

Annual Report
April 2014- March 2015

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 2014 to March 2015 across different organisational focus areas.

I. Strengthening Health System Response to Gender Based Violence (GBV)

I.A. Situational Assessment in Delhi and Chhattisgarh

Last year in Delhi, Sama carried out a Situational Assessment to document and understand the perspectives, practices, and preparedness of public (government) hospitals in Delhi in responding to survivors of sexual violence and domestic violence. Interviews were conducted in a total of 22 hospitals during June, 2013 to May, 2014, through in-depth interviews with healthcare providers who were involved in responding largely to survivors of sexual violence and also domestic violence to some extent. The assessment findings point out to the existing gaps and emerging concerns as well as describe some of the positive initiatives taken by the hospitals. For Domestic Violence survivors there was limited response in an adhoc manner and in the absence of any protocols.

A similar assessment was also carried out in Chhattisgarh by Sama along with Chaupal, in four districts including Raipur, Koriya, Kabeerdham and Mahasamund between the period of January, 2014 to October, 2014. The assessment was able to map, document and understand existing practices with regard to the response of the health care system to GBV in selected areas in Chhattisgarh; and to assess the existing gaps in knowledge, perceptions, practices as well as linkages between the health care sector and other actors. Based on these assessments that provided critical insights into ground realities, strategies for future work in both the states were developed and begun to be implemented.

I.B. Capacity building and Advocacy for Strengthened Health System Response to GBV

I.B. i. Following on from the emerging concerns of the assessment, a Consultation titled *Strengthening Response to Sexual Violence by the Health Sector* was organized in November 2014. The consultation was attended by healthcare providers from 13 public hospitals in Delhi who had also been part of the assessment process. Apart from it there were also representatives of Rape Crisis Cell, Crisis Intervention Centres and 181 helpline and the resource persons included experts from legal and forensics background. The consultation saw discussions around clarity of roles and various aspects of response and legal provisions that had emerged from the assessment findings. Concerns were raised upon having larger dialogues around provision of mandatory reporting, need for strengthened interlinkages with other support/service providing agencies and on addressing the need and willingness for capacity building and technical support on perspectives and skills of healthcare providers towards sensitive and ethical response.

I.B. ii. Both the Situational Assessment and the Consultation point out the need to strengthen linkages and have a systematic engagement with these public health facilities as well as private health sector towards addressing gaps and concerns for an improved response. In the past, Sama has had long association with Safdarjung hospital in Delhi which is a tertiary level hospital under Central Government. This association

has enabled strengthening of the healthcare providers' perspectives and responses within the hospitals as well as created interest and motivation among the healthcare providers to share their experiences with other hospitals in the state. Post assessment Sama has been reaching out to other public hospitals as well.

In the recent years certain positive legal and policy mandates are recognising the role of health sector and providing critical platform for advancing and strengthening health sector's response to survivors of GBV.

I.C. Capacity Building through Trainings, Workshops and Orientations

I.C.i. Orientation to Community based Organisations

A one and a half day orientation was conducted on 28th May and 29th May, 2014 with 24 members of the *Adivasi Adhikar Samiti* members in Manendragarh block of Chhattisgarh. This Samiti is a collective group of women including *Mitanins* and *Mitanin* trainers who work with communities on a range of issues. The strategies used by the Samiti members in addressing the issue of domestic violence in the community were also discussed.

I.C.ii. Strengthening Capacities of Sama Team

An in house orientation on Gender Based Violence as a Public health issue with a particular focus on relevant laws and protocols was conducted at Sama's office. The session included a presentation followed by discussions on linkage between violence and health, gaps and concerns in the present public health response to GBV, relevant legislations and Protocols. The discussions aimed at building a basic understanding of Sama team on the gender based violence as a public health issue, existing gaps and concerns and relevant legislations and protocols.

I.D. Policy Monitoring and Advocacy

I.D.i. Feedback for Nirbhaya Centre

Sama submitted its feedback and suggestions on the concept note of setting up Nirbhaya Centre i.e. the One Stop Crisis Centres (OSCCs) to the Ministry of Women and Child Development (WCD). The feedback and suggestions included demand to have larger dialogues and consultations over the proposed Nirbhaya Centres along with raising concerns around the location of Nirbhaya Centre, accessibility by the survivors, feasibility of having skilled human resources etc.

I.D.ii. Advocacy for implementation of the MOHFW guidelines for medico-legal care for sexual assault was carried out in Delhi as well as in Chhattisgarh. Updates in this regard were disseminated to organisations, who have been part of Sama's initiatives in this area, towards advocacy in their respective states.

