Assisted Reproductive Technologies: Implications for Women’s Reproductive Rights and Social Citizenship

By: Sama-Resource Group for Women and Health

Final Technical Report
10\textsuperscript{th} December 2010

IDRC Project Number: 104780-001

IDRC Project Title: Assisted Reproductive Technologies: Implications for Women’s Reproductive Rights and Social Citizenship

Country: Delhi, India

Full Name of Research Institution: Sama Resource Group for Women and Health

Address: B-45, Second Floor,
Shivalik Main Road, Malviya Nagar,
New Delhi - 110017
India

Members of Research Team: Sarojini NB, Preeti Nayak, Deepa Venkatachalam, Anjali Shenoi, Susheela Singh, Vrinda Marwah, Aastha Sharma, N. Srilakshmi, Truptimayee Rout and Saalai Selvam (Core team and local investigators together).

Contact Information: Sarojini NB
Sama - Resource Group for Women and Health
Email: sama.womenshealth@gmail.com

This report is presented as received from project recipients. It has not been subjected to peer review or other review process.

This work is used with the permission of Sama-Resource Group for Women and Health.

Copyright: 2010, Sama-Resource Group for Women and Health
Abstract
The premium placed on motherhood, social stigma associated with infertility and the cross cutting desire of having a biological child have led to the escalation of birth technologies into a ‘fertility industry’. The provision of these technologies is also ridden with unethical practices especially in countries with a lack/absence of regulation of these technologies, like in India, with grave implications on the health and rights of women availing these technologies. The state too, has been promoting these technologies, without addressing the issue of infertility and its root causes. These ‘birth technologies’ or assisted reproductive technologies (ARTs) have, using a language of choice and rights, not only created a market for donors and surrogates, but have also commercialized and fragmented human reproductive body parts like ova and uteri.

The research attempted to understand the logic behind the use of assisted reproductive technologies (ARTs)\(^1\), its linkage with the variables of caste and class, the State’s response to ARTs, the commodification and extensive commercialization of ART’s and women’s bodies, and the implications of such unregulated technologies.

Key words: infertility, fertility, industry, commodification, and regulation, ARTs

---

\(^1\) These are technologies that assist reproduction, increasing the chances of conception and carrying a pregnancy to term, collectively referred to as assisted reproductive technologies or ARTs. They encompass various procedures ranging from the relatively simple intrauterine insemination (IUI) to variants of *in vitro* fertilization (IVF) and embryo transfer (ET), commonly known as “test-tube baby technology”. 

---
## Contents

The Research Problem...........................................................................................................4  
Objectives..................................................................................................................................5  
Methodology............................................................................................................................6  
Project Activities....................................................................................................................11  
Key Findings............................................................................................................................18  
Project Outputs.......................................................................................................................34  
Project Outcomes....................................................................................................................39  
Overall Assessment and Recommendations............................................................................42  
Annexure...................................................................................................................................46  

Bibliography (of attached outputs / advocacy materials)
I. The Research Problem

In India, infertility-like fertility is socially visible and an object of social control; absence of offspring in a marriage is more conspicuous than their presence. The importance of and desire for a biological child feeds into the promotion of Assisted Reproductive Technologies (ARTs) as ‘miracle cures’ for infertility, thus leading to a surge in the number of ART providers and the people accessing them. This comes with a range of implications. Apart from the obvious health risks that these technologies pose for women users, they deploy also a regressive perspective of women’s roles, eulogizing their fertility and necessitating the medicalization of their bodies and the commercialization of their reproductive tissues.

As concepive technologies, ARTs represented for Sama the other end of what the team was then engaged in—the politics of contraceptive technologies. Given the inadequate research on ARTs in the Indian context, Sama took this up as the theme of a 2004 study exploring the social, medical and ethical implications of ARTs in the three metropolitan cities—Delhi, Mumbai and Hyderabad.

The findings of this study hinted at developments (which took clearer shape in the coming years) meriting further investigation into certain aspects of ARTs. For instance, these technologies did not appear to be isolated medical treatments; they were part of a larger business, which was now growing into a veritable ‘fertility industry’. The operationalization of ARTs in India appeared to be shifting, from urban metros to smaller cities, with chains of referrals emerging as a feature. A pilot study in the ART clinics of Bhubaneswar and Cuttack in Orissa also revealed that IVF was being carried out in batches for cost-effectiveness, subject to the availability of the embryologist and andrologist, both of whom were flown in from Mumbai and Hyderabad. While medical tourism specifically for ARTs from other countries to India continued to attract media and industry attention, local migration of couples from one city to another within India for ARTs was also growing gradually, albeit unnoticed.

Further, the absence of any state regulation raised also significant ethical concerns. Thus, the proposed large-scale study in three states sought to explore

1) access (with reference to class, caste and gender) and
2) industry (with reference to the process of ‘local globalization’) dimensions of ARTs; and,
3) advocacy (with regard to proposed regulatory mechanisms)

Thus, Sama’s field-based study, undertaken from February 2008 to December 2010 by Sama, formed also the evidence base for Sama’s

---

1 ARTS and Women; Assistance in Reproduction or Subjugation, 2007 (Sama Publication)
campaign initiatives, including the critique of the ART (Regulation) Bill and Rules 2008 and 2010. These three objectives saw no change through the course of the research, though the outcomes and findings for each varied.

II. Objectives

The specific objectives of the research were;

a. To document the experiences of women undergoing ART procedures (IVF and IUI) and rigorously focus on the class and caste dimensions vis-à-vis access to ARTs.

b. to explore the growth of the “ART industry” in India by examining the inter-linkages between ART clinics in metro cities to those in smaller towns and to understand the process of “local globalization”.

c. to initiate a public debate around this issue both within the women’s movement and health movement and also initiate policy advocacy for the regulation of the ART industry in India.

These objectives remained unmodified, and were successfully achieved through interviews, observations and FGDs. The research team was able to document the experiences of women users, as well as gather information around access and industry dimensions of ARTs.

Despite a booming medical and even fertility tourism industry, the absence of a centralized database/registry of functional ART clinics, meant that there was no way of knowing the exact number of operational ART centers in a particular area. Thus, the research team had to rely on informal sources of information. In our sample, while no ART clinics were present in rural areas, the number of rural users of ARTs was significant, with clinics in smaller cities acting as an important fulcrum or bridge in the ART industry. These clinics served often as the first point of access for users, providing services at a range of costs, and setting up schemes and collaborations (often with clinics in bigger cities) to expand their market.

Despite the high, and many hidden, costs of ART procedures, the sample consisted of users from different classes, with several willing to push the limits of their affordability in their quest for a biological child.

The caste related data could not be triangulated, though our sample had users from across the caste spectrum. This does not indicate that the market is blind to caste, thus bearing the potential to liberate us from ascriptive identities. Rather, given that caste is classed in India, access to ARTs must be understood as mediated most significantly by class, and therefore by caste, because of this overlap.

A systematic attempt was made to familiarize policy makers and activists with the lack of regulation of the ART industry, and its implications for
women’s health. Sama attempted to bring into the ART discourse perspectives from a range of movements - women’s rights, public health, disability rights, sexual rights and child rights.

**III. Methodology**

**a. Research Design**

The design of this research is essentially exploratory and qualitative. The research seeks to establish the situation on the ground and the growth of the fertility industry, as well as draw generalizations and conclusions through a qualitative method of analysis.

**b. Research Process**

The research was started in February 2008, including both collecting primary data and also the secondary material. A critical analysis of secondary data such as relevant bills and guidelines was also undertaken to develop an understanding of the status of legislation, regulation and policies that affect the ART industry, and to identify the issues that need public debate and discussion. The study also examined websites and brochures of ART clinics, tourism departments, medical tour operators and travel agencies, and advertisements in magazines relating to egg donation and surrogacy. This was an attempt to analyze the content of these promotional materials and to learn about the ways in which ART providers promote their services.

**c. Developing Research Questions**

The specific questions that were sought to be answered in order to achieve the research objectives were as follows:

- a. How do identities of class, caste and sex determine the access to and control over ART treatment?
- b. How do we understand the economic and commercial aspects of ARTs: their provision, proliferation, and implications?
- c. What are the features of India’s emerging ART industry?

**d. The Research Setting**

**Study Area: Selection of States**

Given the fact that hardly any credible data exists on the number, spread and functioning of the ART industry in general and of ART clinics in particular, the possibility of choosing a sample from an unclear ‘universe’ did not arise. Instead, based on the findings of our earlier study conducted in 2006, and also based on extensive discussions on the issue with a range of experts across the country, we decided to locate our present study in three diverse geographical areas namely, the three states of Orissa, Tamil Nadu (TN) and Uttar Pradesh (UP) with diverse human development indicators. There was a deliberate effort to capture the implications of ARTs on diverse
population groups and also be attentive to the regional variations in India. It was decided that one state each from the north, east and south would be studied so as to incorporate the differential socio-cultural and economic backgrounds of the people.

The three chosen states represent the different stages of the development and advancement of the ART industry. While the industry in Orissa is quite nascent, in UP it is growing rapidly and in TN, it is quite advanced with newer forms of partnerships emerging. The study has been undertaken in rural, peri-urban and urban areas of the three states.

**Mapping of the Districts, Clinics and Users**

**Mapping Tools used for the selection included:**

- **Internet Search:** The clinics were initially identified through the Google search engine, lists of ART clinics available on websites like pregnancymd.org, and a list of Best IVF clinics in India published in Outlook. Tourism Departments particularly from TN and UP.
  
