

Workshop on Medical and Reproductive Technologies from a Gender and Rights Perspective

Date: 22 September 2018

Venue: Raipur

Organised by

Sama Resource Group for Women and Health



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The Third National Health Assembly was a two-day long event in Raipur, Chhattisgarh, and saw nationwide participation of organisations and individuals working on health and healthcare, in different capacities. As part of



the Self Organised Workshops sessions on the first day i.e. 22nd September 2018, Sama conducted a workshop titled 'Medical and Reproductive Technologies from a Gender and Rights Perspective'.

The workshop sought to use the lens of gender to address social, ethical and regulatory issues related to medical and reproductive technologies. It further aimed to serve as a platform to stir discussions on

topics like Medicalization of women's body and its related social and ethical aspects; Privatization of health care, emerging medical technology and the commercialization of women's lives; the relationship among social beliefs, science and medical technology; Issues related to usage of new technology, such as limited access and catastrophic out of pocket expenditure.



The workshop commenced with a short skit presented by the Sama team, called 'Par Kiske Liye', which touched upon issues such as contraceptives and free choice, accessibility to medicines and drugs, and uterus transplantation. Using a narrative format, the team highlighted the dilemmas faced by a majority of women who are unable to grapple with the adverse effects, high costs and unfamiliarity of new medical and reproductive technologies. The skit was followed by two sessions led by Vrinda Marwah and Priya Ranjan, respectively.

Reproductive and Medical technologies-complexities of issues

Vrinda Marwah's session largely focused on Assisted Reproductive Technologies and Surrogacy, delving into their interlinkages with other social determinants. Choosing to start the discussion in a participatory fashion, Vrinda opened the floor to comments around the meaning and use of ARTs to the audience itself. These technologies were identified as being useful for those who are unable to have biological children of their own. The session, then, also highlighted prominent types of ARTs (IVF and IUI), their low success rates, and the increased chances for multiple births owing to the transfer of more than one embryos, higher chances of C-

sections, etc. It further touched upon malpractice by medical providers, medical tourism as a way of attracting foreign clients, a lack of regulation and incomplete or improper information given to patients.

Vrinda Marwah explored the interlinkages between Medical and Reproductive Technology, and gendered determinants. She further emphasized on ethical and regulatory issues and health risks in the context of



reproductive technologies focusing on ARTs and surrogacy. Vrinda held a participatory discussion to address these issues. People who cannot have their own children or have difficulty in having children go for such treatments. Though these practices do not really qualify as treatment rather a 'side-step' to have children. Vrinda further mentioned that there are two types of ARTS, namely IVF in which fertilization happens

outside the body and embryo is later implanted in the female and IUI in which the artificial insemination is done. Though both these methods have just 25-30 percent success rate. A few concerns that arise from such use of technology were also pointed out during the session. Since doctors are blindly trying to increase the success rate of these procedures we see increasing number of twins and triplets nowadays, Marwah mentioned. It further leads to increased instances of C-sections as parents are not willing to take any chance/risk. ARTs have turned out to be a business and doctors see it as a 'trade' wherein malpractices like sex selection and medical tourism are rampant. Moreover, it is recommended that only one embryo should be implanted, but since there is utter lack of/no proper regulation regarding the procedure to be followed, doctors do multiple implantations in order to earn profit and even the parents are in favour of it since they are desperate to have a child of their own falling prey to the societal beliefs.

Vrinda also mentioned about Sama's previous work on these issues in the states of Odisha, Tamil Nadu and Uttar Pradesh. She emphasised that from these studies it was found out that doctors do not give complete information to the patients/couples about the procedure, adverse effects and no counselling is done for them. Informed consent is not taken from them and other regulatory issues came to the forefront.