I.D.iii. Advocacy with the Ministry of Health and Family Welfare, State Women and Child Development Ministry

In Chhattisgarh, Sama developed a training module for health care providers on GBV during this period on the request of the Secretary, Health. Follow up will be ongoing to ensure its implementation. Meetings and dialogues were continued with the WCD

ministry towards strengthening linkages between diverse agencies for an improved response.

I.E. Participation in advocacy efforts by other organisations

Sama participated in the following:

- A two day consultation “Approaches to working with the health sector on domestic violence against women: Sharing and learning from Indian experiences” by Centre for Enquiry Into Health and Allied Themes(CEHAT) in September 2014 at Mumbai. The consultation provided space for organisations to reflect on approaches and strategies used, challenges and achievements and lessons learned in engaging with the health sector on violence against women.
- Symposium on Violence against Women: Review of Institutional Responses in India and United Kingdom organized at the Tata Institute of Social Sciences, Mumbai in July 2014. The symposium aimed at reviewing the current social, legal and policy context and new initiatives and responses; and draw from the learning from India and UK to set the larger agenda of scaling up efforts. The participants included researchers, practitioners, activists and students from India and UK.
- National Consultation on Gender based Violence and Sexuality organized by Nirantar for the dissemination of the experiences and findings of a report based on Nirantar’s series of trainings on sexuality and discussions around this.

II. Enhancing Adolescent Sexual and Reproductive Health Rights through Health Systems Engagement

The most recent of initiatives in the realm of adolescent health is the Rashtriya Kishor Swasthya Karyakaram (RKSK) or the National Adolescent Health Strategy that was launched in January 2014. This ambitious health initiative seeks to provide comprehensive services for adolescent girls and boys in the countries through six central components of nutrition, sexual and reproductive health, violence including gender based violence, substance abuse, mental health and non-communicable diseases. The implementation of the RKSK is led by the health system that is expected to facilitate its implementation through convergence of multiple states actors and services. The RKSK provides an important opportunity for engagement on adolescent sexual and Reproductive Health (SRH) issues. However, since its launch was as recent as January 2014, implementation in the states has merely begun.

Strengthening of the RKSK towards improved access to adolescents necessitates sustained engagement in the next years. Furthermore, given the huge deficits in financial provision for health, the need for continued state level advocacy and action become crucial.

Building and strengthening capacities and local resources on adolescent reproductive and sexual health issues by Sama have been ongoing over the past three years in a

focused manner in the five states of Rajasthan, Madhya Pradesh, Chhattisgarh, Jharkhand and Odisha.

II.A. State Level Policy Dialogues Between Organisations and State Officials

Dialogues regarding policy and programme implementation were organised in the months of May and August 2014 in Madhya Pradesh and Odisha respectively. These dialogues facilitated updates on the implementation of the programme – RKSK – highlighted the ground level realities based on monitoring of implementation by organisations in different districts. The dialogues facilitated informing state officials of the gaps and concerns vis-a-vis implementation of the state initiatives for adolescent SRH.

Memorandum (in Odisha) by the Jan Swasthya Abhiyan and Sama were submitted with recommendations for strengthening of the health system response for adolescent SRH.

II.B. Capacity building Follow up Workshops in the States

Three workshops were organised in Jharkhand and Madhya Pradesh to build the capacities of organisations, state JSA partners on adolescent SRH and particularly in the context of the RKSK following its implementation since January 2014. Facilitating dissemination of information about the implementation to grassroots organisations working on the issues of health and adolescents facilitated mobilisation of groups for future follow up and action.

II.C. Group discussions

Discussions were carried out with adolescent groups comprising girls and boys across the five states in continuation with previously held discussion. Twelve meetings and discussions were conducted to facilitate the participation of boys and girls in expression of their needs towards informing and strengthening the RKSK. Further this process sought to mobilise young people to be aware and part of the planning, monitoring of programmes meant to address their needs.

II.D. Meetings with health care providers and health officials

Meetings and discussions with health care providers and health officials were ongoing during this period. Meetings were carried out with 15 key health providers and officials to ascertain the implementation of the RKSK in respective states and to gain updates on State implementation plans. Meetings were conducted with community level health care providers such as Mitanins/ ASHAs/ USHAs as well as with health officials in charge of implementation of RKSK.

II.E. Field visits to monitor, observe health system response to adolescent SRH

Visits to about nine adolescent friendly health clinics were carried out in the states of Odisha, Jharkhand and Madhya Pradesh. These visits provided hands-on experiences of the status of the centres for adolescents set up within health systems and the services they provided. They provided insights into access, challenges to implementation that

were able to inform policy advocacy processes. Visits were also carried out to the helpline for adolescents in Madhya Pradesh to assess and strengthen access to information and linkages.