  The keywords used for web searches were ART clinic, IVF clinic, and infertility clinic and infertility treatment, Assisted Reproduction for each of the states.

- **Advertisements:** A number of magazines were scanned through for advertisements seeking or offering services related to ART procedures. Some of the magazines and newspapers that were looked into are:
  
  English: Outlook, India Today, The Indian Express, The Times of India, Hindustan Times
  
  Hindi: Navbharat Times, Dainik Jagran, Hindustan, Grihashobha
  
  Tamil: Aval Vikatan, Kumudam Snegidhi, Thenmani, Mangayar Malar

- **Telephone Directory Services:** The team members used local telephone directories, the TATA Yellow pages and other telephone services such as Just Dial Service wherever available to get information about ART clinics.

There was an effort to list out the ART clinics functioning within a district as exhaustively as possible, to eliminate any bias. The selection of the districts depended upon the willingness of the ART providers of that district to participate in the research. The final districts where the research was conducted were as follows:

<table>
<thead>
<tr>
<th>S.No./ State</th>
<th>Orissa</th>
<th>Uttar Pradesh</th>
<th>Tamilnadu</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Cuttack</td>
<td>Meerut</td>
<td>Vellore</td>
</tr>
<tr>
<td>2.</td>
<td>Ganjam</td>
<td>Lucknow</td>
<td>Madurai</td>
</tr>
</tbody>
</table>

---

1. [http://www.pregnancymd.org/art-ivf-india.htm](http://www.pregnancymd.org/art-ivf-india.htm)
Selection of the primary respondents
Selection of the respondents in this research was as follows:

- Providers of Assisted Reproductive Technologies (IUI, IVF, ICSI and other variations of IVF) and other staff of the clinic
- Women using ARTs
- Male partners (wherever possible)

In the proposal for this research project the number of clinics to be covered was 30. The number of women undergoing ART procedure to be interviewed was 75. However, as a result of the exhaustive mapping and selection process, 86 women and 43 providers of ARTs like IUI, IVF and ICSI were interviewed across the three states. Of the total number of women, 43 were from TN, 30 from Orissa and 13 from UP who have in the last two years undergone the procedures of IUI, IVF, IVF + ICSI.

Total number of women interviewed

<table>
<thead>
<tr>
<th>State</th>
<th>District</th>
<th>IUI</th>
<th>IUI IVF</th>
<th>IVF ICSI</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>UP</td>
<td>Agra</td>
<td>-</td>
<td>2</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>UP</td>
<td>Allahabad</td>
<td>-</td>
<td>3</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>UP</td>
<td>Benares</td>
<td>-</td>
<td>2</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>UP</td>
<td>Meerut</td>
<td>-</td>
<td>6</td>
<td>-</td>
<td>6</td>
</tr>
<tr>
<td>Subtotal</td>
<td></td>
<td>-</td>
<td>13</td>
<td>-</td>
<td>13</td>
</tr>
<tr>
<td>Orissa</td>
<td>Khorda</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Orissa</td>
<td>Sundargarh</td>
<td>3</td>
<td>11</td>
<td>-</td>
<td>14</td>
</tr>
<tr>
<td>Orissa</td>
<td>Cuttack</td>
<td>5</td>
<td>10</td>
<td>-</td>
<td>15</td>
</tr>
<tr>
<td>Subtotal</td>
<td></td>
<td>8</td>
<td>22</td>
<td>-</td>
<td>30</td>
</tr>
<tr>
<td>TN</td>
<td>Chennai</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>TN</td>
<td>Madurai</td>
<td>9</td>
<td>-</td>
<td>-</td>
<td>9</td>
</tr>
<tr>
<td>TN</td>
<td>Vellore</td>
<td>-</td>
<td>16</td>
<td>6</td>
<td>22</td>
</tr>
<tr>
<td>Subtotal</td>
<td></td>
<td>13</td>
<td>20</td>
<td>10</td>
<td>43</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>21</td>
<td>55</td>
<td>10</td>
<td>86</td>
</tr>
</tbody>
</table>

Similarly, in the provider category, 18 providers were from TN, 4 from Orissa and 21 from UP providing these procedures.

c. Data Collection

Tools of Data Collection
The study attempted to collect information using qualitative techniques such as semi-structured, in-depth interviews and focus group discussions.
**Interview Schedules**
Interview Schedules or lists of open ended questions were prepared to assist the team in their interviews with:
- Providers from both public and private set-ups.
- Women and male partners accessing these procedures.

The interview checklists were pre tested. Based on the pre test results some of the questions were modified.

**Permission letter for the provider**
A formal letter was developed for public and private providers that stated the study objectives prior to the interviews.

**Field-diary**
A field diary was maintained by the research team members to record the dates of the field visits and interviews with all respondents.

**The Process of Informed Consent**
As a research that explores the personal journeys of women, there was strict adherence to ethical principles of data gathering. The researchers provided information about the study, future use of the data being collected, and an estimated time frame of the interview, so as to enable respondents to decide whether they would be able to participate. Participation in the study was completely voluntary and the participants were duly informed about their right to withdraw their participation at any point during the interview. Confidentiality of both women and providers was maintained throughout the study.

Informed consent forms were developed in the native languages of the respondents like Hindi, Oriya, Bengali (most of the respondents at one hospital in TN were from West Bengal) and Tamil. The form was developed and finalised in consultation with the advisory.

The forms were signed both by the respondent and the researcher and a copy of the form was given to the respondent. Wherever necessary the consent forms were explained verbally. The researchers also sought prior consent for audio/video documentation of the interviews.

**d. Process of Data Collection**

**Focus Group Discussions**
FGDs were carried out with communities, and the information collected through these discussions helped in understanding gender relations in the context of infertility, the social stigma of childlessness and the decision to use ART procedures.

**Individual interviews**
Individual interviews were conducted mostly with women users of ART procedures, and sometimes with both women users and their husbands.
These were done with the help of the interview schedule. These interviews addressed gender roles with respect to infertility, violence, economic implications and access to health services by women. Views about the support wives expected and received from their husbands and families were also gathered.

**e. Data entry and analysis**

**Translation, documentation, and codification**

Interviews conducted in the local language were translated into English by the researchers. Gaps were filled by referring to the field diary, or by transcribing the interview tapes, wherever relevant, before the interviews were codified according to the state in which they were held. The interviews were translated as closely and accurately as possible into English, although certain phrases and/or words did not have an appropriate equivalent in English. Codification was done in the following pattern: Initials of the state (such as UP for Uttar Pradesh), followed by ‘P’ for Provider or ‘U’ for User, and the relevant number. For instance, UPP-6 or UPU-3.

**Review**

Once fully documented and codified, the interviews were reviewed. During this process, the research coordinator and other members of the research team went through every interview in detail and gave comments on the content. These observations were used to fill in missing information, as well as to substantiate information that needed elaboration. The incorporation of feedback was done by referring once again to field notes, tapes, transcripts, etc. In some cases, the researchers made subsequent visits to the field to conduct follow-up interviews and to obtain the required information.

**Categorization**

For the purpose of analysis, the fully documented interviews were then categorized using Microsoft Excel sheets. The process of categorization was considered important from the perspective of analysis, as it would enable the organizing of the interview data into categories that could be referred to easily and quickly.

The data were divided into different sections. Within each section, information was further divided or grouped under various sub-headings. For example, under the category ‘Experience of Treatment’, the following sub-categories were added: reason for infertility (male factor/female factor/both/unknown); woman’s/man’s response to medical diagnosis and advice; woman’s experience of going through ARTs; distance from the clinic and commuting experience; change of doctors (frequency and reasons); and side effects experienced.
Chapterization of the report

After successive discussions, the research findings were divided into chapters that would reflect the emerging themes of the study. A working chapterization framework was developed after much discussion, and each chapter was assigned to the researcher best equipped or most inclined to analyze that particular theme, for instance, commercialization of ARTs. The drafts of the chapters were peer-reviewed by members of the research team who gave each other feedback.

Regular meetings were held to map the progress of the chapters, as well as to discuss the conclusions and questions that emerged from the study. This also enabled the researchers to draw from each other’s observations and experiences, to forge connections, avoid overlaps, and to pull the findings together into a cohesive and comprehensive research study.

IV. 1 Project Activities

As per the proposed timeline, the activities undertaken during the project period were divided broadly into 6 phases, in a step by step approach to address the research objectives. However, some activities, particularly those related to the training and orientations of the research team, advocacy and meeting with the advisory team, were ongoing and were carried out at regular intervals through the project. Advocacy efforts around the Draft Assisted Reproductive Technologies (Regulation) Bill and the dissemination of the research findings and the emerging concerns in this context will also continue post the completion of the project.Outlined below are some of the main activities.

Phase I - February - June 2008

a. Literature Review

At the outset, a theoretical understanding of the research area was developed through a review of existing literature on ARTs. For the purpose of scoping and identification of literature, key words such as Assisted Reproductive Technologies, Infertility, Political Economy of Assisted Reproductive Technologies, Implications of Assisted Reproductive Technologies, Medical Tourism, Surrogacy, and Egg donation were used. Material was sourced through;

Libraries across Delhi including those at medical and academic institutions, national libraries etc
Internet Searches, particularly e-databases such as google scholar and IDRC’s online library resource

Online publications and Journals

Given the dynamic nature of discourses in the field of ARTs, only those materials documented post 1990 and meeting the above inclusion criteria were sourced.

