

*Globalization and the state:  
is an era of neo-eugenics in the offing?*

**Margaret Lock**

McGill University, Montreal

The history of technology is usually transmitted as a narrative of progress, one designed above all to bring about the amelioration of the human condition. The radical version of this tale is one of heroism; the conquest of an enemy, whether of the human kind or that of untamed nature. Bioscientific knowledge and its associated technologies are recognized as crucial in the attainment of this ideal today, with the ultimate objectives of achieving freedom, a state that includes release from bodily affliction, and better yet, bodily enhancement and happiness. Of course this dominant ideology has been countered repeatedly, particularly since the early part of the 19<sup>th</sup> century, with dire warnings about the havoc that technology can and will wreak, causing the anthropologist Bryan Pfaffenberger (1992) to comment: «like Shiva in Hindu iconography, technology is at once both creator and destroyer; an agent of future promise *and* of culture's destruction».

In his book *Frankenstein's Footsteps*, Jon Turney writes that the recent history of biology, notably the rediscovery of Mendel's laws at the beginning of the 20<sup>th</sup> century, the elucidation of DNA structure in the middle of the century, and the recent mapping of the human genome making its manipulation possible, are among the most significant products of the Enlightenment promise that pursuit of scientific knowledge will lead, in the words of Francis Bacon, to "the effecting of all things possible". «Biology's dizzy onward rush from potential to real technology» argues Turney, brings to a new pitch the perennial tension of enormous promise, associated with ambivalence and a fear about the future of humankind (TURNNEY J. 1998: 2).

Although genomic hype appears quite frequently in the media, critical comments are less visible, but Jurgen Habermas's book *The Future of Human Nature* is perhaps indicative of the extent to which genetic technologies are causing deep concern among some commentators:

«Genetic manipulation could change the self-understanding of the species in so fundamental a way that the attack on modern conceptions of law and morality might at the same time affect the inalienable normative foundations of societal integration» (HABERMAS J. 2003: 26).

This view of genetic manipulation as “*a force unto itself*” (FRANKLIN S. - ROBERTS C. 2006: 28, italics in the original), hostile to social order and integration, echoes earlier warnings by Jacques Ellul and others about omnivorous, autonomous technology – technology out of control (1964). Habermas’s concerns, shared by other German thinkers, are strongly influenced by the history of National Socialism, notably the research and science associated with the Third Reich.

Given the magnitude of what critics such as Habermas fear is happening, we might expect the state to broaden its customary role of citizen surveillance, and take a lead in exerting control over the implementation of these new technologies of the body – in short, to impose a “politics of vitality” in its own interest (ROSE N. 2007). In this chapter, I will focus on activities involving several of the technologies of «medically assisted procreation» (TESTART J. 1995), to argue for a recognition of complexity and internal dispute that renders hyperbolic arguments inappropriate. At the outset it is important to note that the biopolitics of emerging biomedical technologies exhibit great variation among nation states, with significantly different effects in practice, effects that today have global repercussions.

Among the proliferating technologies of assisted reproduction, I have selected for particular discussion prenatal genetic testing, pre-implantation genetic diagnosis, and sex-selection. My purpose is in part to question the assertions made for several years now by numerous outspoken geneticists, social scientists, and philosophers, who insist that we are entering an era of neo-eugenics as a result of escalating technological interventions into human reproduction. Many of these concerned commentators base their assertions on evidence that individuals and families are apparently increasingly willing, and on occasion guided by authority figures, towards the disposal and destruction of those embryos and fetuses designated as abnormal, sub-normal, or simply not wanted. For these commentators these activities represent a sophisticated version of the “negative eugenics” practiced in the early part of the 20<sup>th</sup> century. Other commentators, although not opposed in principle to all the practices that fall under the rubric of neo-eugenics, are opposed to what was in the early 20<sup>th</sup> century termed “positive eugenics,” manifested today in discussion about enhancement of the human genome – a technical striving for perfection.

