health policies and programmes and provides the space for inputs into the existing programmes towards strengthening them.

- Sama, as part of the national coordination committee of the JSA and co-coordinator of the Delhi state JSA, was actively involved in coordinating processes with organisations, community groups, towards the public hearings on denial of health rights in the public as well as private health sectors. These hearings were initiated by the National Human Rights Commission (NHRC) with the Indian chapter of the People's Health Movement (Jan Swasthya Abhiyan-JSA).

- Sama's work on strengthening health system response to sexual and domestic violence made substantial headway during this period in the states of Chhattisgarh and Delhi.

- Sama's work on young people's SRHR was able to create linkages with 80 organisations and networks across five states working on diverse issues of young people and enabled

strengthened monitoring and advocacy on the National Adolescent Health Strategy or the Rashtriya Kishor Swasthya Karyakram (RKSK).

- Sama has also initiated workshops with young people in Delhi, particularly from socio-economically vulnerable communities in urban areas. These workshops were envisaged as spaces for young people's creative expressions of their needs, aspirations, which Sama plans to build upon towards strengthening young people's health and rights.
- Following Sama's persistent advocacy on the Assisted Reproductive Technology Bill, the National Commission for Women (NCW) organised a consultation on Surrogacy, providing a platform for wider public debate and discussion to input into the ART Bill (2014) provisions. Sama has been involved in various international, national and regional level consultations to review strategies for improving the provisions of the PC (Pre Conception) and PNDT (Pre Natal Diagnostic Techniques) Act organised by various government bodies and bilateral agencies. Sama is also part of the MOHFW's Central Supervisory Board of PC & PNDT.
- Sama along with the Forum for Medical Ethics Society (FMES), Mumbai, the publisher of the Indian Journal of Medical Ethics (IJME), were jointly awarded the coordination of the 2018 XIV World Congress of Bioethics in Delhi in 2018. The theme for the Congress is "Health for all in an unequal world: obligations of global bioethics" and will provide a critical space to centre-stage ethical issues globally, but especially in the South Asian region.
- Sama also contributed articles, papers, blog-posts on these issues to journals, edited volumes and blogs on these work areas.



## OVERVIEW OF ACTIVITIES

## 1. Enhancing Young People Sexual and Reproductive Health Rights through Health System Engagement



Sama conducted workshops and orientations for the organisations for building and strengthening perspectives on adolescent Sexual and Reproductive Health and Rights (SRHR); interacted with the community including adolescents for their perspectives with regard to health information and services for SRHR; and inserting adolescent SRHR into Jan Swasthya Abhiyan (JSA) for policy advocacy in the five selected states i.e. Odisha, Rajasthan, Madhya Pradesh, Jharkhand, Chhattisgarh.



### 1.1. Meetings with health officials, healthcare providers engaged with National Adolescent Health Strategy

*“After our engagement with SAMA, we are better equipped to deal with the issues related to sexuality of the mentally challenged adolescent boys and girls. We feel that now we are capable of creating a better environment in the community about this taboo surrounding sexuality.” (CBO, MP).*

*“For me this training was very helpful. Nor during my ANM training or during the course of my work, I had any input on adolescents. This is the first time I am understood these concepts. The knowledge will benefit the adolescents who come to the clinic and also when I go for village meetings.” (ANM who also does counseling at AFHC, after the workshop in Jharkhand).*

Meetings were conducted with the Health Officials like Nodal officer and Consultant to Adolescent Health in the five States. Interactions were done with District Programme Manager, ASHAs, ANMs, Anganwadi workers and members of community based organisations in these districts.



Sama visited two districts of Madhya Pradesh, namely Satna and Chattarpur (6<sup>th</sup>-8<sup>th</sup> October 2015) to assess the implementation of RKSK in these districts. In Chatra (Jharkhand) and Harda (Madhya Pradesh) capacity building meetings with community based healthcare providers like ASHA, AWW and ANM were conducted.

## 1.2. Workshops with Non Governmental Organisations and Community Based Organisations

- i. The follow-up workshops were conducted with organisations in Odisha, Jharkhand and Madhya Pradesh. Total of 36 organisations participated (20 from 13 districts of Odisha, 10 from 8 districts of Jharkhand and 16 from 10 districts of Madhya Pradesh). The organisations were motivated to interact with the ARSH counsellor, ANMs, doctors, district programme managers and other healthcare providers in District Hospital and Community Health Centre in their respective places, to gather information regarding ARSH/RKSK.
- ii. Sama received requests, following state level workshops, to build capacities of the staff of different community based organisations to address the issue of Adolescents Sexual and Reproductive Health and Rights. A workshop was conducted for Mahila Mandal Sanstha, a community based organisation in Etkhori, Jharkhand.
- iii. Meetings were conducted with organisations in Madhya Pradesh, Rajasthan and Odisha to discuss the assessment of the implementation of RKSK programme in the respective states.
- iv. A simple format was developed and shared with organisations organisations and networks to monitor RKSK implementation. This was expected to enable pooling of information from different regions, districts of the state towards policy advocacy and strengthened RKSK implementation.
- v. Sama organised a two day residential workshop (12 -13 September, 2015) in Jaipur where representatives from community based organisations and non-governmental organisation working in Rajasthan participated. The objective of the workshop was to orient the participants about RKSK, assess the level of involvement of the groups in the implementation of RKSK in respective districts, build linkages between the implementation status of RKSK in Rajasthan and the Programme document in order to identify the issues and gaps between the two and also to know the challenges that participants face at the grassroots level and whether it will be possible to assess the implementation of RKSK in respective districts linking it with their primary areas of work.

*After going through capacity building sessions of Sama, we were able to focus better on the issues of adolescents in our area. In the last 2 years we have conducted sessions with adolescent girls in our field areas. Menstrual hygiene has improved; girls now demand sanitary pads. Sometimes girls even approach ASHAs and ANMs (health care providers) for their health and other problems. The latter are also more involved.  
(Organisation Member, Sehore, MP)*

**vi.** Sama organised a four day residential national workshop (18-21 November, 2015) on young people's reproductive and sexual health and rights where representatives from community based organisations and non-governmental organisations from across the five states participated. The primary objective of the workshop was to develop a comprehensive understanding of Adolescents' Sexual and Reproductive Health and Rights towards advocacy and develop skills to critically analyse policies and programmes.

**vii.** Sama organised a Roundtable on 'Adolescent Sexual and Reproductive Health and Rights (ASRHR)- Challenges and Opportunities' on December 17, 2015 in Delhi. The Roundtable was attended by representatives from 23 Organisations from seven states - Gujarat, Maharashtra, West Bengal, Karnataka, Odisha, Jharkhand and Delhi. The roundtable was also attended by representatives of the National Health Systems Resource Centre (NHSRC) which provides technical support for RKSK implementation. The roundtable provided a platform for discussion on implementation of the RKSK, aspects that were to be operationalised initially and those that would follow. These were useful for organisations towards monitoring the implementation at their end as well as engaging in advocacy efforts.