Further, the material was then thematically classified broadly on the basis of the research objectives into:

- Access
- Health Risks and Implications
- Political Economy of ARTs
- Feminist Debates and Discourses
- Reproductive tourism

On this basis, 30 papers were identified and selected which were relevant to the research objectives. A critical analysis of relevant bills/legislations, guidelines was also undertaken to develop an understanding of the status of legislation, regulation and policies that affect the ART industry and to identify the issues needing public debate and discussion.

While, significant literature was available on the technical and scientific aspect of the technologies, through this exercise it was evident that critical literature on the operationalization of ARTs and their implications in the Indian context was lacking.

b. Formation of the Research Team - Recruitment of Personnel

The core research team, responsible for the co-ordination of the research was recruited during the first phase of the project period. Three members, including the research coordinator, were part of the previous phase of Sama’s research on ARTs and were familiar with both, conceptual issues as well as the methodologies of the research. Two members were also involved in critiquing ICMR’s ART guidelines in 2005. The other members of the research team were recruited through interviews. The research responsibilities were then divided within the team on the basis of their individual skills, experience and expertise.

The local investigators were recruited on the basis of their familiarity with the geographical area, fluency over the local language, understanding of local socio-cultural practices and good communication and documentation skills.

c. Formation of the Advisory

An advisory team was formed to look into the ethical and methodological issues concerning the process of the study and to act as the review board for
the research project. This team included eminent social scientists, researchers, medical professionals, legal activists, feminist scholars and activists, with both national and international level experience.

Regular meetings were held with the advisory members through the course of the project period. In the first phase of the research (prior to the commencement of data collection) a meeting was held to sharpen the focus of the research, frame the research objectives and develop the scope, study areas and the methodology of the research. Subsequent meetings with the advisory were focused on ethical considerations of the research tools in use, dilemmas and practical limitations at the time of data collection and guiding the analysis of the data and structuring of the research report.

Informal meetings with available advisory members were also held as and when required and mutually convenient. The advisory members were updated with the research process through regular correspondence. One advisory member was involved in the review of the research report in the final stages of data analysis and writing.

Phase II - June - September 2008

a. Training and Capacity Building of the Research Team

The research team has been thoroughly trained by the research coordinator as well as by external resource persons through orientations and capacity building sessions and regular mentoring, since the initiation of the research process. The local investigators were also invited to Delhi for regular trainings and orientations.

The initial orientations were held with the following objectives

- To help the team develop a conceptual understanding of the research problem, the rationale and objectives of the research along with the time frame of the activities.
- To develop a theoretical understanding of the various technical and medical aspects of ARTs and issues related to infertility
- To frame questions for the research schedules
- To maintain an ethical and objective perspective while conducting the interviews

The subsequent orientations focused on more advanced stages of research like interviewing skills, documentation and advocacy around ARTs

On interviewing skills

- To make amendments to the interview schedules for providers and users after testing them in the field.
- To strengthen interviewing skills of the team while interacting with respondents from different regions and socio-economic backgrounds.
- To orient the team in conducting focus group discussions and interacting with women’s groups.
On documentation
- To provide a guideline for the documentation of interactions in the field.
- Repeated emphasis on maintaining daily diaries for detailed documentation.
- To clarify the importance of reviewing and revisiting interviews soon after to identify and address lacunae in the transcripts
- Peer review of the interviews
- Constant reworking was encouraged for the reports and interviews conducted to improve content and enhance skills.

On data analysis
- Use of the SPSS software for data entry and analysis
- Preparation of frequency tables with available data using analytical software.
- Categorization
- Collective brainstorming over the structure and form of the research report.

Critiquing policy documents
An in-house workshop was also conducted with a specific focus on the Draft ART (Regulation) Bill in which the research team collectively discussed and analyzed various sections and clauses of the Bill. The team also developed a detailed and in-depth critique of the Draft Bill which was sent to the Ministry of Health and Family Welfare (MOHFW) and the Indian Council of Medical Research (ICMR).

Sharing of experiences
Regular meetings were also held to take stock of the progress of the research and to share their experiences and discuss problems faced in the field, while interviewing, mapping or documenting the narratives, and to collectively find solutions for challenges faced. There was also a mechanism for peer review of documented interviews, wherein the researchers provided feedback on each others’ documentation and highlighted the gaps in the interviews. Documenting interviews in as much detail as possible was encouraged and a separate section on ‘observations’ was included.

b. Developing Research Tools and Instruments

During this phase, research tools and instruments such as the interview schedules, Consent forms, and permission letters, etc. were developed, pre-tested and modified in consultation with the advisory members.

Phase III - September 2008 - June 2009

a. Data Collection

Identification of Respondents and Conducting Interviews
In this phase, the research team was engaged in the process of data collection through informal and semi structured interviews with women and
men users as well as providers of ARTs. In order to achieve a nuanced understanding of referral patterns and the extent and scope of the industry, interviews were also conducted with gynaecologists, public health officials, and other staff at clinics and public health setups.

**Conducting Focus Group Discussions (FGDs)**

Focus Group Discussions were also conducted to gather the perceptions regarding fertility/infertility. The discussions were held through community-based organizations in the areas, and also through Anganwadi workers, Auxiliary Nurse Midwives (ANMs), Accredited Social Health Activists (ASHAs). In some cases, personal contacts in specific villages were also useful in building rapport with the women of the village. The discussions were held in Anganwadi centres, school courtyards, temples, homes of ANMs, training spaces of the organizations that assisted in conducting the discussions.

**b. Press Conference on the Draft ART (Regulation) Bill, 2008**

Following Sama’s consistent advocacy efforts to make the Draft Assisted Reproductive Technologies (Regulation) Bill and Rules, 2008 available in the public domain, members of the research team developed a detailed clause by clause critique of the document. Sama’s concerns with the Draft bill were then disseminated through a press conference organized by Sama in November 2008 to highlight the lacunae/ concerns with the Draft Bill. A brief note on the same was also developed and disseminated widely to both the electronic and print media.

**c. Developed a Brochure on ARTs in Hindi: Prajanan Mein Sahayak Taknikiyan, 2009**

Sama has developed a brochure on some of the most common techniques for assisted conception. The information, provided in Hindi, gives the details of the procedures like IUI, IVF, and ICSI in a simple and lucid manner. The brochure creates an alternative resource in Hindi (most information available on the same is in English) with which to disseminate technical details and implications of these procedures. The effort has been to demystify the technical language so that it is easily understood by all. The brochure continues to be disseminated through Sama’s training programs and has been well received by community based organizations, who have expressed a keen interest to use it in their respective work areas while sharing the information.

**Phase IV - June 2009 - February 2010**

**a. Data Compilation and Analysis**

In the fourth phase of the research, the team spent considerable time compiling all the available data, translating and transcribing interviews and FGDs wherever relevant. The data was entered into simple frequency tables and analyzed to identify emerging trends as a precursor to the writing process. At this stage the reviewed literature was revisited to identify
underlying theoretical discourses that would substantiate the available data and visualize the structure of the research report.

b. Policy Brief for New Parliamentarians on ARTs, July 2009

Sama in collaboration with Centre for Legislative Research and Advocacy (CLRA) and The Parliamentarians’ Group on the Millennium Goals (PG-MDGs) has developed a policy brief on Assisted Reproductive Technologies (ARTs). The document has been developed as part of the Welcome Kit for the Parliamentarians, with a specific focus on the (Draft) Assisted Reproductive Bill & Rules-2008. Important concerns and lacunae in the (Draft) Bill along with policy recommendations have been clearly articulated in the policy brief. Mr. Jairam Ramesh, Minister for Environment and Forests, Ms Agatha Sangma, Minster of State for Rural Development and 35 other MPs in New Delhi launched the Kit. As the document will directly reach out to the Parliamentarians, it would serve as an important tool for Sama’s ongoing advocacy on the issue of ARTs.

Phase V and VI - February - December 2010

a. Development of the Research Report

In the final phases of the research, a substantial amount of time has been spent in conceptualizing, structuring and the writing of the research report. The preliminary drafts of the report went through several rounds of internal review, along with external reviews and comments from members of the advisory as well as other experts.

b. Regional Workshop on Infertility and Assisted Reproductive Technologies: A gender perspective, September 27-28th, 2010: Raipur

Sama conducted this workshop on September 27-28, 2010 at Raipur, Chhattisgarh for activists from community based organizations and networks from the States of Chhattisgarh and Jharkhand, towards initiating discussion on infertility and ARTs, based on Sama’s research.

The two-day workshop was attended by 35 participants from 10 districts of Chhattisgarh and a majority of the participants were working with diverse groups on a range of issues including women’s health and rights, adivasi rights, children’s health and rights, disability rights, mitanin (health worker) program, etc. The workshop initiated discussion around the essentialization of motherhood, the devaluation of certain types of motherhood; and issues and politics of infertility. The workshop also provided an opportunity to equip participants with technical information about Assisted Reproductive Technologies including Surrogacy; their social, ethical, economic and medical implications, including the possibility of sex-selection using these technologies. The workshop was also able to discuss the concerns regarding the draft ART Bill (2010).
c. International Consultation on Unraveling the Fertility Industry: Challenges and Strategies for Movement Building, January 22nd -24th, 2010: Delhi

Sama organized an International Consultation titled, *Unraveling the Fertility Industry: Challenges and Strategies for Movement Building* in Delhi from the 22nd to the 24th of January 2010. Over 90 participants from more than 10 countries included activists, scholars and researchers from different movements and contexts, especially from those countries which have been experiencing the implications of these technologies. Journalists, film makers and students were also part of the Consultation.