### *Improving the stock of nations*

Eugenics is an inflammatory term, and its use must be carefully demarcated. Francis Galton, who created the modern version of this appellation in the late 19<sup>th</sup> century, proposed that the “human race” might be improved along the lines of animal and plant breeding that had long prevailed in husbandry. “Undesirables” would be eliminated, and efforts would be made to permit the multiplication of “desirables” – activities that he labeled negative and positive eugenics. The only means available to achieve these objectives in Galton’s day was to enact policies in which the state was assigned control over the reproductive lives of those individuals designated as a burden to society. Sterilization, almost all of it involuntary, was the method by which this was usually accomplished. Much less was done to encourage positive eugenics, although several government initiatives in the United States and Europe encouraged people to emulate those families deemed by officials to be particularly healthy in mind and body.

Eugenics was firmly consolidated initially in the United States. As Daniel Kevles puts it: «Eugenics was British by invention and American by legislative enactment» (KEVLES D. 1984: 92). Charles Davenport, an American biologist well versed in the science of his day, devoted his time to the creation and collection of family pedigrees. Among other things, he observed that “pauperism,” “criminality,” and especially “feeble-mindedness” were, in his estimation, heritable. On the basis of these observations Davenport argued that individuals with such traits should be prohibited from reproducing so that defective protoplasm might be eliminated from the gene pool. In 1912 Davenport proclaimed: “Prevent the feeble minded, drunkards, paupers, sex offenders, and criminalistic from marrying their like or cousins or any person belonging to a neuropathic strain. Then the crop of defectives will be reduced to practically nothing” (DAVENPORT C. B. 1910: 12).

The Harvard geneticist E.M. East went further than most of his colleagues, and argued that the biggest challenge lay hidden in the population of heterozygotes – the unaffected carriers of just one of the supposedly defective genes. His recommendation was to put whole families under surveillance; a matter of urgency he claimed, because “civilized” societies permit the numbers of “defective” people to increase by means of medicine and charities that interfere with natural selection and keep them alive (EAST E. M. 1917). Comments such as these were well publicized, and thousands of Americans gave financial support to the activities of the Eugenics Record Office in Cold Spring Harbor, of which Davenport was the director. Eugenics was transformed rapidly in the early part of the 20<sup>th</sup> century from a rather

obscure science created by Francis Galton and his colleagues into a major political movement.

Nikolas Rose (2007) reminds us that the biopolitics of the first part of the 20<sup>th</sup> century was driven in large part by the concept of “degeneracy,” initially set out in the mid 19<sup>th</sup> century by Herbert Spencer when formulating his ideas about social evolution. A pervasive fear of the time was that the quality of populations as a whole, and hence the vitality of nations, was under threat because people who had inherited weak constitutions and were lacking energy and of low intelligence were likely to “breed” faster than others, thus diluting the “germ plasm.” Applied eugenics could purge the population of this unwanted degeneracy.

It is sometimes forgotten that many staunch supporters of eugenics in the early part of the 20<sup>th</sup> century were progressive-minded socialists, including such prominent figures as Emma Goldman, George Bernard Shaw, H. G. Wells, and Margaret Sanger. Among these writers and activists, the eugenics movement was recognized not only as a means to improve the biological stock of nations, but also as a foundation for social reform. Margaret Sanger wrote that «Those least fit to carry on the race are increasing most rapidly... Funds that should be used to raise the standard of our civilization are diverted to maintenance of those who should never have been born» (SANGER M. 1922: 98).

It was only when contraceptive technologies became available that reproduction could potentially be manipulated successfully on a population-wide basis. The early birth control movement strongly supported Sanger's position, and a 1940 joint meeting of the Birth Control Federation of America and the Citizens Committee for Planned Parenthood was entitled “Race Building in a Democracy.” It was not by chance that family planning in the United States initially targeted African Americans living in East coast inner cities (WASHINGTON H. A. 2006: 198).