Vrinda Marwah also initiated discussion on Surrogacy and the two kinds of techniques used for it. One, where the surrogates egg/eggs are used and second where the embryo is implanted in the surrogate's body without her egg being used in the process. She also highlighted various debates and issues around surrogacy like that of altruistic vs. commercial. To address the issue further she questioned, what should be done about surrogacy? The information given to the surrogates is incomplete, misleading and conditional. The contract made is usually in the language unknown to the surrogates. Hostels for the surrogates are sites of further humiliation and enhances their vulnerabilities. Payments are not made directly to the surrogates, stakeholders involved look out to maximize their self-interests. Also, these payments are made in instalments like first instalment is given to the surrogate when the embryo is successfully implanted in the surrogate so on and so forth. She further stressed upon that there are no

laws, policies or regulations in place for the protection of surrogates. Mostly surrogates are married women with proven fertility, for them it becomes necessary to seek their husband's permission beforehand. Very few women who are single or separated become surrogates. In some parts of India, like in Gujarat, there are these surrogate hospitals unlike in Punjab where such procedures are not so visible. Moreover, what kind of care does the surrogate receive after the delivery is also an important factor to be considered, questioned Vrinda.

To encourage more participation from the audience, Vrinda questioned how many people support ban on surrogacy? To which various responses came from the audience like consent of surrogate mother is extremely important else it becomes a criminal act. There's a need to change society's mind-set around the incessant need to have their own children and adoption should be encouraged. Though Vrinda intervened and mentioned adoption cannot be made compulsory for infertile men and women since it's also a reproductive right to want one's own genetic offspring.

She also highlighted that Sushma Swaraj announced in the past a ban on commercial surrogacy and allowing only altruistic surrogacy. She further stressed that to look at this aspect deeply it comes across that this ban on commercial surrogacy and allowing altruistic surrogacy will lead to pressure on women at home encouraging their exploitation in the family. This ban draws its roots from nationalist and patriarchal ideologies where women are supposed to be selfless and nurturing mothers. To close the discussion she also emphasized that the ban would just lead to a black market for surrogacy with even worse conditions for the surrogates without any regulation in place for their protection.

Technology development, medicalisation and commodification-analysis from public health and gender perspective

The session led by Priya Ranjan took off from Vrinda's session, using ARTs as an example of the close ties between technology and society. He argued that while science and technology are often seen as neutral signs of progress, they cannot be seen devoid of societal values and norms. This, he said, was evident in the advancement of ARTs despite the high risks and low success rates, due to the social desire for biological children rather than adopted children or childlessness. He highlighted the importance of children within society to fulfill the need for furthering lineages, maintaining caste lines and to bestow upon women their essentialised role of mothers. Priya Ranjan also stated the paradox of continual advancement within the medical sciences coupled with the deaths of millions, each year, and due to basic illnesses. This he attributed to the fact that medical advancement is led not by a desire to improve health conditions but by large pharmaceuticals companies looking to make profits. This means that there is less research around basic diseases such as malaria, tuberculosis, etc., which affect the majority of the population; and increased research around diseases that affect a smaller but richer minority.

Priya Ranjan's talk focused on social, economic, and historical context in which the market of bio-medical technologies have emerged in India. He started by stating a paradox and proposed that by the end of his talk he seeks to establish the linkages between the two seemingly contrast aspects of this paradox. The paradox stated by him was- '*medical science has advanced, but millions of people die every year due to basic illnesses*'.

He emphasized on the need to understand the connection between technology and science. In common parlance, both the technology and science are held synonymous to being 'good' and signifying 'progress'. In terms of ART, if we see, the fundamental question is that why do people want a biological child of their own? Despite such low success rate, higher health risks, why is there so much emphasis on advancing and use of the ART methods; why the aspect of adoption or willingness to live without a child is not so much discussed, probed Priya Ranjan. He took the discussion ahead by stating that it is so because, having a biological child has the larger social acceptance within the society, and technology



such as ART is based on this essentialism of motherhood, on this need of having a biological child that has been essentialised within the society. The advancement of technology has happened because of this essential social need, which has also led to its commercialization. Therefore, we see that science has remained highly invested in building its innovations on the societal needs and related aspects which could be problematic, mentioned Priya Ranjan. This could be complicated further by the fact that biological child is also essentialised for maintaining the boundaries of caste, taking forward blood lineage, property etc. How many inter-caste marriages happen in our society? He further mentioned that even now we often hear about incidents of killings in situations of inter-caste marriages.

