

The Gene Express: Speeding Toward What Future?

Opening address for Sama's International Consultation on
Unraveling the Fertility Industry: Challenges and Strategies for Movement Building
New Delhi, India, January 22-24, 2010

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Welcome and thanks. I am truly honored to have been asked to give this address.

I would like to begin today by underlining the importance of this consultation. It comes at a time in which developments in genetic research and assisted reproductive technologies are occurring with great speed, not just technologically but in terms of the growth of new markets in a world where the compression of time and space is a hallmark of capitalist globalization. This speed poses a political challenge to us. Do we jump on the express train and try to catch up, or instead do we take the local, stopping for awhile at diverse places along the way to reflect, digest, synthesize and strategize?

Sama's 2006 consultation on ARTs provided a rare opportunity to do exactly that – to slow down and think things through for a change. It has resulted in a fine book that we will celebrate tomorrow, along with Sama's 10th anniversary. I'd like to acknowledge that anniversary now by asking for the first of many rounds of applause for Sama's wonderful work.

Three and a half years later this consultation again offers us the luxury of slowing down and thinking together, which is actually a necessity if we are going to build a movement that takes on ARTs in all of their complexity. While we don't know in advance the precise outcomes of this meeting, we do know that the process, organized with great wisdom and care by the Sama team, will be rich, intense and inspiring. At the end of it we will have moved far forward or at least figured out our next destinations.

At the peril of carrying the train metaphor too far, I'd like to spend my time today reflecting on what I see as some of the main stops along the way – the central thematic clusters that come to my mind.

First are the broader contours of **geneticization** of which ARTs are one dimension, but not the only one. First coined by Abby Lippman, geneticization is the process by which genetics increasingly has come to explain not only health and disease but to normalize and naturalize social differences as biologically based. The genetic code, a term originally derived from computer science, has now burgeoned into a full-blown genetic discourse that shapes the knowledge and experiences of our bodies and the world, whether we like it or not. Geneticization is more than eugenics, and it manifests differently depending on whether you are rich or poor, young or old, black or white, man or woman, from the global North or from the global South. In a sense it is a discourse composed of multiple languages that share certain words and rules but not others, and it is often hard to find the right translator. It is double-edged, providing rewards as well as punishments, posing risks at the same time as it purports to minimize them. The DNA test that frees the wrongly convicted prisoner is simultaneously a tool of authoritarian surveillance; so-called individual choice becomes individual burden when the pregnant woman is told she is carrying a disabled fetus; hopes of cures are dashed against the rocks of exorbitant expense, bad science and false pharmaceutical claims.

Geneticization is at once reductionist and expansive. It reduces us to smaller and smaller parts of ourselves at the same time as those parts acquire value and enter national and global economic circuits. Women's bodies in particular have become a kind of genetic capital for biotech research and reproductive technologies. We are no longer whole, but are instead the sum of our parts.

Of course it is important to look not only at what geneticization includes, but what it excludes: the structural violence of poverty, discrimination, toxic environments and lack of access to health care that produces the most widespread and serious risks of sickness and death. Add to that the health risks of ARTs themselves – the impact on women's bodies of egg harvesting, surrogacy, multiple births. At this conference let us affirm our right to reclaim the meaning of risk, including the right to determine what information and knowledge are used to define it.

The second thematic cluster is that of the **market**, or rather markets. We have to understand very concretely how ART and related markets work if we are going to be politically effective. It is not enough to just repeat the mantra of neoliberalism; we have to consider the diversity of markets and the extent of state support and facilitation of them in countries such as India, China, South Korea, Singapore, the UK, Israel and the Czech Republic. One of the great things about this conference is how we will be looking at different national experiences in this regard.

Some of the key issues that come up around markets are:

The connection between the fertility industry and scientific research, for example, how spare eggs, embryos, aborted fetuses, placentas, umbilical chords and other tissues from the former supply the latter;

The transition of ARTs from a niche luxury market to a larger, if not mass market;

The relationship between reproductive tourism and medical tourism – and even old-fashioned tourism. For example, egg “donors” are being wooed to India with promises of exciting tours afterwards – give your eggs and then go to the Taj Mahal;

The way gestational surrogacy, in separating the components of conception, helps to create a larger market for each, and how Preimplantation Genetic Diagnosis has expanded the market beyond infertile couples;

The transformation of ethics and informed consent from principles into marketable commodities, and similarly how “donation” is deployed to mask market transactions and to turn gifts of blood and body parts into private property;

The role of advertising in boosting both supply and demand, the role of media in normalizing through sensationalizing ARTs, and the ideological impact of both in terms of feeding market speculation;

The politics of regulation. This is one of the trickiest issues we face. Some liberals argue that what is needed is clearer establishment of property rights in order to regulate the ART market. Are our body parts then the

latest enclosure of the commons? What kind of regulation do we want, can we get, should we demand?