**viii. Expressive Arts Workshops**

Workshops with young people from vulnerable communities were carried out during this period with the objective of providing safe and creative spaces to express themselves about their selves, their dreams and aspirations, their lives and contexts.

Three such workshops were conducted with different groups of young people in three different communities in Delhi – The Hope Project at Nizamuddin Basti, Shramik Sangathan at Hastasal, and Udaan home for girls at Najafgarh Road. The workshops used a combination of story writing, body movement and music to facilitate an expressive medium of interactions with the young people. Sama conducted these workshops with the support from an external resource person who is a creative arts person.



## 2. Strengthening Health System Response To Gender Based Violence



## Strengthening Health System Response to Gender Based Violence

The initiatives in Delhi and Chhattisgarh explored the different contexts and levels of health system engagement and response to GBV. Chhattisgarh was chosen as one of the locations other than Delhi towards understanding decentralised response to GBV. Sama collaborated with *Chaupal*, an organisation which works on health and rights issues in Chhattisgarh, to take this forward in the state.

### 2.1 Delhi Level Activities

#### 2.1(a) Initiatives with healthcare providers in the public and private health sectors

- i. Meetings were held with Head of the Obstetrics and Gynaecology Department or Medical Superintendent or Nodal Officer, who are in-charge of handling One Stop Crisis Centres for the sexual violence survivors in three Delhi government hospitals, namely Guru Tegh Bahadur Hospital, Sanjay Gandhi Memorial Hospital and Deen Dayal Upadhyay Hospitals. These meetings enabled insights and updates into the functioning of these One Stop Crisis Centres at the hospitals.
- ii. In-hospital workshops were organised for the staffs of Swami Dayanand Hospital and Bhagwan Mahavir hospital (Delhi Government hospitals) to build capacities of the health care providers – doctors, nurses, etc. on providing care and medico-legal aspects of response to survivors of sexual violence.
- iii. Sama also initiated dialogues with private hospitals in Delhi during this period. Visits and interactions with some of the hospitals - St. Stephen's Hospital, Sir Ganga Ram Hospital, Holy Angels Hospital and Max Superspeciality Hospital provided information about the perspectives and engagement of private hospitals with the issue of GBV – especially sexual violence. A couple of the hospitals also requested future orientations for their staffs.
- iv. A Meeting for health care providers from across hospitals in Delhi was organised in December 2015 on the Law, Guidelines for Health System Response to GBV. The

*"I came to attend this training for improving and upgrading my knowledge. I want to take active participation in the sample collection process while medical examination of a sexual assault survivor is been done by the examining doctor. From the training I got to learnt how to make the patient ready for medico-legal process, how to ensure the privacy, to take consent and that there is no need to collect irrelevant sample. It was a good training and it helped me improve my knowledge regarding the subject and it should be continued in future too."*

*(A staff nurse who attended Sama's training on Medico legal care and response towards GBV survivors)*

*"I attended this training as I felt I must be aware of the recent guidelines while working in the casualty. I found the information useful on two finger test that this procedure should be stopped and how it further adds trauma to the survivor, and that I should not write anything which is leading to the mention of the character of the survivor."*

*(CMO who attended Sama's training at hospital)*

meeting focused on orientation and discussions around the amendments/changes in law and guidelines for doctors and other health care professionals, service providers. The meeting also provided the space for exchange of views, practices and queries across hospitals and to learn from each others' experiences.

### ***In Chhattisgarh***

Sama organised a half-day 'Consultation on Medico-legal care for survivors of Sexual Violence' in Raipur, Chhattisgarh on August 1, 2015 in collaboration with the Department of Obstetrics and Gynaecology, Dr. Bhim Rao Ambedkar Memorial Hospital, Raipur and Chaupal, to discuss the MoHFW Protocols and Guidelines for medico legal care and response to sexual violence survivors. The consultation was attended by sixty healthcare providers from public and private hospitals, members of the Federation of Obstetric and Gynaecological Societies of India (FOGSI), representatives from the State Department of Women and Child Development and other service providers. Dr. Jagadeesh N Reddy, a forensics expert and a member of the drafting committee of the MoHFW Protocols and Guidelines for health system on sexual violence, made a presentation and responded to the queries of the participants at this meeting.

### **2.1(b) Initiatives with organisations and building interlinkages**

(i) Towards building awareness on guidelines for the health system and strengthening engagement with the health system on GBV, Sama organised a meeting of organisations in Delhi that work on health rights, women's, children's rights, IT/social media issues in communities as well as at the policy levels. Organisations who have had several years of experience of working with and supporting survivors who were part of the meeting flagged the realities of survivors who access the health system in situations of GBV. This meeting, organised in March 2016, was perceived as extremely useful for Delhi organisations working on these issues and prompted regular meetings and exchange towards strengthening engagement with health system as well as its monitoring for survivors' better access to care and justice.

(ii) Sama organised a Roundtable on Health System's Response to Domestic Violence (DV), bringing together a small group of individuals, organisations to deliberate on the role of health systems response to DV. The roundtable held in Delhi on March 30, 2016 was attended by 18 organisations who discussed existing health system response to domestic violence and future action and strategies to engage collectively. Development of draft protocols for DV as well as other collective policy advocacy efforts towards strengthened health system response were some of the action points that emerged.

## 2.2 Chhattisgarh Level Activities

### 2.2(a) Initiatives with community based organisations (CBOs) and health care providers and also building linkages between various stakeholders

- i. Sama held a two and a half day capacity building workshop in August 2015 at Raipur, Chhattisgarh on 'addressing Gender Based Violence as a Public Health Issue' with various community based organisations' representatives from various parts of the state. Sessions were conducted on the framework of GBV and its relationship with the health system, medico-legal care guideline and protocols for survivors of sexual violence, along with a brainstorming exercise on developing a health care guideline and protocol for the survivors of domestic violence.



- ii. Sama was invited as resource persons to facilitate / conduct a workshop in November 2015 organised by Chaupal over two days in Raipur. The workshop was organised for grassroots women leaders including women panchayat leaders, community based health activists, urban Mitanin leaders, and others from about 12 districts of the state. The 30 participants in the workshop worked on a range of women's health and rights issues in their respective communities – dalit, adivasi, urban poor, young people, children, women with disabilities and others. The aim of the workshop was to reach out to community women leaders and activists to build their capacities and knowledge about gender based violence and health towards strengthening their linkages with the health system especially in the context of GBV.