Technology and science as evident in the current discourse has emerged within capitalist economic system. Any assumption that science is 'objective' needs to be challenged, he emphasised. Since independence, the political idea of India levied focus on 'technology' and equated it with the notion of progress. Essentialising technology – from the view of the market, we need to question the 'technology is progress' rhetoric, mentioned Priya Ranjan.

Priya Ranjan added the gender dimension by bringing to the forefront that if any woman does not become a mother, her life is turned into hell ranging from various discriminations and exploitation that she may be made to go through. It is a myth that-technology and science is always progress.

He further took the discussion forward by stating that there are many scientific developments today-gene technology, DNA engineering etc. Historically it was seen during the time of economic depression that 'capital' discovered this potential market and worked towards making it a profitable sector in the decade of 1980's. Policies were brought in simultaneously to encourage such technological advancements. Genetically modified organisms were given patents. A lot of research used to be within the government institutions; US changed this scenario and expanded the research and development within this to private sector. The relationship between medical technology and market is neither organic nor natural, rather it has been pushed and established within the capitalist system.

He also mentioned old data shows that how pharmaceutical companies invest 90 per cent of their money in developing medicines that cater to illnesses of only 10 per cent of people; while only 10 per cent of their

investment is towards saving lives of the rest 90 per cent of the population. Focus is on medicines for rich countries and rich people. Less research is seen in diseases like malaria and TB. He further stated that, if we look at the example of clinical trials in this country, Supreme court in past had issued clear guidelines for proper conduct of the trials; following which there was a clear decrease in the number of trials meaning that the poor norms and conduct of trials in India makes an opportunity for corporate players like pharmaceutical companies. The recent example from Rajasthan also showed how the company had flouted all the protocols and proper guidelines for conduct of the trial; people from Dalit communities were taken from the villages saying that there is some health camp, and they were given experimental drugs without any consent, or following any due process.

Coming back to the same paradox, we get a picture wherein the newer medicines or innovations are coming up which remain unaffordable to the larger section of the people, and poor people are also violated in the process of such new developments, mentioned Priya Ranjan.

He concluded by talking about an RTI to DCGI, the data from 2005-2017 showed that 5,000 people had died in the country owing to clinical trials; 20,000 people had suffered from SAE (serious adverse events); but in only 187 cases people or their families had received any sort of compensation.

Discussions:

The two sessions were concluded with a round of questions. The question and answer session began with the participants asking various queries to both the speakers. One of the participants asked about the link between market and technology: Why do we see that some diseases are held as priority at a given time but then the focus completely waters down on the same, like AIDS was given so much importance in last decade but today we do not see the same focus on it; who controls such focus on the health issues?

To this Priya Ranjan replied that, the government's expenditure on health in India is one of the least in the world, so any withdrawal of focus or priority also shows the lack of resources been put in by the government. Today, if AIDS is not seen as a priority that doesn't mean that the issue is not there.



Our health system is fragmented, there are vertical health programs, focus is given on illnesses rather than strengthening the health system. As a result, the comprehensive health system approach is missing. Vrinda further added that while there are various players involved including international organisations within process of determining health priorities, or what issue will get focus within policies, AIDS control program of India has been a successful program and that too needs to be recognized. Also, this success was possible because its implementation was done in participation with social groups who were affected, like sex workers etc. Unlike other programmes this was not a top down approach,

rather the affected communities owned the issue and a lot of mobilization around it came from the bottom. Certainly, whether focus has been shifted and why calls for further debate.

Another participant from the audience commented that the issue of women with disabilities and their pregnancy, are often side-lined in these discussions and we should at least raise from platforms such as these. Vrinda stated that this is a very relevant point. It's a point about constituencies and identities in this discourse. Within the debates on surrogacy, women with disability are more seen as constituencies of using surrogacy rather than being a surrogate. Discussions are required focusing on such constituencies or identities from both the demand and supply side.