Some of the main objectives of the Consultation were to:

- Comprehend the advancements and debates around scientific research on infertility care, stem cells and cloning and examine the research priorities in the context of access to basic health care, public health and policy, research, ethics and practice
- Map out how different kinds of ‘infrastructure’, agencies and agents facilitate the movement of technologies and results of research; the movement of those in search of such facilities, and those willing to ‘host’ such facilities [through surrogacy, egg donation etc]
- Share and exchange information emanating from activism, research, practices, policies and regulatory mechanisms gathered from the ground from across the world and thereby enable the development of a framework for ethical norms and regulations; Cull out strategies being used in various countries and examine whether they can be used trans-nationally.
- Build collaborations and networks as an effort towards movement building around new reproductive and genetic technologies.

Some of the main points that emerged from the presentations were:

- The interaction of technologies with poverty, business and commerce, religion, race/ethnicity, class and patriarchy in various contexts around the globe. The interaction between ARTs and the growing field of Biotechnology, and the implications of this interaction.
- The differential perspectives of the states/governments towards these technologies across the globe, the roles assumed by them in dealing with these technologies, and the underlying reasons for these
- The public health systems and policies and the way in which these address the underlying causes of infertility and the arguments of occupational patterns, environmental changes, lifestyle changes that have negatively affected fertility levels, which create conditions where people have to undergo these technologies.
- The strategies developed by activists and groups across the globe working on these concerns, the outcomes of these, and the challenges faced by them.
A report based on the discussions of the Consultation has been developed by Sama, and widely disseminated both at the national and international level. It is also available on Sama’s website.

d. Study tour towards building networks and dissemination of information
Two members of Sama delivered lectures at academic institutions (Harvard School of Public Health, Tufts University and Hampshire College), on issues around Assisted Reproductive Technologies (ARTs) in the United States over a period of two weeks, from 14th September to 29th September 2010. The Sama team also interacted with members of organizations such as Our Bodies Ourselves, Centre for Genetics and Society, International Women’s Health coalition, Global Fund for women and Hesperian Foundation. The key findings and conceptual challenges emerging from the research on the issue of ARTs were shared in these interactions.

IV.2. Key findings from the research
The following section examines some of the main findings of the research:

a. Infertility and medicalization of women’s bodies

• The definitions and understandings of infertility were found to be fluid across communities. However, there is an increased medicalization and pathologization of the condition and its causative factors, with the industry pushing for early medical intervention, including ARTs.

• Stigmatization and ostracism continue to mark the experience of infertility, with misconceptions surrounding ARTs often forcing couples to keep their ‘treatments’ a secret, sometimes even from family members. Simultaneously, the growing ART industry deploys, and thus re/produces, the hetero-patriarchal institution of marriage followed by childbirth. Thus, more and more women users seek ARTs to be ‘delivered’ from the trauma of childlessness (overt or covert), and to avail a higher status within the family and the community.

• It is not surprising to find that women bear a disproportionate burden of the blame for infertility, including for male factor infertility. Further, women often internalize this burden, with many experiencing shame, guilt, and anger, both at oneself and at others.

• An increased awareness of the availability of assisted reproduction for couples experiencing infertility was observed even amongst communities in remote and rural villages. However, information and knowledge regarding fertility cycles and the causative factors of infertility were lacking and often misconstrued. Community
perceptions of infertility were influenced also by other beliefs (religious, cultural, etc.) that may consider infertility a predetermined or predestined condition rather than a disease.

- Providers tended to put forward populist perceptions of the causes of infertility such as lifestyle, age at marriage, and delay in pregnancy, thus homogenizing the experience of infertility for all couples (particularly women), and blaming them at least in part for their condition. Only in exceptional cases was attention paid to causes such as occupational hazards, environmental reasons, iatrogenic factors, and other preventable conditions, such as long-standing STIs, RTIs, and other persistent infections and diseases.

- With even basic preventive care for infertility and its causative factors largely absent in the public sector, the growth of the private ART industry is being promoted.

b. Access to ARTs

- The decision to avail infertility ‘treatment’ was not taken in a vacuum or in isolation. It is the result of a combination of socio-cultural and economic factors, and is also governed by institutions such as the family and ties of kinship. It was also clear—particularly in the absence of regulation (and possibly in the event of lax monitoring and implementation of ART regulations in the future)—that ART clinics were run according to the whims, perceptions, compulsions, and positions of individual providers.

- It was evident from the sample that ARTs were being accessed largely by married couples. There were no LGBTQ, single, or HIV positive users in the sample, and many providers expressed their objections (including moral objections) to making ARTs available to these constituencies. However, at the same time, some providers were making their services available to gay couples of foreign origin.

- Although the sample has users from across the caste spectrum, this should not indicate that the market is blind to caste, thus bearing the potential to liberate us from ascriptive identities. In India, given that caste is classed, access to ARTs must be understood as being mediated most significantly by class, and therefore by caste, because of this overlap.

- While ARTs were accessed by users from across different religions (Hindu, Muslim, Christian, Jain, and Sikh in the sample), religion can be understood as often circumscribing the limits of technology use, as
much as technology is deployed in ways that preserve and perpetuate religious affiliations.

• Caste and religion were also particularly relevant in the eugenic trends observed in the context of donor gametes and surrogacy arrangements, wherein donors/ or surrogates from particular castes or religions were preferred over others.

• Despite the high, and many hidden costs of ART procedures, the sample consisted of users from different classes, with several willing to push the limits of their affordability in the quest for a biological child.

• The impact of ART procedures on women’s lives, including the disruption to their work, was clearly brought out by the study. Some providers perceived women’s work and careers as the main cause of delay in marriage, and therefore of infertility. However, upon investigating the age profile of women users in the sample, including age at marriage this does not appear to be the case.

c. Growth and proliferation of the ART industry

• The interaction of patriarchal ideology and market forces constitutes the larger framework within which the ART industry in India is growing, with an increasingly market-driven approach to infertility. This growth is linked to the proliferation of the larger biotechnology industry globally.

• Given the lack of any formal state-regulated registration of ART clinics and affiliated set-ups, it is difficult to arrive at any definite numbers regarding the extent of their growth; nonetheless this growth is clear from anecdotal evidence, including industry reports.

• The extent of the growth of the ART industry has not been uniform across cities, districts or states, with different areas displaying differential growth trends. Further, while clinics are situated in predominantly urban areas, they are reaching out also to users in rural areas and in different cities and states.

• As a part of the growing ‘reproductive tourism’ market, ARTs and related arrangements like surrogacy are increasingly being offered along with other tourism packages to cater to foreign demand. The reasons for this growth include significantly lower costs, superior technology, medical expertise, lack of regulation, and English-speaking providers, coupled with the marketing of Indian ‘exotica’.
The fertility industry comprises of a range of stakeholders, including players from both private and public tourism agencies, private health care establishments, consultancy agencies, law firms, and state and central governments. With increased globalization of medical services, this range cuts across geographical boundaries and now includes actors stationed in different countries.

Drawing on evidence pertaining to the functioning of other profit-driven markets, the ART industry also deploys common strategies to bolster the demand for these technologies. These measures include inflating success rates and undertaking aggressive advertising, such as attractively designed websites, brochures, advertising on walls, and hoardings in streets, near adoption agencies, on local cable channels, bus stops, etc. Clinics also organized subsidized camps for infertility diagnosis, give discounts and money-back offers. These serve to promote the ‘product’—the precious biological child—while blurring into the background, concerns and complications that come with any medical intervention (like side effects, cost, and efficacy).

The ART industry enjoys the support of the Indian state. On the one hand, the state offers incentives for the setting up of ART clinics, such as the facilitation of medical tourism with lenient visa norms and subsidies on infrastructure costs. On the other hand, there are less tangible forms of state ‘incentives’ for industry, such as through inattention to public health and the absence of regulation for private health care, thus allowing the unhindered commercialization, ethical violations, and non-accountability of ART clinics to persist.

This reluctance of the state to regulate the ART industry, in turn, jeopardizes the concept and practice of political and social citizenship. ARTs thus reopen older debates around social citizenship, while also engendering new debates about economic participation and legal-political citizenship. In doing so, ARTs transform the very notion of social citizenship itself, expanding it to include larger debates.

d. Practice

The absence of any legally binding regulatory mechanism is exploited by providers. Practices like sex-selection, multiple-embryo implantation, and even the inducement of pregnancy in post-menopausal women, were observed in a few clinics.
• Despite some variations based on education, socio-economic background, and access to alternative sources of information like the Internet, most users were found to have scant, inadequate, and piecemeal information about their ‘treatment’.

• The process of obtaining informed consent was treated by both providers and users alike as a mere technicality, with very little attention being paid to the content of the consent form. A lax attitude was observed in the taking of consent, with several instances where no form had been signed or where forms were signed without being read. The form was in some instances signed by only the husband or an educated relative instead of the couple themselves.

• Similarly, in many clinics, the important aspect of counseling was addressed superficially, with its scope being limited only to information giving. Support and therapeutic counseling were absent, with very little attention paid to the emotional well-being and mental health status of users.

• The ART industry employs no standardization of costs for the various procedures available; a wide variation in costs was found not only across the three states but also between clinics in the same state. The costs quoted often left out other hidden costs, including money spent on travel, accommodation, medication, and loss of wages.