The eugenics movement, supported by many geneticists, grew stronger during the depression of the 1930s (PAUL D. B. - SPENCER H. G. 1995) and research into diabetes, epilepsy, syphilis, feeble mindedness, and other diseases was motivated not merely by an interest in the mechanism of the diseases, but by a concern about their financial burden to society. In the United States it is estimated that something like 50,000 individuals were forcibly sterilized during the first half of the 20<sup>th</sup> century. This practice was replicated in Canada, South Africa, and across northern Europe, including the socialist countries of Scandinavia, with Germany being by far the most extreme example. Lawsuits in connection with these practices that persisted in all these countries until the 1970s continue to the present day.

Similar programs were developed in Japan and China where, as in Europe, implementation of compulsory sterilization was spearheaded by intellectuals (OTSUBO S. - BARTHOLOMEW J. R. 1998).

The historian Diane Paul raises an important question in connection with the entire eugenics movement: «Did eugenics rest on an elementary mistake?» she asks (1998: 117). Eugenicians in the early part of the 20<sup>th</sup> century argued explicitly that mental defects are linked to a recessive Mendelian factor (in today's language, an allele), leading some commentators to suggest that eugenicians were in error if they believed that by sterilizing only those individuals thought to be "defective," the "factor" for defectiveness would thereby be eliminated from the population. Paul notes that the eugenics movement expanded after the time when the mistaken beliefs of some early eugenicians had been thoroughly exposed. After reviewing the literature of the day, she came to the conclusion that the majority of eugenicians were satisfied that eugenic sterilization, even though they knew it would not eliminate the "factor" from the population as a whole, would nevertheless slow down deterioration, making sterilization practices highly worthwhile (PAUL D. 1998: 128). In other words, rather than rigorous scientific argument, the prevalent ideology of degeneracy, shared by very many influential people of the day prevailed, and justified the widespread implementation of government-supported programs.

### *Genomics and neo-eugenics*

Perhaps the first scientist to proclaim the rise of a *new* eugenics in the latter part of the 20<sup>th</sup> century was Robert Sinsheimer. He is a molecular biologist who, in the 1980s, was Chancellor of the University of California at Santa Cruz, at which time he was the first to propose that the entire human genome should be mapped. Earlier, in the late 1960s, he had declared: «a new eugenics has arisen based on our understanding of the biochemistry of heredity and our comprehension of the craft and means of evolution». Sinsheimer went on: «For the first time in all time a living creature understands its origin and can undertake to design its future... Today we can envision that chance – and its dark companion of awesome choice and responsibility». Sinsheimer explicitly contrasted the old eugenics with what he envisioned as a much improved new eugenics associated with molecular genetics:

«To implement the older eugenics of Galton and his successors would have required a massive social program carried out over many generations» he argued, «... Continuous selection for breeding of the fit, and a culling of the

unfit», would be required but: «The new eugenics would permit in principle the conversion of all of the unfit to the highest genetic level... The horizons of the new eugenics are in principle boundless». (SINSHEIMER R. 1969: 13).

When commenting over 20 years later on Sinsheimer's widely-read diatribe, Evelyn Fox Keller asks: «From what might such extraordinary confidence have derived?» (FOX KELLER E. 1992: 290). She notes that in the late 1960s no human gene had been precisely located and molecular genetics was in its infancy. Fox Keller suggests that Sinsheimer and other like-minded scientists of the day were no doubt determined to have an effect on the course and funding of scientific research. In their minds, emerging molecular genetics had the potential to dethrone physics as the favoured basic science, and they were not above resorting to hyperbole to bring this about. Clothed in the language of individual choice genetics was poised to receive a massive infusion of research funding and government support, as long as the matter could be handled in such a way as to convince those in power that this new eugenics would result in societal improvement.

Hyperbole such as that of Sinsheimer was never confined to a few interested scientists and, moreover, has been on the increase in the intervening 35 years. In 1988, for example, the United States Office of Technology Assessment (1988: 86) made the claim that the new genetic information ensures that each one of us in the near future will have «a paramount *right* to be born with a normal, adequate, hereditary endowment». Using remarkable wording, this report asserted that: «new technologies for identifying traits and altering genes make it possible for eugenic goals to be achieved through technological as opposed to social control». The report discusses without reservation what is described as a «eugenics of normalcy», namely «the use of genetic information...to ensure that...each individual has at least a modicum of *normal genes*» (*ibidem*: 84, emphasis added).