II.F. A small group consultation was organised with representative groups from the five states to deliberate in depth future strategies towards improving access and implementation of health system response to adolescent SRH services in the five states.

III. Building Capacities and Linkages” Assisted Reproductive Technologies and Surrogacy

III.A. Monitoring and informing policies, laws with regard to ARTs and Surrogacy

III.A. i. Sama continued to advocate for placing of the ART Bill in the public domain as well as informing key persons, parliamentarians about the issues and concerns with the Bill Draft.

III.A.iii. Sama was invited to be part of a panel on ‘ARTs vs. Adoption in the Indian Scenario’ at the 25th Annual Meeting of the Indian Society for Study of Reproduction and Fertility (ISSRF) in association with WHO at Mumbai in February 2015. Sama was part of a panel discussing the linkages between ARTs and adoption in the contemporary scenario wherein infertility and infertility treatment are on the rise in urban India. The discussions were moderated by and part of conversations with the Indian Council of Medical Research regarding the ARTs Bill and the need to give adequate importance to adoption within policy discourse on infertility.

III.A. iv. The International Forum on Inter-country Adoption and Global Surrogacy at The Hague, The Netherlands during 11-13 August 2014

The forum that was organised during 11-13 August 2014 at the Hague sought to build an evidence base for international adoption and surrogacy problems and/or best practices that might inform Hague Convention policy makers and Hague Convention on Inter-country Adoption (HCIA) Central Authorities. The focus on the Forum was largely “the status of children” both vis-a-vis international adoption as well as transnational surrogacy and to explore the parallels and distinctions between them. Sama was invited to deliver the Keynote Address on Commercial Surrogacy in the Indian Context as part of the Global Surrogacy Practices Track at the Forum. Deepa represented Sama at the forum and presented the keynote and participated in the plenary sessions as well as the breakout sessions of the Global Surrogacy Practices Track. Sama was also invited to present and discuss the film on ARTs and surrogacy – “Can We See the Baby Bump Please”.

III.A. v. Sama participated and presented at the International Seminar on *Assisted Reproductive Technologies in Northern and Southern Countries: Issues, Challenges & the*

Future in October 2014 in Mumbai The Seminar organized by INED, CEPED (France) and IIPS, UNFPA (India) aimed to identify and understand the varied impacts and issues related to ARTs and surrogacy. The International Seminar was attended by ICMR representative and academics working in the area of ARTs.

III.A. vi. *Participation and Presentation at the Fifth National Bioethics Conference, Bangalore*

Sama presented on the panel on 'Ethics and Reproductive Health' at the National Bioethics Conference in Bangalore in December 2014. Organized by the Indian Journal of Medical Ethics, the conference brought doctors, academics, researchers and civil society activists working in the area of medicine and reproductive rights to our panel. Presentations on Sama's work on surrogacy and assisted reproductive technologies were met with conversations and ethical questions on the kind of impact the surrogate's psychological and physical health has on the child. There were queries regarding the kind of stigma that is associated with being a surrogate mother, as well as questions regarding ethical and unethical practices within the commercial surrogacy arrangement.

III.B. Strengthening Capacities and Linkages on Surrogacy and Assisted Reproductive Technologies in India

In the southern region, the discussions on assisted reproductive technologies and commercial surrogacy took place with around 70 participants from varied backgrounds - sex workers, anganwadi workers, persons from the *kothi* and transgender community, students of law and public health, community level activists working in the area of gender-based violence, from Karnataka and Andhra Pradesh. Sama collaborated with Vimochana, National Law School of India University, Sangama (Karnataka) and Women's Initiatives (WINS) (Andhra Pradesh) for facilitation and mobilization; some of the organizations / institutions also contributed equipments and space. The discussion were intense and panned a range of questions - on labour, work, comparisons between surrogacy and sex work, the manner of "asexual" reproduction defined by ARTs, the denial of rights of transpersons, and others from LGBTQI communities. Questions around regulation with regard to safeguards for surrogate's health and the child's rights, issues around parentage in the context of surrogacy were also raised. Anxieties about the violation of surrogates' rights, conditions of living in hostels, for example, were also discussed.