*"In a case that I was providing support to the survivor, I was able to tell the police inspector on the case that SDM permission is not required for medical examination of victim of sexual assault. This was possible with the new knowledge gained in the Sama workshop."(CBO representative, Chhattisgarh)*

Meetings were held with the members of Adivasi Adhikar Samiti during a two day visit to Manendragarh in Koriya district of Chhattisgarh. Discussion regarding protocol and guidelines for health care system to provide a better response towards survivors of sexual violence. The copy of Chhattisgarh government order on implementing the updated protocols was shared.

*In the meeting with Adivasi Adhikar Samiti, a collective of women largely from marginalised communities at Manendragarh in Koriya district of Chhattisgarh (in August, 2015), Sama team was apprised of the situation of a CBO member who had been facing violence at her home. Despite repeated follow ups with the local police station, no complaint was registered; instead, the survivor and the collective members had to face stiff resistance by the police in acknowledging the case of violence. Following the previous workshops by Sama, they had gained some understanding of the Protection of Women from Domestic Violence Act (PWDVA) and the rights of survivors and were wanting to initiate such action for the first time. They had never met the Protection Officer, a designated officer as per the ACT before, and were not clear about registration of a DIR (Domestic Incident Report) under the PWDVA. Sama team members facilitated the process, and the Protection Officer then filed the DIR and forwarded the application seeking reliefs from violence, to the magistrate. This process enabled in creating an interface between the collective from the community and the Protection Officer under PWDVA, following which Sama got feedback that the collective and protection officer was working in tandem and cases of domestic violence from the community were enabled to access health care and justice.*

- iii. Sama organised a two days legal workshop with the Community Based Organisations (CBOs) on February 24-25, 2016 in Raipur. The need to do a Legal Workshop came as a need over time with the CBOs that the understanding on provisions and processes of Protection of

Women from Domestic Violence Act (PWDVA) and other laws like Criminal Law Amendment 2013 (CLA), Protection of Children from Sexual Offences Act (POCSO) were weak. The focus of the legal workshop was to build an understanding towards provisions and associated processes with PWDVA, CLA,POCSO, and other related laws on GBV. An external legal resource person from MARG organisation, Advocate Noor Alam was invited to facilitate the sessions during this workshop. The participants were very keen to know about specific sections of law, knowledge of which they could apply while assisting any case or supporting any survivor as a part of their work.

### **2.3. Participation in capacity building efforts by other organisation/hospitals**

- i. Sama participated in the Regional Consultation on Guidelines and Protocols for Medico-Legal Cases-Strengthening Health sectors response to Violence Against Women jointly organized by World Health Organisation (WHO) and Ministry of Health and Family Welfare (MoHFW), held on December 29-30, 2015 in Kolkata.
- ii. Sama participated in a workshop in August 2015 on the invitation of the Ram Manohar Lohia (RML) Hospital with regard to the 'Guidelines on Management of Sexual Assault Cases' organised by Department of Obstetrics and Gynaecology. Sama responded to some of the queries raised in the course of the workshop.
- iii. Sama participated in the Delhi level AMAN network meeting held in January 2016. The AMAN network comprises of organisations working on various aspects and issues of gender based violence.Sama shared updates from its engagement with the health system and one stop centres in Delhi hospitals on the issue of strengthening response to GBV, during the meeting.



### **2.4. Regional Level Workshop**

Sama along with Jan Swasthya Abhiyan-Odisha organised a one and a half day regional workshop in Bhubaneswar in March 2016 with organisations from Odisha and Jharkhand. The workshop was attended by 44 participants from 14 districts of Odisha and 3 districts of Jharkhand from about 27 organisations. The participants were from community based organisations (CBOs), networks, women's groups, JSA members and individuals working on the issue of health, education, agriculture, gender, women empowerment, child labour, gender equality, domestic violence, trafficking, sexual harassment, justice, freedom and equity, child rights & protection etc. The workshop provided a platform for the coming together of



organisations engaging with the issue of GBV at multiple levels to build synergies towards strengthening accountability of the health system and the state. The workshop also discussed collective future strategies for response and organising. A core group emerged from the workshop as part of the Jan Swasthya Abhiyan Odisha to take forward the discussions and plans deliberated in the workshop for sustained engagement on the issue.

### **2.5. Training on GBV and Health for Social workers/counsellors at Delhi Police Stations**

Sama team members were invited as resource persons for a day-long training on right to health, reproductive and sexual health and health impact of gender based violence, held on March 18, 2016 at the Special Police Unit for Women and Children, Delhi. The session was part of a month long training series organised by Resource Center for interventions on VAW, TISS in agreement with NCW and Delhi Police to provide technical support to 11 Special Cells for Women/ Counseling Units for women facing violence in Crime Against Women (CAW) Cells of Delhi. The training was organised for 22 social workers and two coordinators recently recruited by the Delhi Police for the programme. The aim was to enable them to address cases of women who come to seek help at the respective police stations for GBV or in distress of any kind and provide a multi-agency coordinated response to enable women to lead a violence free life.

The session covered Introduction to Right to Health, reproductive and sexual health and discussed the process of addressing such cases using case studies. It also provided a perspective on the Medical Termination of Pregnancy Act (MTP) and PC&PNDT Act and discussed in detail the health aspects of Gender Based Violence and mandatory protocols on how the health system should respond to it.

### 3. Exploring Mental Health Issues among Young Women



Sama has initiated an exploratory qualitative research on ‘Exploring Mental Health Issues among Young Women, including that in early marriage’ which was conducted in two districts of Rajsamand and Pratapgarh districts in the states of Rajasthan and Uttar Pradesh respectively. This research is informed by Sama’s long-term engagement with young women, their rights, health and the felt need to understand and address their mental health. The findings of Sama’s earlier research on ‘Early Marriage and Health’ identified the lack of focus on mental health and well being of young women. This research aims to understand the contributing factors to mental ill health including implications of early marriage among young women; and to assess the mental health issues, needs including and health care and support of young women, including those in early marriages.

### **3.1. Advisory for the research**

An advisory comprising of experts in the area of mental health/ well being was formed and an initial meeting organised, which meeting enabled development of guidelines, sharpening of the methodology and other aspects of the research.

### **3.2. Development and Piloting of research tools**

The tools for the study (Focus Group Discussion, Key informant Interviews and In-depth Interview guides) were developed and piloted in December 2015 in Lalitpur district of Uttar Pradesh with support from Sahjani Shiksha Kendra. Sahjani Shiksha Kendra is an organisation which aims at empowering women and adolescent girls through literacy and education, by linking their lived realities to its educational initiatives.

### **3.3. Data Collection**

The field research included FGDs with young girls in the age group of 15-20 years and young married women in the age group 18-24 years; In-Depth interviews with young women both married and unmarried between 18-24 years and Key Informant interviews with health practitioners, traditional healers and other service providers working with young women. The research data is in the process of being transcribed, coded, organised towards analysis.