• At the same time, the end product—the desired child—is considered to be ‘above’ all financial calculations of cost and is seen as a justifiably demanding but rewarding investment. This attitude often leaves the user more vulnerable to unethical practices such as repeated cycles.

• There are no standard ‘treatment’ protocols for ART procedures, which paves the way for the exploitation of users, both physically and economically. While lack of standardization may be a general characteristic of the private health sector as a whole, the differences in the ART industry—both within and across different procedures like IUI, IVF, and ICSI—are substantial and alarming.

• Surrogacy as a practice and as an issue continues to be viewed with a degree of novelty in smaller towns and cities, although its reach is expanding.

• Although the ICMR guidelines explicitly prohibit the involvement of ART clinics in sourcing surrogates or arranging surrogacy contracts, even within the small sample size of this research study, there were
clinics that were directly involved in sourcing the surrogates. This trend was observed more in Tamil Nadu where the industry is in a relatively advanced stage. In Orissa, on the other hand, providers were still reluctant to engage in commercial surrogacy, fearing legal and moral complications.

e. Multidirectional and multifaceted infertility treatment

• While ARTs are accessed by users to have a biological child, they are not the only form of intervention or treatment sought. A range of interventions are pursued, sometimes in combination, including ARTs, allopathic medication, alternative systems of medicine (such as Unani, Sidha, Ayurveda, homeopathy, and home remedies) and also religious and faith-based interventions. In most cases, while alternatives might not be accessed at the start of infertility treatment, they are usually accessed at some stage.

• Economic and demographic variations (both across and within states) feed into the ‘treatment’ trajectory of couples experiencing infertility. For instance, it is a well-established fact that the availability of infrastructure in the location where people live (urban, rural, hilly area, etc.) has a direct impact on their health-seeking behavior; this is also the case with ARTs.

• Gynecologists were the first point of contact for most users who accessed infertility treatment. The reasons why users chose a particular provider included reference by friends or family, proximity to the clinic, and/or information that other couples with similar problems had benefited. The attitude of the providers, as well as the outcome of the ‘treatment’, also affected ‘treatment’-related decision-making.

• While in many cases, the couple was unaware of their exact diagnosis and the details of their treatment, women were almost always much less informed than their partners or husbands, including when the ‘treatment’ was for female factor infertility.

• It was not uncommon to find the use of ART ‘treatment’ shrouded in secrecy, with some users even accessing clinics in other cities to maintain anonymity.

• In a majority of the cases, opting for ART treatment was not only a significant financial, emotional, and physical investment, but also a long-term one that could continue for years on end, perhaps without the desired result ever being achieved.
• ARTs are not considered the final stage of infertility treatment by users. ART users communicated their faith in both scientific, technological, medical interventions and in other belief systems like religion. This blurring of the line between science and faith applicable to other kinds of medical interventions is also evident in infertility ‘treatment’.

f. ARTs and public health

• Services for infertility care, including basic screening facilities, are conspicuous by their absence in the public health system. This includes health infrastructure for addressing preventive and secondary causes of infertility, which can be dealt with at a preliminary stage. Many couples felt that they had no option but to access private-sector treatment for infertility, including ARTs. This raises larger questions of access, equity, and affordability.

• Even though public health set-ups were the initial point of contact for a few users in the sample, none continued their treatment there (because of non-availability and other factors).

• While in Tamil Nadu and Uttar Pradesh, the public health infrastructure is relatively well developed, Orissa offers a picture of complete contrast, with public health facilities for infertility being almost non-existent.

• At least one of the tertiary-level public hospitals in the state capital of Uttar Pradesh (Lucknow) was providing ART facilities till the level of IUI, and was in the process of being upgraded to the level of IVF/ICSI. In comparison, one of the main public hospitals in the state capital of Tamil Nadu offered tubal recanalization and treatment for tuberculosis (a causative factor for infertility). In Orissa, it was observed that some of the providers in public health set-ups were providing IUI in their privately run gynecology clinics.

g. Implications of ARTs

• Users’ narratives highlighted several implications of ART use. These include, but are not limited to, deterioration of health, with a direct impact on the physical and social functioning of individuals, increased health risks faced by children born through ARTs, psychological problems and increased stress level, geographical and social relocation, strained sexual relations, disruption of work and daily routines, and financial instability.
• While the movement of users from one health facility to another, across towns, cities, districts, states, and even countries, is known to occur, short and long-term geographical relocation was observed amongst ART users in this sample, resulting in many cases of complete reconfiguration of social worlds and realities.

• Users’ narratives raised concerns that ARTs enhance ‘choices’ with regard to the intended child through practices like sex-selection and genetic pre-screening, thus setting the stage for sexism and consumer eugenics.

• Women’s experiences reflected the coercive nature of their supposed ‘choices’, given that they were faced with the option of either using ARTs with their adverse consequences, or remaining childless with its own set of negative implications.

• The responsibility for childlessness and its ‘treatment’ rested disproportionately with the woman and her natal family. Often, the woman’s parents, siblings, and family were expected to provide financial as well as emotional support for ARTs.

h. Policy and monitoring

Although ICMR and MOHFW have proposed legislation to regulate ARTs, the Draft Bill (2008 and 2010) tends to safeguard the interests of the private-sector ART providers and to promote the growth of the ART business. Rather, the legislation should focus on regulating the providers of these technologies and safeguarding the rights and interests of users, particularly women, by incorporating provisions to prevent misuse and malpractice, and by promoting accountability.
Some concerns regarding the Draft ART (Regulation) Bill and Rules 2010:

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

(Sama’s critique of the Draft Bill (2008 and 2010), refer to the Policy Brief in Annexure)
Ongoing Activities

a. Advocacy

Sama has been addressing concerns around Assisted Reproductive Technologies (ARTs) through various strategies, including action research, advocacy, and information sharing. Advocacy around ARTs and related issues has been central not only to the research study, but also to Sama’s larger efforts as a resource group for women and health. Advocacy constituted one of the three key objectives of this study, and was also the logical extension of the other two objectives, translating the research findings into policy recommendations, and generating awareness and discussion through the dissemination of these findings. Although much of this was sought to be consolidated and concretized within the research period, advocacy is by nature an ongoing exercise.

As such, the research findings will continue to inform Sama’s work around the medicalization of women’s bodies, technology, bioethics, regulation, and so on. Although public health was not the focus of this research, Sama’s advocacy efforts have been—and continue to be—situated within a larger framework that recognizes the inter-linkages of ill-health in general, and of infertility in particular, with social determinants (such as poverty, patriarchy, and hazardous occupations), and stresses the need for universal health coverage, thus mandating the strengthening of the public health system.

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

i. Policy-level engagement

The study provided much needed evidence from the ground to strengthen the demand for regulation, highlighting instances of unethical medical practices and the potential for abuse of women’s health and users’ rights in the absence of standard protocols. For instance, mechanisms for providing information and counseling were found to be absent or limited in most cases. The need for an expanded regulatory framework that is not restricted to ART clinics alone emerged clearly from the study, given the multiple actors involved in the ART industry. Further, such a framework would need to consider newer aspects of technology, such as embryonic stem cell
research, that uses ‘spare’ IVF embryos, thus raising ethical concerns such as obtaining informed consent from users. Given that there are no systematic and credible data on clinics (registration, infrastructure, services offered, etc.) or on health risks (of both procedures and drugs), the study reinforces the need for long-term information collection towards the monitoring and review of ARTs. Engagement with policy making was done by educating and sensitizing policy makers, such as parliamentarians, officials of national bodies, and representatives of state agencies.

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

During the research period, in 2008, MoHFW and ICMR released the ART (Regulation) Bill and Rules, 2008. This was made public at Sama’s national consultation on ‘ARTs: Emerging Concerns and Future Strategies’ in September 2008, where nearly 70 participants provided feedback on the contents of the Draft Bill. Sama drafted and released a detailed critique of the Draft Bill at a press conference in November 2008. In February 2009, MoHFW directed ICMR to take into consideration some of the concerns raised by Sama while revising the Draft Bill (2008).

In 2010, the Draft ART (Regulation) Bill and Rules, 2010, prepared by ICMR and incorporating revisions to the previous draft bill, was made available. This draft was also examined and a critique of its problematic provisions was developed by Sama. (For a critique of the Draft Bill, 2010, see Annexure 3).

Sama also participated in consultations organized by state bodies such as the National Commission for Women (NCW), and has conducted meetings with the state chapters of NCW. From the outset, the state was regarded as an important agent of change and was sought to be engaged with proactively.