Sarojini Nadimpally added that when SAMA had these consultation with other social movements, we also talked to voices from disability perspective. Within surrogacy people could even opt for PGD which could be also linked to detection of any disability, it is a very polarized issue and debate right now and there seems to be no consensus. Another participant mentioned that women's body and technology forget other identities of women when talking about reproductive health and women. What about women with disabilities, other identities- rural, urban, caste, class etc?

To this Vrinda Marwah answered by, mentioning that she agrees to the above concern. She further added that today was to talk about what is happening in ARTs and surrogacy. What are the policies? There are more questions of surrogacy- who benefits, how it affects different women/people in general. Pre-implantation genetic diagnosis is also done for checking disability.

A participant asked if we as in the society consider surrogacy a 'right to work'. What are the parallels between surrogacy and sex worker? Vrinda added that moral boundaries are drawn by the workers themselves. We see the



natural match when we step back. What are the consequences in case of a breach in surrogacy contract? Asked another participant. To which Vrinda mentioned that lawyers represent the commissioning couples. Surrogates have little say. The contracts hang over their heads. It is rare for the surrogates to take the couple to court. The common issue is around the citizenship of the child born through surrogacy. The final question asked by another participant was that the fundamental

question is that whether surrogacy should be there or not?

Vrinda answered to this stating that there is need to have more consultations and arguments within the groups and movements to have this answer. Right now there is no agreement on just one answer within different movements.

Finally, to wrap up the workshop vote of thanks was presented to the audience for their time with special mention to Heinrich Boll Foundation for their support to extend a helping hand for conducting the workshop.

Workshop on Reproductive and Medical Technologies from a Gender and Rights Perspective
22nd September 2018

Participant's List

#	Name	Organization
1.	Vrinda Marwah	University of Austin
2.	Priya Ranjan	I.P College, University of Delhi
3.	Kumar Alok	-
4.	Pranjal Ranjan	Centre for Catalyzing Change
5.	Sayan	JNU
6	Shilpa	MPBGVS Bhopal
7	Shabana	MPBGVS Bhopal
8	Rahul Sharma	MPBGVS Bhopal
9	Dr. M. Ramadevi	Janavignana, Telangana
10	Shilpa Krishna	University of Hyderabad
11	Ameer Hamza	Action India
12	Shruti Arora	The YP Foundation
13	Renu Arya	The YP Foundation
14	Asha Mishra	MPBGVS Bhopal
15	Mukta R. Yojo	SHRC, CG
16	Anju	SHRC, CG
17	Neelam	SHRC, CG
18	Usha Singh	-
19	Sukanya Majeed	The YP Foundation
20	Lalita	SHRC, CG

21	Dueli	SHRC, CG
22	Rubi Soni	SHRC, CG
23	Sonia Gill	AIDWA
24	Monica Sharma	JNU
25	Jeet Kunwar	JNU
26	Reena	JSS-Bihar
27	Kamayani	JSS-Bihar
28	Kalyani	JSS-Bihar
29	Leelawati	Chaupal
30	Somwati	Chaupal
31	Sukhmanti Singh	Chaupal
32	Maan Kunwar	Chaupal
33	Sumitra	Chaupal
34	Illikhba	Chaupal
35	Asotiya	Chaupal
36	Rajni Kashyap	SHRC, CG
37	Mamta Devi Chauhan	SHRC, CG
38	Arehana Kushwana	SHRC, CG
39	Anju	SHRC, CG
40	Neelam	SHRC, CG
41	Vandana Gupta	SHRC, CG
42	Lalita Merawi	SHRC, CG
43	Ananga Negi	RARE, Odisha

44	Amita Pitre	Freelance Consultant
45	Ashu Sahu	SHRC, CG
46-56	Pallavi, Pratibha, Deepa, Sarojini, Noyana, Susheela, Rizu, Adsa, Megha, Oshin	Sama Team