### **3.4. Capacity Building Session on 'Perspectives on understanding Women's Mental Health'**

Sama organised a session with Dr. Renu Addlakha on 'Perspectives on understanding Women's Mental Health'. The session was held on March 5, 2016 and was based on her book 'Deconstructing Mental Illness: An Ethnography of Psychiatry, Women, and the Family' highlighting prevalence of mental disorders in women, stressors for mental ill health in women, violence and mental health and treatment of mental illness in women.

## 4. Public Health, Ethics and Rights



Sama's work in advancing the right to health and health care is critical in the current context with increasing withdrawal of the state in provision of health care, growing privatisation and corporatisation, public private partnerships, which have a disproportionate

impact on girls and women and marginalised communities. These trends have caused increased indebtedness and further exacerbation of poverty. Sama's work, which is informed by the intersection of the right to health and women's rights, is well placed to advancing the right to health and health care, particularly of girls and women and other marginalised communities and to strengthen health system response and accountability.

### 4.1. Country Assessment/National Inquiry on Human Rights in the Context of Sexual and Reproductive Health and Well Being

Sama has been invited by the National Human Rights Commission (NHRC), the highest body in the country for the protection and promotion of human rights in the country, to carry out a country assessment on sexual and reproductive rights. The current initiative operationalises the mandate of the NHRC of India, to "study treaties and other international instruments on human rights" as well as to "review the safeguards provided by the Constitution of any law for the protection of human rights" to make recommendations for their effective implementation.

Sama will be particularly looking into the area of reproductive health and will document existing international framework and language on human rights with regard to SRHR and analyse the compliance of the legislative and policy framework in India against it.

It will also map and legal and policy framework, demographic data on sexual and reproductive health and rights in India towards identifying compliance, gaps and making recommendations for reform in law, policy and praxis. The outcomes of this process are expected to be far

reaching for the reinforcement of sexual and reproductive rights as human rights and will foreground areas for strengthening as well as non-compliance, discriminations.

#### **4.2. Feedback to the National Health Policy**

Sama provided feedback to the National Health Policy (NHP) that was placed in the public domain for comments and feedback. Sama submitted detailed comments as well as alternative formulations on a range of issues that the organisation works on – women’s health, gender based violence, ASRHR, ARTs and Surrogacy and access to medicines and compensation in the context of clinical trials.

#### **4.3. Engagements with National Human Rights Commission (NHRC) and Jan Swasthya Abhiyan (JSA)**

- i. Sama contributed in drafting the guidelines for the proposed series of public hearings on Health rights across India during 2015-16. The hearings are collaboratively organised by the NHRC and JSA. These hearings focuses on reviewing human rights violations in context of the public and private health care services in India, with a view to drawing attention to key systemic and policy related issues, along with issuing a range of related recommendations. Sama will play an important role in the public hearing going to be held in Chandigarh In January 2016.
- ii. Chandigarh: The Preparatory meeting for the Northern Region NHRC-JSA public hearing was organised on the 19<sup>th</sup> July in PGIMER, Chandigarh. The JSA representatives from Delhi, Haryana, Himachal Pradesh and Punjab attended the meeting. The structure and format of the public hearings was discussed in the meeting. The tentative dates for the Northern Region NHRC-JSA public hearing was fixed on the 16<sup>th</sup> and 17<sup>th</sup> February 2016.
- iii. JSA-Delhi Meeting was held on October 27<sup>th</sup> at the Indian Social Institute. It was coordinated by Indira from JNU and Deepa from Sama. The aim of the meeting was to discuss the action plan for Delhi level evidence gathering for the NHRC-JSA North Region ‘Jan Sunwai’ scheduled in March 2016. Some of the key areas discussed for evidence gathering were clinical trials on women and children, denial of treatment under RSBY or other private group insurance, repeated violations/ failure of delivery of promised services by bigger private hospitals, Women and Children health issues, Status of public health facilities- Urban PHC status- Infrastructure, medicine availability, human resource among others.
- iv. Sama participated in the NHRC-JSA public hearing held for the western region on January 6-7, 2016 held at Tata Institute of Social Sciences in Mumbai. Different cases of health rights denial and medical negligence were presented and heard by the NHRC benches sitting in for the hearing.

#### **4.4. Ninth Common Review Mission (31<sup>st</sup> October –7<sup>th</sup> November 2015)**

Sarojini as a member of MSG and Sama was invited to be a part of 9th CRM for Delhi State by MOHFW. This state led initiative seeks to monitor progress assess gaps and flag recommendations by experts in the area of public health. Sarojini provided written reports and inputs for follow ups, including the need for an analysis of the last Common Review Missions towards an analysis and understanding of the outcomes of the process. She proposed that this could be carried out collaboratively by the government along with Sama and other organisations.

#### **4.5. International review and accountability processes Post 2015 Agenda / Sustainable Development Goals (SDGs)**

##### **i. Sustainable Development Goals (SDGs)/ICPD**

##### ***ICPD Beyond 2015 review process***

Sama participated in the Global Strategy meeting between UNFPA and CSOs on Beyond 2014 and Post 2015 at Lisbon in December 2015. The meeting was to facilitate an interactive dialogue with UNFPA on the advancement and implementation of the ICPD beyond 2015 outcomes in the context, monitoring and implementation of Agenda 2030.

Sama was also a part of country level discussions on how CSOs can partner to ensure that the outcomes of the ICPD Beyond 2014 review process are taken forward and integrated in the best possible way into the post 2015 agenda, including through a responsive monitoring and evaluation framework.

##### ***Consultative Meeting on SDG-Goal 5-Achieve gender equality and empower all women and girls; 25<sup>th</sup> August 2015***

Consultative meeting was held on 25<sup>th</sup> August 2015. This meeting was being held at a juncture where the target indicators were in place but there was scope to work on their final format. The aim of the meeting was to discuss specifically on Goal 5 and take inputs on all its indicators- what needs to be included, modified.

#### **4.6. “Framework to Monitor the Implementation of the GOI of the Recommendation it accepted at the Second Universal Periodic Review”**

Sama was invited to participate in the Northern Regional meeting on “Framework to Monitor the Implementation of the GOI of the Recommendation it Accepted at the Second Universal Periodic Review” held in Chandigarh. Sama submitted points on GBV and Sex selection and ARTs.

#### **4.7. Programme on Gender and Health Course at MGAV University, Wardha (18<sup>th</sup>- 20<sup>th</sup> November 2015)**

Sama conducted a three day programme on Gender and Health for the students at Mahatma Gandhi Antarashtriya Hindi Vishwavidyalaya (MGAV), Wardha from 18th to 20th November. Sama was invited from the Department of Women's Studies at MGAV as resource persons for the three day Programme on Gender and Health course for the students.