<table>
<thead>
<tr>
<th>The state bodies that Sama engaged with included:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ministry of Health and Family Welfare (MoHFW)</td>
</tr>
<tr>
<td>Indian Council of Medical Research (ICMR)</td>
</tr>
<tr>
<td>National Human Rights Commission (NHRC)</td>
</tr>
<tr>
<td>Planning Commission</td>
</tr>
<tr>
<td>National Commission for Women (NCW) and State Commissions for Women</td>
</tr>
<tr>
<td>Ministry of Women and Child Development (MWCD)</td>
</tr>
<tr>
<td>Parliamentarians</td>
</tr>
</tbody>
</table>
A policy brief on ARTs for newly elected parliamentarians, following the general elections of 2009, was developed by Sama as part of an initiative by the Centre for Legislative Research and Advocacy (CLRA) and the Parliamentarians’ Group on the Millennium Development Goals (PG-MDGs). The policy brief was aimed at sensitizing parliamentarians to the shortcomings in the draft bill, so as to facilitate informed discussion in the Indian parliament. Sama was also involved in the analysis and critique of other policy documents. These included the Ninth, Tenth, and Eleventh Five Year Plans, as well as the second Reproductive and Child Health (RCH) Program and the National Health Policy.

ii. Interactions with the community
Interactions at the level of the community—both through FGDs and orientations with community-based organizations—formed the axis around which Sama’s understanding of infertility, gender, and society evolved. These sessions involved much discussion on patriarchy, health, and access, which problematized both local cultures and larger structures. The gendered burden of childlessness and the associated stigma and violence were emphasized strongly, and participants also drew attention to related problems, such as malnutrition, anemia, tuberculosis, violence, and inadequate public health care, that were often causative factors for infertility.

These interactions were important opportunities for disseminating information on infertility, ART procedures, as well as the proposed ART legislation. The organizations and networks that participated were working on diverse issues and with diverse constituencies, including women from dalit, adivasi, and Muslim communities.
iii. Consultations

Conversation around ARTs is still nascent, and an important focus of Sama’s work has been to encourage related debates within various social movements. This is significant considering that issues pertaining to ARTs occupy a complex intersection between technology, health, gender, commerce, and sexuality. Further, technology is developing too fast to be regulated by laws, guidelines, or even social norms. Discussions on ARTs must focus on the future course of action for the women’s and health movements. During the course of the study, it became clear that there is an urgent need for further discussion on these technologies, for debates on the different views expressed within various social movements, and for the development of strategies to deal with the many concerns posed by ARTs.

In the last three years, Sama has organized two consultations—at the national and international levels—to initiate dialogue that will integrate diverse perspectives on ARTs and surrogacy into a collective articulation of non-negotiables with regard to women’s health and rights. That this industry is no longer restricted to state borders is a well-established fact—‘globalization of reproductive process, labor and tissues by cross-border sourcing of reproductive labor through surrogacy and egg donation and medical tourism . . . has facilitated the commercialization and commodification of women’s bodies and reproductive tissues’(Sama, 2010:2).

Sama sought to link its advocacy efforts with the current global discourse through an international consultation, held in January 2010 that focused on the commercial, economic, and ethical aspects of ARTs. This consultation, titled ‘Unravelling the Fertility Industry: Challenges and Strategies for Movement Building’, was attended by over 90 participants from more than ten countries. It was an attempt to build a network of scholars, policy makers, activists, and medical practitioners who are working on reproductive technologies, as well as to learn from the experiences of regions that are witnessing the implications of these technologies. The participants discussed possible strategies for responding more effectively as a campaign or a movement to ARTs, both locally and globally, including the possibility of establishing an international regulatory framework.

Similarly, consultations and workshops organized by coalitions and networks such as Jan Swasthya Abhiyan, National Bioethics Conference, World Bioethics Conference, People’s Collective for Economic, Social and Cultural Rights, provided the fora where concerns and demands with regard to ARTs could be highlighted and linked with other agendas.

Universities and other institutions of higher education were tapped, both nationally and internationally. Lectures and seminars where ARTs could be discussed provided an opportunity not only for the dissemination of the
research findings, but also for influencing future research on a range of issues. Sama was, in turn, approached by researchers, students, filmmakers, and journalists who were looking to consolidate their understanding of ARTs, including surrogacy, in India. Sama engaged the media as a significant tool to mobilize public opinion. This was done through contributions to newspapers and journals (including peer-reviewed journals), TV interviews, as well as press conferences and press releases.

The complex nature of the issues involved in infertility treatment and ARTs, as well as the range of individuals, organizations, and institutions that need to come together to work on this issue, emphasizes the need for continued alertness, preparedness, information sharing, and strategizing. Advocacy serves as a critical, although challenging, means with which to affect understandings and to effect interventions. As such, the findings of this research study will enable activism for women’s health and rights within India’s ART industry.

b. Dissemination of Findings and Concerns

Throughout the research period Sama has been contributing significantly towards building a knowledge base on Assisted Reproductive Technologies, a significant aspect of which is the dissemination of this information through the strategies given below. In this effort Sama has also attempted to bring into the ART discourse perspectives from a range of movements – women’s, health, disability rights, sexual rights, child rights, bioethics etc. to facilitate continued discussions and debates on the commercial, economic and ethical aspects of Assisted Reproductive Technologies and to develop strategies to take the issue forward. These efforts were carried out at two levels:

- Knowledge creation and dissemination - 
  a. Publishing articles in reputed journals, magazines and newspapers 
  b. In-house Material development

- Organizing and participating in Seminars, Conferences, Consultations and Workshops.
Some of the issues of concern that have emerged from Sama’s research and advocacy efforts are:

- How can we protect women’s health and rights at a time when oocytes are an important research ‘raw material’? Global economic disparities, unregulated cross-border trade in human biogenetic material (like aborted female fetuses), and unregulated practices in ART clinics in some countries have led to unethical and uninformed sourcing of embryos and women’s oocytes.

- Can surrogacy be considered a form of livelihood or is it becoming a temporary survival strategy for some economically vulnerable women in countries like India?

- New markets for women’s labor under globalization deploy women’s bodies in highly gendered and sexualized roles. While surrogacy pushes the limits of women’s labor from the private to the public, and from care to work, the accompanying objectification and rampant exploitation of their bodies pose serious threats to their health and rights. While we question notions of chastity and naturalness that make reproduction acceptable only within marriage, we must also challenge the interlocking structure of capitalism and patriarchy that are normalizing, almost glorifying with an altruistic veneer, the buying and selling of women’s body parts and bodily labor.

- Choices, while constrained and constructed, must also be recognized as contributing to the operation of hetero-patriarchy. Are women who choose to be surrogates victims, or agents, or do they occupy a position somewhere in the middle? Is the body a legitimate resource? Or is this line of argument a slippery slope of relativism for women? How do we balance our questioning of women’s choices with our respect for their right to self-determination, given that in surrogacy ‘exploitation and opportunity are bound and wound up in one’? (Hartmann in Sama, 2010)

- With varying laws across countries regarding citizenship and nationality, how do we decide on the nationality of the child born to a surrogate? For instance, twins born to a surrogate in India for a German couple have been refused citizenship by both the countries.

- Do ARTs reinforce hetero-normativity or do they de-link reproduction from hetero/sexuality and marriage and actually make biological parenthood an option for LGBTQs?

- How can we ensure that ARTs are not misused for sex-selection or for creating only ‘able’ babies with desirable gender and other traits?

**IV.2. Project Implementation and Management**

Effective implementation of the project’s activities required rigorous and thorough planning and management of key components such as the research design, human resources, time frame, financial resources, etc. towards optimizing the outputs, outcomes and impact of the activities.
a. Regular and ongoing processes of review, updating, monitoring and feedback

Processes of review, updating and monitoring were carried out with regard to all aspects of the research project as well as at different levels of the project.

These processes were extremely crucial for the project’s effective and timely implementation. Review, updating and monitoring was carried out by all members of the research team involved, per research site.

These processes were ongoing and regular with differential timelines set for varying aspects of the project. While the field level research process required daily updates, review and monitoring, others such as budget, documentation, etc., followed previously determined timelines.

The process of review and updating also played an important role in assessing and minimizing any risks and optimizing opportunities that presented themselves in the course of the research.

b. Documentation of the research

Substantial investment of time and efforts was involved in documentation, possibly the most important and exhaustive process of the project. This included building capacities of the team in documenting, formulation of guidelines and formats to facilitate the process, as well as regular feedback and modification towards enhancing quality.

Maintaining daily diaries and documenting every detail of the visit was repeatedly emphasized. Feedback on documentation and reworking was encouraged on the reports and interviews conducted that helped in improving the analysis and rigor of the content, as well as the documentation skills of the team.

Management of the documents throughout the research period, although challenging, was planned and implemented, with previously identified member(s) of the research team involved in it.

c. Involvement of community, researchers, organizations / groups

Discussions and meetings with women from the community in areas where the research was ongoing, and with representatives of organizations and other researchers were extremely useful in identifying and strengthening the research based on their knowledge of the local situation and practices.

Identifying and selecting local investigators, coordinating / organizing meetings with the community were also facilitated by them.
Since advocacy was one of the main objectives of the project, several individuals, groups, organizations from India and abroad were involved, strengthening the process and well as facilitating wider outreach of the emerging issues and concerns.

V. Project Outputs

The following were some of the significant outputs from the project:

a. In-house Publications

- **Research Report**
  This report is based on Sama’s research, ‘Assisted Reproductive Technologies: Implications for Women’s Reproductive Rights and Social Citizenship’ conducted in the 3 states of Orissa, Uttar Pradesh and Tamilnadu.

- **Summary Research Reports in regional languages, 2010**
  Summary Reports in two languages (Oriya, Hindi) based on Sama’s research ‘Assisted Reproductive Technologies: Implications for Women’s Reproductive Rights and Social Citizenship’.

- **Consultation Report**
  *Unraveling the Fertility Industry: Challenges and Strategies for Movement Building, A report, 2010*
  The report presents major issues and concerns, challenges and strategies around the proliferation, commercialization and routinization of Assisted Reproductive Technologies that emerged from the International Consultation organized by Sama in January 2010.