A third cluster of issues relates to **science**. Not only the corporatization of scientific research in the last decades, but the increasingly porous borders between public finance and private gain play out in the ART field. In the U.S., for example, due to changes in the law, universities and non-profit institutes can now patent federally funded research results. Science has never been pure, but the profit motive now muddies waters more than before, helping to push the direction of research towards commercial applications. One question that we might consider in these next few days is how progressive feminist epistemologies and interventions could reshape the nature of genetic research itself, from the framing of questions down to laboratory experiments. We need to be bold and scientifically literate enough to assess what role genetic research might play within a progressive, feminist health framework.

Last but hardly least are the intersections between **gender, sexuality, race, class, disability, nationality and ARTs**. Here there are many obvious hierarchies and dichotomies as well as less obvious ones. Take race, for example. While it remains true that white women's reproduction continues to be valued and black women's discouraged – fertility treatments for white women, population control for black women – Dorothy Roberts reminds us that the ART market is now expanding in the US to target more women of color, particularly for PGD. In addition, race as a genetic category is being mobilized by the pharmaceutical industry in order to obtain patent protection and drug approval. Geneticization thus plays the race card multiple ways, and we are going to have to develop new understandings of race and racism if we want to intervene in or put a stop to the game.

In the case of gestational surrogacy in India, hierarchies of gender, race, caste, class, religion, ethnicity and nationality are startlingly clear: at the apex well-off couples from abroad and rich Indian clinic directors although those couples too can be exploited by an industry based on patriarchal values and false hopes; in the middle medical personnel and surrogate brokers; at the bottom poor women serving as rentable wombs. The latter are exploited for sure, receiving a small fraction of the fee, but that fraction represents a considerable sum of money to buy a house or business, send a child to school, pay for a family member's medical

operation. Exploitation and opportunity are wound and bound up in one -- how do we disentangle them?

In terms of selection for disability, much has been written about the problematic context in which women are making the “choice” to abort a disabled fetus or in the case of IVF, to screen out embryos that carry the risk of future disability or chronic disease. But as time progresses, we need to look at the results of this process further down the line. For example, disability rights activists in the US point to how the population of people with Downs Syndrome is now shrinking, leading to more isolation and lack of community. Meanwhile, the search for genetic cures for conditions such as autism takes attention and resources away from desperately needed support services for autistic people and their families. As the neoliberal safety net shrinks, class privilege comes to determine even more than before who can afford services and who cannot.

As for sexuality, ARTs have allowed lesbian and gay couples to have biologically related children and make families, and thus ARTs have been hailed by many as disrupting gendered reproductive norms. Yet we also have to ask how the notion of the biological middle class nuclear family actually gets reinforced in the process. And what about adoption? Is the focus on ARTs taking attention away from the need to fight for the rights of lesbian, gay, bisexual, intersexual, and transsexual people to adopt?

Scholars such as Rose and Novas argue that we are entering an era where the nature of citizenship itself is changing: geneticization is producing a new biocitizen who has the responsibility to manage health risks and live life through acts of calculation and choice. What does this do to those who have not achieved full citizenship in the traditional sense? What is the relationship between the biocitizen and the non-citizen? Are there parallels between the immigrant who gets put on the fast track toward US citizenship if he or she joins the army and the Latina immigrant who gets a green card because she is willing to serve as a surrogate? How about the women in Anand, Gujarat who are literally producing citizens of other countries, while they remain second or third class citizens in their own, subject to a state-imposed two child norm when it comes to their own offspring?

One thing we must remain attentive to is how the health and psychological burdens of ARTs are profoundly gendered, falling mainly on women, while so much of the language used to analyze them is not.

Concepts like biocitizenship, for example, are useful tools, but if we're not careful, they can obscure rather than illuminate gender inequalities. Here at this conference gender is central as are the other intersections with sexuality, race, class, nationality and disability. I believe we have the possibility of not only moving our politics forward, but the theoretical dimensions of the ART debate. Not to put pressure on anyone, but this is truly an historic opportunity.

Before I conclude, I'd like to speak briefly about some of the political dilemmas/tensions that may come up at this meeting because I believe it is better to face them squarely than sweep them under the rug:

One is the issue of abortion rights, particularly important in my country. The issue of abortion rights around disability is a minefield, but so too is the question of whether or not we should make strategic alliances with anti-abortion groups opposed to the egg trade and other ARTs. A similar issue came up around population control when anti-abortion activists actively sought to make common cause around sterilization abuse.

Second is the question of how we view poor women being hired as gestational surrogates. Clearly, they are performing a type of reproductive labor, so we do support them to get better work conditions and fairer remuneration? There are some of the same fault lines here as in the support sex workers' rights vs end prostitution debate.

Third regards whether or not to ban certain reproductive and genetic technologies. Will a ban drive them further underground and criminalize the most vulnerable people? Here there is a parallel with the controversy over whether to ban the use of ultrasound technologies used in sex selection.

No doubt we will have to thrash out points like these, but in the process it is important to remember our common commitments to end patriarchy, ensure health care for everyone, and work for social, economic and environmental justice in all their many forms. While keeping one eye on ARTs, we need to keep the other on the broader political agenda that challenges the very idea of geneticization as the key to progress. We must resist the individuality that geneticization pushes on us -- the nano-partitioning of our genes, our blood, our bones, our minds, our hearts -- with an alternative vision of community and collectivity in which all of us are citizens and all of us are whole.