#### **4.8. Pre-Conception and Pre-Natal Diagnostic Techniques (PCPNDT)**

##### ***4.8(a) Conference on "International Policy Dialogue on Pre-Natal Sex Selection" (8<sup>th</sup> July 2015)***

Sama participated in the conference organised by Centre for Social Research on "International Policy Dialogue on Pre-Natal Sex Selection" at IHC on July 8, 2015. There were discussions and dialogues on trend of sex selection and implementation of PCPNDT Act in India. There were presentations on Asian countries' experience on the issue and policy.

##### ***4.8(b) Meeting on implementation of PC-PNDT Act with Delhi Health Minister (18<sup>th</sup> August 2015)***

Sama was invited for a consultation meeting called at Delhi Secretariat on August 18, 2015 by State Health Minister. Consultation with different NGOs on the role of NGOs in supporting the implementation of PCPNDT in Delhi state and addressing the issue of gender biased sex selection.

#### **4.9. Roundtable organised by South Asian Women's Forum**

Sama participated in a round table organised by South Asian Women's Forum (SAWF) to discuss, review and reflect on current anti-trafficking initiatives being funded in South Asia and also examine the concept of stigmatised labour.

### **5. Ethics and Rights**

#### **i. The World Congress of Bioethics (WCB)**

Sama along with the Forum for Medical Ethics Society (FMES), Mumbai, the publisher of the *Indian Journal of Medical Ethics (IJME)* ([www.ijme.in](http://www.ijme.in)) jointly hosting the 2018 XIV WCB in Delhi in 2018. The theme for the Congress is "***Health for all in an unequal world: obligations of global bioethics***" and the Congress will provide a critical space to centre-stage ethical issues globally including on universal healthcare.

## ii. Participation in a Panel at Annual Institutional Ethics Review Board of Jawaharlal Nehru University, New Delhi on January 7, 2016

Sama was invited to contribute to the Panel on 'Concerns during Research on Women' at a National level seminar organised by Jawaharlal Nehru University Institutional Ethics Review Board. The seminar focused on ethical and other issues revolving around health research and was attended by over 40 participants including academics, researchers, students, EC members etc. Sama's panel contribution saw deliberations



on topics like issues and safeguards while conducting research on female victims of domestic violence, women affected with HIV/AIDS, research on vulnerable population. The other themes for the seminar included methodological issues in community health research, issues concerning juveniles and vulnerable communities, caste, race, scarcity, poverty and disability, etc.

## iii. Consultation on Bio (Medical) Economies Today: Understanding Issues of Ethics, Markets and Labour (29<sup>th</sup> - 30<sup>th</sup> May 2015)



Considering the growing concern on several issues pertaining to biomedical technologies, it becomes important to understand the linkages of these technologies with market, labour and ethics in the wake of neo-liberalisation within the health sector. Sama deliberated on exploring these issues through a two day consultation on "Bio (Medical) Economies Today: Understanding the issues of Ethics, Market and Labour". The consultation was held on 29th and 30th of May 2015 at USI, New Delhi. The objective of the consultation was not to arrive at particular policy solutions or develop positions or situate ourselves for or against these technologies, but to

acknowledge the need to rethink meanings, deeply familiarise ourselves with how we have arrived at the present moment and to explore what can be the ethical and just ways to respond to the possibilities that biotechnologies have presented before us.



Over a span of two days, four panels were planned to structure the deliberations: Panel 1 - Locating Labour Today: New Trends and Concerns; Panel 2 - Technology and Identity; Panel 3 - Regulation and Ethics; Panel 4 - Medicalisation and Political Economy. Sama made a presentation on “Surrogacy in India: A new form of women’s labour/work”.



## 5. Research and Advocacy on Access to Medicines and Compensation in Clinical Trials



Currently Sama is engaged in a project on ***‘Drug Research and Access to Medicines: Emerging Issues, Challenges and Strategies’***. The project has three components: (a) research, (b) advocacy, and (c) knowledge creation. The research consists of two studies:

### 5.1 Study on access to medicines for which trials were conducted in India

The study emerges as a logical continuation of the work that Sama has been involved with on various ethical and regulatory issues. While in the previous research Sama explored the perspectives of clinical trials participants, this study focuses on quantitative data emerging from the clinical trial registries, marketing and sales of new pharmaceutical products etc. Previous research had thrown up issues of post trial accessibility and affordability of drugs. Often the drug tested is not marketed in the country and even when marketed it is so highly priced that it becomes unaffordable to the majority of Indian population. Sometimes the drugs are irrelevant in the Indian public health context making the trials as mere mechanisms for testing the safety

and efficacy on patient population and generating evidence. These issues indicated towards the need for a study exploring the affordability and accessibility of such new medicines for the population at large.

**The objectives** of the study are to look at the a) availability of drugs for which trials were conducted on Indian population during the time period 2005-2010, b) if drugs get registered, are they marketed, and c) if marketed, are they made available at affordable prices.

The study is based on secondary data and collated data from the US and Indian clinical trial registries. The sales data was collected from PharmaTrac 2015. Other web based sources and official websites of Central Drug Standard Control Organisation, India, USFDA and European Medical Agency and patents website in India were used. Information for 657 phase 3 clinical trials (P3CT) conducted between 1<sup>st</sup> January 2005 and 31<sup>st</sup> December 2010 were included in the study. Data on 307 drugs emerging from these trials were explored for market approval and pricing and sales data of 177 drugs that were marketed were captured from these different sources.

## **5.2 Study on Compensation for clinical trial injuries: comparative analysis of seven countries**

One of the major concerns that came to the fore during the maelstrom that the clinical trial sector faced in recent years was regarding the reporting and compensation for adverse events including death related to clinical trial injuries. Ethics, medical ethics and human rights mandate that medical management and compensation ought to be provided in case of harm during or after clinical trial participation. Sama has been involved in efforts to uphold and protect the rights of participants, be it through activism, advocacy efforts or through building evidence through research to support the advocacy efforts and to support the policy making process. During the course of deliberations, it emerged that while ethics and human rights frameworks are universal, the operationalisation and underlying policies guiding the compensatory mechanism differ among different countries.

**Objectives:** A systematic review of the compensation mechanism in different countries and comparisons of the implementation mechanisms will inform the debate and policy making process pertaining to clinical trial compensations at both national and international levels. The countries included in the study are India, South Africa, Germany, Russia, Canada, Brazil, South Africa and the UK. In addition to the policy documents and legislations, published papers and studies, clinical trials registries, websites of the country regulatory bodies and case laws related to clinical trial injury compensation were looked at.

### 5.3. Advocacy

#### i. **Workshop on 'Ethics and Regulation of Clinical Trials in India' on January 8-9, 2016 at YWCA, Mumbai**

Sama organised a two day Capacity Building Workshop on 'Ethics and Regulation of Clinical



Trials in India' on January 8-9, 2016 at YWCA, Mumbai. Workshop saw the participation of 37 participants from different Community Based Organisations, health networks such as JSA, Institutional Ethics Committee members, students, academicians, and researchers.