III.C. Screening of the film Can We see the baby bump please and discussions on ARTs and Surrogacy

(i) In rural areas at the community level – Madhya Pradesh

As part of continued engagement with grassroots organizations and community workers, four screenings of the film were carried out in the districts of Dewas and Indore of Madhya Pradesh in the month of February 2015. The screenings was held in association with Eklavya, a non-governmental organization working on education. The film screenings and discussions were organised with different groups - young girls, community level activists working on varied social issues. Some of the issues that were

flagged during the discussion included: breast feeding, citizenship of the child born out of surrogacy, international rules that regulate surrogacy outside India, inadequacy in the information given to the surrogate mother on the health risks associated with this arrangement, death of the surrogate mother during the gestation period or at the time of the delivery and the insurance or compensation followed with it. Discussions on the practice of egg donation and questions around the influence of the dominant caste system in such practices were also flagged. The role of agents, doctors and others in the industry were discussed based on Sama's research as well as the film.

(ii) Screenings in urban resettlement areas

Sama conducted screenings in association with the organization Action India in the *basti* of Seemapuri in West Delhi in November which was attended by 30-35 women from the community. Participants shared that they had heard of local clinics and agents seeking surrogates from amongst *basti* residents thereby bringing into focus the ways in which urban slums are turning into target areas for surrogacy recruitment.

(iii) For Academic institutions – colleges, universities for young people

- Sama was invited to screen the film, "Can We See the Baby Bump, Please?" at ITM University, Gurgaon. Being a law college predominantly, the participants were mainly from the law department that included students, faculty and researchers. The discussion focused on the issues and concerns pertaining to various provisions of the e Draft Bill. Issues around citizenship of the child born out of surrogacy, the rights of the surrogate over the child born out of surrogacy were debated.
- 'Can we see the baby bump, please?' was screened at Dr B R Ambedkar University, Delhi for postgraduate students of Gender Studies, followed by an invigorating discussion on surrogacy and its relationship to larger issues concerning choice and reproductive health. The interaction involved cross-referencing Sama's research findings with their theoretical and syllabi-related questions.
- In November a group of 25 undergraduate students and faculty members from the University of Chicago visited Sama for a session as part of their Study India Programme. The film *Can We...* was followed keenly and was an eye-opener for many of the students who also inquired about Sama's research and advocacy interests in the area of assisted reproductive technologies and surrogacy.

Orientations for students and media

- As part of our continued conversations with students and academics on surrogacy and ARTs, a research student from the College of Wooster in the United States had a discussion regarding the issue of reproductive rights and policy in India especially in relation to surrogacy and ARTs.

- Sama was part of a panel discussion organised by the Centre for Health Law, Ethics and Technology, OP Jindal Global Law School on "Regulation of Assisted

Reproductive Technology in India: where are we now and where are we going?" in April 2014.

- Sama presented at the National Law University, Dwarka in September 2014 based on the research on commercial surrogacy during a "National Seminar on Surrogacy", as part of a panel that also included National Commission for Women Member Ms Shamina Shafiq.

- Conversations regarding legislation on surrogacy and ARTs were the point of engagement with media such as the Canadian Broadcasting Corporation who were keen on knowing the modalities of the arrangement and the ways in which the law is taking these into consideration.

- **Film Screening in Germany**

Sama was invited to screen the film "Can We See the Baby Bump Please" and to lead a discussion following the film screening at The Lichtenberg-Kolleg, Georg-August-Universität Göttingen, Germany, on 30th April 2014.

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III.D. Research and Outreach

We are involved in documenting our meetings and workshops emerging from the film screenings and discussions on ARTs and surrogacy. These are becoming important documents to further inform our policy advocacy work and our training outreach.

III.E. At South Asia Level - Conversations in Sri Lanka

Sama team members visited Sri Lanka during 15–19 December as part of the scheduled inter-South meetings and dialogues on commercial surrogacy and assisted reproductive technologies. As part of the engagements in South Asia, Sama seeks to share initiatives and experiences on ARTs and surrogacy and through this process foster a deeper understanding of the issues and exploring areas for convergence and action. We met a number of groups and individuals and held screenings in Colombo that helped us gain insights into the manner in which the ARTs and surrogacy industry works in Sri Lanka.

III.F. Knowledge Resources

- Sama also authored a piece on migration and reproductive and sexual rights in relation to the surrogacy industry in India for the TARSHI blog: *InPlainspeak*.

An information sheet on ARTs and surrogacy in Hindi was completed during this period. The info-sheet addresses commonly held misconceptions regarding ARTs and focuses on technological alternatives that can help overcome fertility issues.

- Sama also featured in a radio broadcast by the British Broadcasting Corporation (BBC), India also on surrogacy.

IV. Action Research and Advocacy on issues around Clinical Trials

Sama has been consistently involved in public engagement through capacity building workshops, the development of information resources on clinical trials. Sama has also been involved in dialogues with policy makers, and through legal intervention towards informing policy and legislation for regulation, the setting of ethical standards, and the

implementation of good practices in clinical trials. Through submissions to the government on various amendments, Sama has drawn the attention of the policy makers to the important issues related to rights of the clinical trial participants.