- **Brochure**
  *Prajanan Mein Sahayak Taknikiyan: A Brochure on Assisted Reproductive Technologies (Hindi), 2009*
  The brochure provides information in Hindi about some of the most common procedures - IUI, IVF, ICSI - for assisted conception towards easy comprehension and wider outreach.

b. Contribution to journals and newspapers

- **Surrogacy: Law’s Labour Lost?, The Hindu, July 25th, 2010**
  The article presents the inconsistencies in the revised Draft ART Bill of 2010, particularly with regard to provisions about surrogacy and citizenship.

- **Assisted Reproductive Technologies - A Critique, Indian Association for Women’s Studies (IAWS) - Special Issue Newsletter, December 22nd, 2009**
The Article examines the extent of commercialization of Assisted Reproductive Technologies including surrogacy in the context of increasing medical tourism and the growth of an ART ‘industry’.

  This paper talks about some of the important concerns in the Draft Bill highlighting the need for a pro-people and pro-women legislation.

  The article highlights the concerns and limitations of the (Draft) Assisted Reproductive Bill and Rules-2008 and argues for a more comprehensive legislation that simplifies the process, eliminates intermediaries, prohibits activities that may lead to exploitation and establishes practices that uphold the dignity of those accessing ARTs.

- **The Draft ART (ART) Regulation Bill: In Whose Interest? Indian Journal of Medical Ethical January - March 2009**
  This article talks about some of the important concerns in the Draft Bill.

- **Commercialisation of Surrogacy in the Indian Context, Medico Friend Circle Bulletin: 330, August-September 2008**
  The article focuses on commercialization and other issues around surrogacy arrangements that have not been addressed in the National Guidelines for the Accreditation, Supervision and Regulation of ART Clinics in India.

- **Guidelines not Enough, Enact Surrogacy Laws, Hindustan Times, 8th August 2008**
  The article emphasizes the urgent need for regulation of surrogacy arrangements in order to protect the health and rights of surrogates.

**c. Contribution to visual media- television and documentary films**

- Sama was part of television talk shows and documentaries on the issue of surrogacy on LokSabha TV, Doordarshan, etc. Other channels such as NDTV, 9x, Reuters Television, etc. also approached Sama for inputs in the issue. Radio Canada approached Sama in November 2010 as part of a radio documentary about the growth of the surrogacy industry with focus on Canada, USA and India.
- Sama provided critical inputs to the co-directors of the film, ‘Made in India’ which looks at cross border commercial surrogacy, especially on the issue of regulation.
- Sama members were also approached by B&B Films, a documentary production company based in Rome, Italy for
their recent project on ARTs in India with a special focus on Surrogacy.

d. Presentations at conferences, seminars, meetings and academic institutions

- **The ART of regulation: A critical look at the Assisted Reproductive Technology (Regulation) Bill 2010**, presented at the Third National Bioethics Conference held at the All India Institute for Medical Sciences (AIIMS), Delhi between 17th and 20th November, 2010. Another member of Sama also presented a paper on the emerging linkages and concerns between ARTs and Stem cell research in India.


- **Assisted Reproductive Technologies and Stem Cell Research: Standing at Crossroads?** presented at the 10th World Congress on Bioethics held in Singapore from 28-31st July. Through the presentation Sama members were able to highlight the questions related to ARTs and Stem Cells in India, thereby taking the discussion forward within a wider international audience and engaging with the ethics discourse.


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

- **Unraveling the Fertility Industry: ARTs in the Indian Context, January 2010** The paper presented at the International Consultation on Unraveling the Fertility Industry: Challenges and Strategies for Movement Building as a part of the session on Global Experiences: South Asia, tried to draw attention towards the ART Industry in India and its features.

- **ARTs and Sex- Selection** at the Round Table discussion on ‘Femicide: The Role of Science and Technology, India Court on Dowry and Violence against Women organized by Vimochana, July 2009
A Reproductive Technologies, from the perspective of the campaign and advocacy on the issue was presented at the ‘Basics and Beyond Training for Trainers’, organized by TARSHI (a Delhi based group working on reproductive and sexual health issues) in March, 2009.

ARTs in the Era of Medical Tourism at the Conference on Health Equity and Human Rights, by the Indian Association of Social Sciences and Health (IASSH), Pondicherry, March 2009.

Adoption and ARTs at the National Seminar on Adoption, Laws, Minorities and Current Challenges organized by the Dr. K.R. Narayanan Centre for Dalit and Minority Studies, Jamia Millia Islamia University, February 2009.

Infertility and Assisted Reproductive Technologies, at the Women’s Health Assembly, organized by Prayas, Jaipur, June 2008.

e. Lectures at American universities, September 2010

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

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

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

f. Strengthening Linkages and Movement Building: Some Milestones

An International Consultation on the commercial, economic and ethical aspects of Assisted Reproductive Technologies titled Unraveling the Fertility Industry: Challenges and Strategies for Movement Building was organized by Sama in Delhi from the 22nd to the 24th of January 2010. During this three day consultation, over 90 participants from more than 10 countries- including activists, researchers, and academics — came together to discuss issues and concerns around the growth and proliferation of the ART industry. Discussions began with an overview of the current global
political economy context, followed by region-specific sessions that brought
in local experiences from countries that are facing the implications of these
technologies. Each day concluded with a discussion on the possible
strategies for movement building, which were consolidated in the final
session on the final day.

A Google Group was initiated for participants of the consultation to
facilitate continued discussions regarding updates and efforts in respective
countries; to connect and reflect collectively and to plan and share
strategies to act at the global level.

g. Policy Outputs

- **Policy Brief on Assisted Reproductive Technologies (ARTs) for
  Parliamentarians, 2009***
  Sama along with Centre for Legislative Research and Advocacy (CLRA)
  and The Parliamentarians’ Group on the Millennium Goals (PG-MDGs)
developed a policy brief focusing on the (Draft) Assisted Reproductive
Bill & Rules-2008 providing policy recommendations. This was part of
the Welcome Kit for the newly elected parliamentarians, following
the General Elections of 2009.

- **Critique of the Draft Assisted Reproductive Technology
  (Regulation) Bill and Rules 2008 (in English and Hindi)**
  A critique of the ART Draft Bill 2008 with recommendations was sent
to the Ministry of Health and Family Welfare and Indian Council of
Medical Research. The critique was widely circulated among state
autonomous bodies like the National Human Rights Commission
(NHRC), the Planning Commission, other organizations, print and
electronic media, and activists from the health and women’s
movement, disability rights movement, and sexuality rights
movement. The Bill has been translated into Hindi to create
awareness among community-based organizations, especially in the
northern and central regions of the country.

  Sama has also critiqued the revised version of the Draft ART
  (Regulation) Bill, 2010, based also on the recent experiences from
  the research; the dissemination of the critique and advocacy around
  it is ongoing.

- **A presentation on Surrogacy in India** in the context of the Draft
  Assisted Reproductive Technologies (Regulation) Bill 2008 at the
  National Consultation on The Medical, Legal and Social Aspects of
  Surrogate Motherhood: Towards a Gendered Perspective’, organized
  by the West Bengal State Women’s Commission, the Women’s Studies
  Cell at Kolkata University and the West Bengal Ministry of Health and

- **Participation in a Consultation on Surrogacy**, organized by the
  Ministry of Women and Child Development (WCD), June 2008, Delhi.
Participation and presentation on Assisted Reproductive Technologies: The Larger Picture, at the Consultation on Surrogacy and Assisted Reproductive Technologies organized by the National Commission for Women (NCW), April 2008, Delhi.

Orientations on concerns and limitations of the Draft Bill for groups, organizations and networks and UN agencies, etc. with the aim of disseminating information as well as enabling participating groups to draw linkages between their areas of work and issues in ARTs.

(Although these publications were not supported financially by IDRC, they are included in this report given their relevance as advocacy tools; advocacy being one of the primary objectives of the current project.)

Some milestones in policy advocacy

In response to Sama’s critique and recommendations regarding the Draft Bill, the Ministry of Health and Family Welfare in February 2009 had directed the ICMR to take into consideration some of the concerns raised by Sama at the time of revision of the Draft ART (Regulation) Bill and Rules, 2008.

Advocacy and follow up with the ICMR resulted in the presentation of the ART Regulation (Draft) Bill for public debate and discussion in September 2008. The Draft Bill was also put up on the ICMR website for public comments and feedback as result of these efforts.

VI. Project Outcomes

I. The process and findings of the research and advocacy initiatives have contributed to:

- The global debate on ARTs and surrogacy; consolidation of existing knowledge, understanding and analysis of ARTs, surrogacy, the fertility industry, tourism, role of caste and class vis-à-vis ARTs and surrogacy.
- Initiation of discussion among activists, community based organizations, networks, academics, researchers, media towards wider dissemination and mobilization; discussion across social – women’s, disability, sexual rights, ethics, health - movements has facilitated flagging of issues around these technologies in their work; and their perspectives informing the discourse on ARTs.
- Filling the existing gap in the lack of literature and providing for a nuanced, evidence-based understanding of the operationalization of ARTs in the Indian context. Several of Sama’s published articles and reports mentioned above on the issue of ARTs are being used as reference material by researchers and academics working on allied issues.
- Creation and strengthening of linkages with researchers, activists, academics, organizations, and networks engaging on issues of
biotechnology, ARTs, surrogacy, etc., nationally as well as globally, especially around the campaign on ARTs, surrogacy.