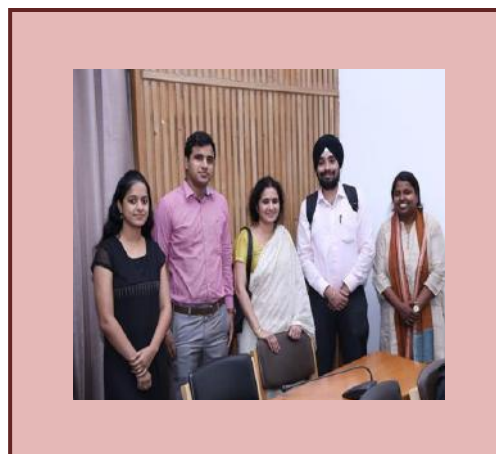
Five resource persons holding expertise and experience in the

field of bio-ethics research, legal scenario concerning clinical trials; were invited to facilitate the technical sessions during the workshop. The workshop saw an active involvement from the participants and engaging discussions on the topics like Ethics of Clinical Research, laws and regulatory mechanisms, cases highlighting ethical violations, current scenario of clinical trials in India etc.

A working session towards the end of the workshop wherein participants deliberated on different aspects of compensation for clinical trials based on a case study gave the participants an opportunity to apply the different principles and concepts assimilated over a two day period. The written feedback received from the participants showed appreciation of the teaching methods that simplified the concepts as well as a keenness to be part of further trainings and conducting such trainings in their respective organisations.

#### ii. **Youth Workshop on Intellectual Property, Public Health and Access to Medicines on 18-22<sup>nd</sup> December 2015 at Institute for Studies in Industrial Development (ISID), New Delhi**

Sama participated in the four day workshop that was organised by ISID along with Peoples Health Movement (PHM) and Prayas to coincide with the 4<sup>th</sup> Global congress on Intellectual Property and Public Interest



held in Delhi. The workshop had themes on intellectual property rights and access to medicines, WTO and TRIPS- evolution, consequences, legal aspects and reform proposals, Indian patent law and policy history, trade agreements, TRIPS-plus demands and public health, alternate models for research and development etc. Sama conducted two sessions on clinical trials and women's movements in the workshop. Participants of the workshop included young researchers, activists, journalists, scholars, public health professionals and students.

**iii. Global Congress on Intellectual Property Rights and Public Interest**

The Global Congress is an important platform for scholars and policy advocates working on intellectual property from a public interest perspective. Sama presented a paper based on its research on access to medicines at the access to medicines tract of the 4th Global Congress held at Delhi in December 2015. The paper presented the preliminary findings from the access to medicines study and was received enthusiastically by the audience comprising of scholars, activists and practitioners.

The Congress aimed at bringing in an intersection of law and policy and using it to expand access to quality, affordable medicines and health technologies for all. Participation and dissemination of our research findings in this platform is significant as it brings together like minded organisations working towards the same goal of improving access to medicines.

**iv. Expert Round table on clinical trials, corporate accountability and health rights litigation, Berlin (8<sup>th</sup> October 2015)**

Sama participated in the Round Table held in Germany on 8th October 2015. The round table was co-organised by Wemos, SOMO and European Centre for Constitutional and Human Rights (ECCHR). The round table provided a robust platform for discussions and exchange of ideas and information on various ethical and human rights questions raised by the global proliferation of the clinical trial sector. The meeting also deliberated on the issue of litigation as one of the ways to bring ethical and human rights concerns to public domain and strengthen the protection of trial participants.

**v. XVII Humanitarian Congress on "Understanding Failure – Adjusting Practice" in Berlin (October 2015)**

Sama participated in the XVII Humanitarian Congress in Berlin held on 9<sup>th</sup> October 2015 at Charite University. Sama was a part of the panel on "The right shot: the struggle to ensure access to effective vaccines" along with Frank Mahoney, IFRC and Tom Roth, Access Campaign MSF. Sama's presentation was focused on New Vaccines for All: Why, Which and When.

**vi. Contribution of case studies to FERCI**

The Forum for Ethics Review Committees in India (FERCI) is the Indian chapter of FERCAP (Forum for Ethics Review Committees- Asia Pacific) and works towards improving understanding and implementation of ethical review of biomedical research in India while incorporating the significance of local cultural values. FERIC facilitates training and education opportunities for health research stakeholders and is an important platform for reaching out to ethics committee members who play a significant role in the ethical conduct of clinical trials. Sama contributed two case studies to FERIC to be used as a resource material in training with specific focus on the theme of compensation in clinical trial injuries.

## **6. Assisted Reproductive Technologies (ARTs) and Commercial Surrogacy**

### **6.1. Inter and Intra South Dialogues, Capacity Building and Advocacy on ARTs and Commercial Surrogacy in South Asia**

The project activities included policy advocacy, creating awareness on the ethical and legal issues through interactions with multi-stake holders through screening of the film and discussions; also reflection on the operationalisation and the politics of Assisted Reproductive Technologies (ARTs) in South Asia – in countries such as Sri Lanka, Bangladesh and Nepal. The initiative provided the platform to share lessons from activism, policy and industry and provoked a South Asian dialogue on the complexities surrounding surrogacy while informing perspectives and linkages of local organisations, networks. This can facilitate much needed on the current impasse within trans-national debates and action on this issue, and build their capacities to organise and lead.

Sama's visit to Dhaka from 23<sup>rd</sup> to 25<sup>th</sup> May, 2015 helped build a congregation and conversation between India and Bangladesh in the area of assisted reproductive technologies and commercial surrogacy. The film 'Can we see the baby bump, please?' was screened and discussions were held at universities, women's rights organisations, and international NGOs. The format of the meetings revolved around the film screening and a discussion with the audience about the film and discussions regarding commercial surrogacy in India. The conversations on surrogacy and assisted reproductive technologies helped to develop a keener understanding of the ways in which reproductive health issues are structured in South Asia, and the future course to be taken in this regard.

The screening at the Dhaka UNFPA office was followed by an in-depth discussion with members of groups working on gender and sexuality issues. Questions were asked about the kind of religious sanction around surrogacy in India, considering Islam expressly disallows commercial surrogacy explaining its institutionalised absence in Bangladesh. Other questions included queries regarding the contract and its modalities and the ways in which it is structured. The health of the surrogate and her rights in the arrangement were important nodes of discussion. There was also considerable interest on the kind of legislation being enacted in India to regulate/ govern commercial surrogacy.

The James P Grant School of Public Health, BRAC University invited Sama for a screening of the film that included an audience of academics, public health professionals, and medical doctors. The conversations at the School focused majorly on the rights of the child born out of surrogacy. Deliberation over transnational aspect of reproductive rights also formed the major

part of the discussions wherein the participants tried to develop pathways of reproductive rights to altruistic surrogacy. Further, structural issues including stigma, dislocation, and caesarean section delivery vis-à-vis surrogacy were also discussed at length at the screening. Diverse perspectives were noticed at the screening ranging from participants talking about children being a blessing from God to essentialising motherhood.