IV.A. Research

Sama has initiated two key areas for research and has just initiated this process. The areas include (i) access to medicines for which trials were conducted in India; and (ii) study on compensation mechanisms in India and other countries..

Iv. B Policy Advocacy

i. Submission of comments on the formula for compensation in drug trials for adverse events other than deaths

Sama submitted its analysis of the formulae for calculating compensation devised by the CDSCO based on the Workmen Compensation Act and calculating compensation based on wages of an unskilled laborer in Delhi.

ii. National Seminar on Compensation in Drug Trials In July 2014, Sama took initiative and organized a national Seminar on Compensation in Drug Trials in Delhi in collaboration with LOCOST, TWN and PHFI. The Seminar aimed to deliberate on various issues related to compensation in India including the review of existing formulae on compensation towards discussions and formulating recommendations for future engagement. The seminar was attended by varied stakeholders including Principal Investigators, Ethics Committee Members, Pharmaceutical industry network representatives, academicians, civil society groups, and Deputy and Health Advisor. The emergent themes of this seminar have been shared with the Ministry of Health and Advisor to the Health Minister.

iii. Public Lecture in Germany

Sama was invited for a Public Lecture to speak on Clinical Trials: Ethical Challenges on 29th April 2014 at Institut für Sozialmedizin, Epidemiologie und Gesundheitsökonomie Charité - Universitätsmedizin Berlin, Berlin.

IV.C. Knowledge Creation and Dissemination

In our effort to make the information on clinical trials more accessible to clinical trial participants, we have translated the English info-booklet on clinical trials into Marathi language for wider dissemination. This is already available in Hindi.

V. Advocacy on Sex selection

Sama was also invited to participate in the 22nd Meeting of the Central Supervisory Board constituted under the PC & PNDT Act (1994) regarding the review of the PCPNDT Act to include ARTs within its gamut to prevent pre-conception sex determination. The deliberations were attended by the Union Minister for Health and

Family Welfare, Minister for Women and Child Development and other policymakers, along with academics and other public health and women's organizations.

Sama was invited to a meeting hosted by the Ministry of Health and Family Welfare on the PCPNDT act and the need for revisions in relation to assisted reproductive technologies and their incursion into the practice of sex selection. The Minister took in cognizance the ever-present danger of ARTs being actively used for the purpose of pre-conception sex selection, and asked for Sama's feedback regarding clauses within the existing bill that may need re-engagements or re-working.

VI. Research on Early Marriage and Health

Early marriage continues to take place amongst adolescents for a large number of young men and women in India. The practice of early marriage affects both boys and girls, but it affects girls with higher incidence and greater intensity. While the age at marriage for women has increased over the years, yet a large number of women are married off at a very young age. Early marriage has far reaching health consequences for the young girls. The young girls are at a disadvantaged position in the marital home to negotiate aspects of their own sexuality and health. They are under pressure to prove their fertility which results in early pregnancy. This has adverse consequences for their mental and physical health. During adolescence, food and nutrient needs of the body are high as this is the time when the body undergoes rapid physical changes. When this is coupled with pregnancy the nutrient requirements of the body go further up. However, the young girls lack access to proper and adequate nutrition in the marital home which results in maternal anemia. This in turn leads to high rates of maternal mortality and high incidence of low birth weight babies. Early marriage also increases exposure to reproductive morbidity and mortality. It exposes the young girls to contracting sexually transmitted diseases including HIV/AIDS. Exposure to domestic and sexual violence is also common among young brides which adversely impact their mental and physical health.

In view of the above, Sama has undertaken a research with the primary objective of understanding and ascertaining the linkages between early/ child marriage and health, the current role(s) and strategies by the health system in addressing early/child marriage as well as towards recognition and addressing of the implications for the health of women in early marriages.

A report *Dataspeak: Early Marriage and Health* has been published based on the secondary review and analysis of data and literature on early / child marriage, adolescent health, health outcomes of early / child marriage.

The data reviewed includes health and demographic survey statistics and indicators, central and state policies, programmes and strategies. The report highlights major gaps or issues based on the review and analysis of the available data on early marriage and health. Based on the identified gaps or issues the research draws attention to some areas for future inquiry that are critical to young people including those in situations of early marriage.

VII. CEDAW

Sama was invited for the 58th CEDAW session for NGOs on 30th June 2014 at CEDAW Secretariat, Geneva, Switzerland to provide country-specific information on issues relevant to the implementation of the Convention by the State parties.