- Informing / influencing policy and legislation - evidence from the research has strengthened advocacy efforts towards ensuring that the legislation - the draft bill - is more comprehensive from the perspective of health and human rights.

- Recognition of Sama as a key knowledge resource working on the issue. Sama has come to be recognised as the key/prime group working on issues of ARTs and surrogacy, and has been approached by activists, students, researchers, film makers, journalists, and policy makers who seek inputs on various aspects of ARTs and surrogacy. Sama has had a positive influence on the work of other individuals and groups.

- The research study contributed to strengthened knowledge and understanding of infertility, the nature and functioning of the ART industry, etc. Some of the specific outcomes include:
  
  - The mapping of the ART industry, its growth, proliferation and commercialization; mapping of diverse actors and agencies involved in the industry; global links to the local ART and surrogacy industry.
  
  - Insights into the extent and manner of medicalization of women’s bodies in the context of infertility and ARTs and the role of the industry in augmenting it; provide basis for Sama’s future work around the medicalization of women’s bodies, technology, bioethics, regulation, and so on.
  
  - Documentation of trends of how caste, class and religion influence various aspects of users’ access to ARTs as well the ART markets eugenic prescriptions based on them.
  
  - Understanding of the fertility industry’s role in reinforcing hetero-patriarchal institutions; subjective and arbitrary functioning raising serious concerns for users of these technologies; documentation of the health and other implications of ARTs for users.
  
  - Consolidation of evidence base for advocacy: reiterating the urgent need for legislation to regulate the industry; the unhindered growth of the private sector in provision of services for infertility, including ARTs while extremely limited services or complete absence of services for infertility and causes leading to it, apparent in the public health system.
• Enhanced capacities of the research team in research design, data collection, analysis and drafting of the research report; the research team’s understanding and skills to address methodological and ethical issues.

II. Methodological Challenges
It is important to establish at the outset that no definite generalizations can be made from the research results. While qualified inferences can be drawn from the primary data, it must be borne in mind that the small size of the sample, which was selected rather than random, was limiting.

➤ Access to data
In the absence of a credible, centralized and government run or certified database/registry of functional ART clinics, there is no adequate and accurate way of knowing the exact number of operational ART centers in a particular area; the research team had to rely on a network of informal sources for information.

➤ Limited availability of Literature
Secondary literature, particularly on the Indian context, was found to be insufficient.

➤ Access to clinics and users
It was difficult for Sama, as an NGO in general, and a policy monitoring and advocacy group in particular, to garner access to actors such as ART clinics, sperm banks, surrogacy agents and hostels, surrogates, ART users and so on.

Since the providers are the point of entry/access for the researchers, it is a challenge when providers are unresponsive and disinterested, or when they refer the researchers only to women users who are ‘success stories’.

➤ Conducting Interviews
Gender norms make it difficult to interview women in certain spaces (such as the waiting rooms of hospitals, which are usually crowded) or ask certain questions openly, particularly when more intimate details may be sought in the company of husbands or mothers-in-law. Further, it may be upsetting for women to narrate their experiences of childlessness and the associated stigma and despair, as a lot of these are traumatic to recount and relive.

It is difficult to conduct certain interviews because of logistical problems. For instance, some providers conduct IVF in batches/camps, which are held only on certain days of certain months, and allow a small window to access a large number of women users.
Some of the providers refused to answer questions like costs of procedures, availability of surrogacy services, amounts paid to commercial donors, etc.

➢ Generalizability Issues

By tracking the rising use of ARTs and the demographics of those who seek out these procedures, potential barriers to access come clearly into view. These include wealth/income, costs, marital status, sexual orientation, religion, caste, etc.

While there was no conscious attempt to include predominantly Hindu respondents, they formed the majority of users in this purposive sample. This is also related to their demographically higher proportion in the population.

Though our sample has users from across the caste spectrum, this should not indicate that the market is blind to caste, thus bearing the potential to liberate us from ascriptive identities. In India, given that caste is classed, access to ARTs must be understood as mediated most significantly by class, and therefore by caste, because of this overlap.

Several providers did not want to share the costs of their services with us. Of the ones who did give information on costs, the figures quoted were vague and off-hand, and providers did not detail what they did or did not include, such as hospital stay and cost of drugs. Again, in the absence of a registry or database, we could not verify/cross-check these figures, except by also asking users (who could be equally unclear about the exact among spent and its break up, given the long drawn nature of treatment).

➢ Problems encountered during FGDs

In most of the villages particularly in Orissa, we found a clear ‘ghettoization’ of certain communities. For instance, members of the Dalit community were unable to participate in discussions involving members of upper castes. Similarly, Muslims were often found to be segregated from the rest of the community. In those situations, FGDs were conducted separately and exclusively for these communities, so as to enable a more thorough understanding of the issue.

VII. Overall Assessment and Recommendations

There has been little understanding or analysis of the political economy of ARTs, towards addressing the issues and challenges—conceptual, political, ethical, medical, legal etc-- in ARTs in the context of infertility. Sama has developed a detailed policy brief on the regulation of ARTS. The exchange of information emanating from activism, research, practices and regulatory mechanisms gathered from across the country has enabled the location of
discussions and debates on ARTs within the framework of women’s health, rights and social justice.

The following are some of the recommendations and future areas of inquiry that have emerged from the research:

- ARTs in a globalized world are the end services and products of a chain of actors and organizations that dot the globe. This complex chain can be mapped ethnographically so as to highlight both the experiences of the actors (for instance, the meanings they attach to these processes and their negotiations of modern technology) as well as the operationalisation of the chain itself (for instance, how connections and recruitments are made, and how finances are arranged by clinics).

- Credible and accessible information on ARTs, such as success rates, side effects, and costs, is very important for couples. Without this, users cannot be considered to have given ‘informed consent’ for ARTs in the true sense. Standards for the kinds of information that must be mandatory, should be put in place to ensure ethical care for those who seek ‘treatment’.

- A central database for registration, monitoring, and data collection should be in place to provide data on the number of ART clinics and their outcomes; number of cycles performed, number of live births, number of failed cycles, sex of the children born, number of surrogacy cases, and so on.

- A code of good practice regarding the provision of counseling services and obtaining of informed consent should be developed to ensure transparency and the ethical administration of ARTs.

- The ramifications of pregnancies in older women and couples have also not been examined, although this has been the focus of media attention. There is a lack of long-term studies on the health risks for women and children, both procedural and drug related, in ARTs. This is of critical importance, especially in high-risk pregnancies (such as post-menopausal and/or multiple-embryo implantation pregnancies).

- Information should be provided on the preventive and curative aspects of infertility treatment, and appropriate and effective information campaigns should be designed to reduce stigmatization and social exclusion of infertile women and men. Information on adoption should also be made available.
• The impact of pregnancy loss, both material and emotional, has not been studied, although its rate of occurrence in ARTs is high.

• Researchers in the future may want to address the themes of why childlessness is increasing, among whom, and where, as well as the contexts that compel some couples to access ARTs rather than other options, such as adoption or voluntary childlessness.

• The primary causes of infertility, particularly their linkages with larger determinants such as livelihoods, need more research and documentation.

• Religious perceptions of infertility and ARTs have not been studied in-depth. There is a need to understand local interpretations and accommodations of religion, rather than only doctrinal stands taken by different religions.

• The impact of ART procedures on women’s lives, including the disruption of their work, daily routines, and social relations, was clearly brought out in the research study. Some providers perceived women’s work and careers as the main cause of delay in marriage, and therefore as responsible for their infertility. This is an important area for future research.

• Services for infertility treatment should be integrated into larger reproductive and child health services. A policy on infertility care could be formulated as part of an integrated reproductive health care program, based on an analysis and evaluation of the availability, functioning, and effectiveness of the actual health care infrastructure. Investigations for infertility could be conducted at various levels of the health care system. For instance, service provision at the level of the subcentre or urban health post could include couple counseling on fertility-related issues and appropriate treatment and referral for RTIs and STIs. At least some services should be available at the level of the primary health centres, while specialized tests and advanced treatment could be provided at the tertiary level.

• Health care providers at each level need to be trained to impart screening, examination, diagnosis, referral, and treatment services for infertility as appropriate.

• Questions of regulation need to be explored. Given that ART provision, including surrogacy, is crossing borders in today’s world, the possibility of creating an international regulatory framework or guideline should be considered. Further, proposals for ART regulation
in India need to be revisited and read together. For instance, the report of the Law Commission (2009) recommends a complete ban on commercial surrogacy, while the ICMR guidelines (2005) and MoHFW’s Draft Bill (2008 and 2010) seek to regulate the same.

- The use of embryos—the by-products of IVF—for stem cell research is a practice that needs further and systematic investigation in the Indian context. Further, inter-linkages of ARTs with sex-selection also need further examination and strict regulation.

- The boundaries of nationhood and citizenship are being redefined through ARTs. As such, nation states need to better respond to citizenship issues that arise in the case of international surrogacies.

- Several ethical issues in ARTs still need to be explored. For instance, in gamete donation, whose rights prevails; those of the child to know, or those of the parent(s) and donor(s) to protect their privacy and autonomy?

ARTs present a route through which to examine adoption more closely. Adoption may not be an initial option for some infertile couples, who would rather submit to complicated kinship ties through technological intervention (with the gamete donor, surrogate, etc.) in order to have their own biological child. Further, the newer forms of kinship and family ties that are created with the use of ARTs, are also areas for future research.
Annexure

i. Bibliography of outputs / advocacy materials (attached)