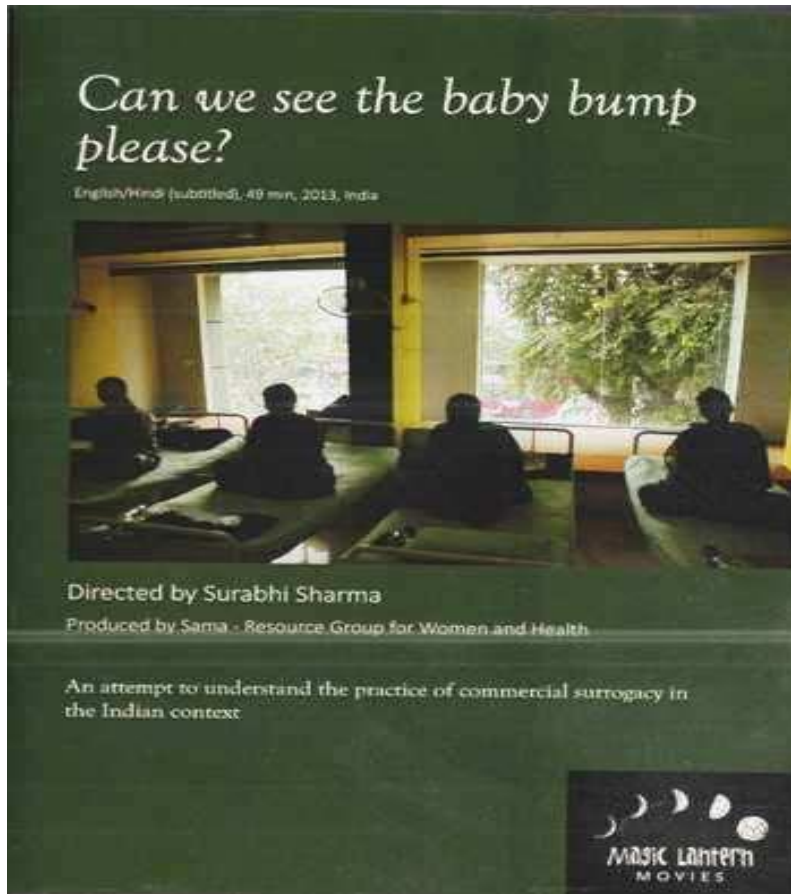
Sama was also invited by Naripokkho, one of the long-standing women's groups in Dhaka working on issues including gender-based violence, communalism to screen the film at their community office. The screening was attended by members of Naripokkho and other women's groups and organisations.

## **6.2. Monitoring and informing policies, laws with regard to ARTs and Surrogacy**

- Sama met the Minister of Health and Family Welfare, Government of Delhi, and the Health Coordinator at the Delhi Secretariat to brief them on Yuma Sherpa case (an egg donor who dies during the egg retrieval process in an IVF clinic).
- Sama met with the Secretary, Women and Child Development, to discuss the draft of Assisted Reproductive Technology (Regulation) Bill, 2014.
- A letter was sent to National Commission for Women on Sama's work on ARTs and the issues and concerns pertaining to the pending draft bill on ARTs.
- Follow up on Yuma Sherpa case: Concerns pertaining to the case of Yuma Sherpa's death were also shared with the Commission. Sama had previously, in 2014, had filed a complaint with National Human Rights Commission (NHRC) to investigate Yuma's death during a procedure of egg donation at a private fertility clinic in Delhi. The case was then forwarded to Delhi Medical Council for further investigation. Very recently, in the month of May, Sama was asked to be part of the inquiry initiated by the Medical Council, Government of Delhi as a principle complainant to investigate the case of Yuma Sherpa's death during an egg donation procedure. Sama was asked to testify in front of the council and present its views regarding her death. Further, an RTI was filed in the above mentioned case to obtain the relevant documents such as post-mortem report, medical records, and others required for further action.
- In May 2015, Sama was invited for the **'National workshop on Unpaid Work: Developing a Roadmap'** by UN Women South Asia in New Delhi to speak on surrogacy in a session on policies and discourses on unpaid work. The discussions aimed to inform the demand for equitable rights and recognition of work and labour within the household and outside that many women perform. And while surrogacy is paid and commercial in India, the way in which it is constructed and arranged makes it exploitative for surrogates in India. The National Commission for Women (NCW) in collaboration with UN Women, United Nations Population Fund (UNFPA) organised a Consultation on ARTs on 15<sup>th</sup> October 2015 at Vigyan Bhawan, New Delhi. Sama has



been requested to provide technical expertise towards the Consultation. Sama made a presentation on Surrogacy in India-an overview of the context, issues and challenges. The film “Can We See the Baby Bump, Please?” which explores the questions and concerns through the experiences of the surrogate women was also screened at the workshop.



- Sama played an important role in bringing the Draft Assisted Reproductive Technology (Regulation) Bill, 2014 to the public domain. Sama has also critiqued the draft of Assisted Reproductive Technology (Regulation) Bill, 2014 and sent the critique to the NCW and the Ministry of Health and Family Welfare in November 2015.
- Sama met the new Director General of Indian Council of Medical Research and had a discussion about ethics, ARTs, surrogacy and clinical trials.

### 6.3. Screening of the film and discussions on ARTs and Surrogacy

#### A. Urban Resettlement Colonies (*bastis*)

- i. Community workers from various *bastis* in Delhi came together during a screening of the film ‘Can We See the Baby Bump, Please?’ held at Gautampuri, an urban resettlement

colony on 21<sup>st</sup> June 2015. An audience of 20 women grassroots workers watched the film and participated in discussion afterwards regarding the practice of commercial surrogacy and its impact on women's bodies. The *basti* screenings were an interesting exercise in understanding how public perception regarding surrogacy was being constructed in an urban slum.

- ii. 'Can We See the Baby Bump, Please?' was screened on 28<sup>th</sup> August 2015 at JantaMazdoorColony which was attended by about 47 women. Many of them expressed that they have never heard of this nor were they aware of its happening in India. Discussions took place on the issues of compensation, health risks of surrogates and pay, the process of surrogacy, insurance, motherhood, informed consent, and the Draft Bill of Assisted Reproductive Technology (Regulation) Bill 2013.

#### **B. For organisations, networks, academic institutes in India**

- i. Screening of the film, "Can We See the Baby Bump, Please?" was organised by Sama along with JSA Chhattisgarh on 3<sup>rd</sup> August 2015 at Raipur, Chhattisgarh. Around 30 people from community based organisations working on issues pertaining to Gender Based Violence, health and domestic violence came together for the screening of the film.
- ii. Film, "Can We See the Baby Bump, Please?" was screened at O.P. Jindal Global Law University on the 3<sup>rd</sup> September 2015. The participants included students as well professors from varied backgrounds from the University. The discussion focused on the issues and concerns pertaining to consent form and the Draft Bill. Concerns vis-à-vis citizenship of the child born out of surrogacy were also raised and addressed at the same time. Deliberation over the rights of the surrogate on the child born out of surrogacy formed the major chunk of the screening at the University. The students were interested to take up Surrogacy as their research topic and hence showed their interest in visiting Sama for more resources on Assisted Reproductive Technologies (ART) and the arrangement of Surrogacy in the entire gamut of ARTs.
- iii. **Presentation at the Gender Park Conference, Kerala**  
Sama was invited by the Kerala Government to be a part of the International Conference on Gender Equality (ICGE-1) as resource person to speak on the issue of '*Reproductive and Sexual Health rights of women/Infertility and surrogacy*' in the session Health and Well-being in November, 2015.
- iv. A half-day interaction with the group of 35 community level team members from MASUM, Pune – Maharashtra was organised at the Indian Social Institute, Delhi in October 2015. Sama's varied work areas with regard to adolescent health, gender based violence, ARTs, etc. were shared and discussed. Sama's film 'Can We See the Baby Bump Please?' was also screened for the group, followed by a discussion on the rights of surrogates and current ongoing debates on the ART Bill for regulation of the industry in India.

- v. Academics from various universities such as Syracuse University, University of Chicago, Graduate Institute of International and Development Studies, Geneva, University of Edinburgh, visited Sama to know more about Sama's work on a range of issues.
- vi. A group of students from Smith College, USA visited Sama on January 21, 2016 to learn about Sama's work particularly on the issue of ART. A presentation on Sama's work and work on ART was made to them, along with the screening of '*Can We See The Baby Bump Please?*', followed by an interactive discussion with them by the Sama team.

## 7. OTHER ACTIVITIES

### 7.1. Celebration of 15 years of Sama (29<sup>th</sup> May 2015)

On 29<sup>th</sup> May 2015, Sama celebrated its fifteenth year anniversary in the midst of friends and board members. The Sama-Zubaan publication “Reconfiguring Reproduction” was released by Dr. Syeda Hameed, former member of The Planning Commission, Government of India. The evening had music by Dr Syeda Hameed and her team and slam poetry by young students from Delhi University.



## 7.2. Staff Capacity Building

Capacity building sessions were organised for the Sama team.

- Vrinda Marwah, young feminist researcher conducted a session on 'Contemporary Debates on Surrogacy'
- Vaibhao Ambhore, public health expert conducted an orientation on Clinical Trials
- Amrita Nandy, feminist activist conducted a session on 'Motherhood' where she shared her PhD work, which discusses motherhood by looking at non-normative mothers

## 7.3. Knowledge Resources and Dissemination

### i. Publications/papers

This period has seen a significant achievement where Sama's work on ARTS was published as an edited volume by Zubaan publishing house. Few significant journals have published articles by Sama. Sama has also contributed to the reputed blogs such as WIRE, SCROLL and Kafila.

- i. Sama's edited volume "Reconfiguring Reproduction: Feminist Health Perspectives on Assisted Reproductive Technologies" (2015) has been published by Zubaan, feminist publishing house in Delhi.
- ii. N. Sarojini and Nandy, Amrita (2015) "Government aims to offer women birth-control shots. But are they risk-free?". Scroll.in <http://scroll.in/article/759560/family-planning-government-wants-to-provide-women-birth-control-injections-but-are-they-risk-free>
- iii. Adv Veena Johari, Vaibhao, S Srinivasan and N Sarojini, Amar Jesani (2015) "Clinical Trial-Related Injury." Economic and Political Weekly 50.14. pp 20-22. [www.epw.in/commentary/clinical-trial-related-injury.html](http://www.epw.in/commentary/clinical-trial-related-injury.html)
- iv. Subha Sri B, Sarojini N, Vaibhao Ambhore, Deepa Venkatachalam (2015) Bilaspur sterilisation deaths: evidence of oppressive population control policy. Indian Journal of Medical Ethics. <http://www.issuesinmedicalethics.org/index.php/ijme/article/view/2172/4651>
- v. Anandita and N Sarojini, et al (2015). "Branding Mother India". Kafila.org <http://kafila.org/2015/05/24/branding-mother-india-sarojini-n-anindita-majumdar-veena-johari-and-priya-ranjan/>
- vi. Sarojini (2015). "For Motherhood and for Market: Commercial Surrogacy in India". In El Baoudamoussi, Samira and Rainhorn, Jean- Daniel (ed.) "New Cannibal Markets" (p 105- 122).
- vii. N Sarojini, Priya Ranjan. (2015) Needed, an Assisted Reproduction Law that Doesn't Discriminate Against Single Women. <http://thewire.in/2015/12/02/needed-an-assisted-reproduction-law-that-doesnt-discriminate-against-single-women-16524/>

### Forthcoming opportunities and submissions:

- i. Sama has approached Orient Blackswan to publish the ethnographic work on Commercial Surrogacy; a book proposal was sent.

- ii. The Asian-Pacific Resource and Research Centre for Women (ARROW) has invited Sama to contribute a working paper on Surrogacy and reproductive justice towards their thematic paper series.
- iii. Sama has been invited to contribute a paper for the volume on Health status in India, published by Oxford University Press (OUP) This paper is based on clinical labour- based on the experiences of participants of clinical trials and surrogate mothers.
- iv. Sama has submitted a manuscript to the anthology on Assisted Reproductive Technologies in the Global South and North to be published by Routledge in 2016.
- v. Sama was also invited to submit a manuscript on Feminist Methodologies towards another edited volume by Dr Kalpana Kannabiran and Prof Padmini Swaminathan to be published by Routledge in 2017.
- vi. Sama submitted a case study on its work on gender based violence on the invitation of CEHAT, Mumbai towards an edited volume.

## **ii. Sama's Website**

The website has been reconstructed and updated by enhancing access and readability of the information. The website was revamped to make it more user friendly and to showcase the work and resource material in a more effective manner. The separate subthemes featured in the website allows for ease of navigation and locating the relevant material. The various resource materials including papers and articles developed by Sama, capacity building tools, consultation reports, fact finding reports, policy briefs, research reports etc. have been made available through the website.

## **iii. Archives**

The primary objective of creating the archives was to construct a robust database of relevant information or knowledge resources on clinical trials and other thematic areas. We have developed five major focus areas for archiving available material sourced from multiple sources. The five major focus areas include clinical trials, assisted reproductive technologies, adolescent health, gender based violence and early marriage and health to coincide with the focus areas of Sama's engagement currently. Sub-categories have been created under each focus area to allow for ease of search and locating the article and to collate articles based on their specific focus areas. This is ongoing and is expected to be completed in the following year.

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