Continuities between the rhetoric employed in early 20<sup>th</sup> century eugenics and that associated with the human genome project are not difficult to discern. In the same year, the European Commission, the executive arm of the European Union, published a report entitled Predictive Medicine: Human Genome Analysis. This report states that Predictive Medicine «seeks to protect individuals from the kinds of illnesses to which they are genetically most vulnerable and, where appropriate, to prevent the transmission of genetic susceptibilities to the next generation» (KEVLES D. 1992: 72). This document notes that the major diseases of our time - diabetes, cancer, stroke, coronary heart disease, and psychiatric disorder - are the products of interactions between genes and the environment. The rationale for Predictive Medicine rests on the assumption that we cannot hope to control

the environment, and hence we should «seek to protect individuals from the kinds of illnesses to which they are the most vulnerable and, where appropriate, to prevent the transmission of genetic susceptibilities to the next generation» (*ibidem*: 71). This “neoeugenics,” designed to eliminate unsuitable embryos and fetuses through the implementation of genetic screening programs followed by abortion, was fostered in the conservative 1980s and early 1990s with the blessing of Margaret Thatcher and like-minded politicians specifically in order to allay future health care expenditure (*ibidem*: 72).

In contrast to the 1930s, this proposal for Predictive Medicine met with considerable opposition in which German Greens, activist Catholics, and some British conservatives formed an unlikely alliance. The report was countered through an initiative headed up by a West German Green, Benedikt Härlin, who warned that «a modern test tube eugenics» might be on the horizon, one that could disguise more readily than its cruder antecedents «an even more radical and totalitarian form of “biopolitics”» (*ibidem*: 74). Daniel Kevles, commenting on these debates, makes it clear that Härlin is neither a luddite nor completely opposed to genetic testing, rather he was searching for a way to make a genetic program palatable to the German public, and safe to put into action. Härlin’s activism was so successful that a revised, heavily modified proposal was the result, with some clear restrictions outlined, including the prohibition of human germ cell research, dropping the term predictive medicine (which implied that genetically vulnerable people should not transmit their susceptibilities to the next generation), and a demand for public accountability.

### *The tenacity of hyperbole*

Despite publicized concerns about the envisioned negative effects of genetic testing, the hype about the enriched future that it will bring about persists, including among some well-known scientists. An early and oft-cited example was expressed by Daniel Koshland, a molecular biologist and past editor of *Science*, who argued in that journal: «no one will profit more from the current research into genetics than the poor». He made it clear that what he had in mind was that “weak” and “anti-social” genes would slowly be “sifted out” of the population entirely (KOSHLAND D. 1988). Koshland’s language is particularly crude and little different from that of the early 20<sup>th</sup> century eugenicists, but today it is exceptional. Fox Keller and others have noted that the language most often used no longer supports the implementation of eugenics via government instituted social

policies in the name of the good of society, the species, or even the collective gene pool, as was the case early in the 20<sup>th</sup> century (1992: 295). Instead, we are now in an era dominated by the twinned ideas of being “at risk” for named diseases and having the right to individual choice in connection with decisions about health and illness. Genetic information will furnish, it is claimed, the personalized knowledge that people need in order to realize their inalienable right to individual health and the health of their families. The assumption is that, with such knowledge at hand, publics will practice self-governance – “genetic prudence” – as part of the new politics of vitality (NOVAS C. - ROSE N. 2000).

The historian Daniel Kevles comments that «the eugenic past is prologue to the human genetic future in only a strictly temporal sense» for the reason that, quite simply, «it came before». Nevertheless he is concerned, not about genetically engineered imagined futures, nor about a state mandated program of eugenics that he assumes could only be implemented by authoritarian regimes, and is therefore entirely out of the question in most parts of the world, but rather about the short-term effects of molecular genetics. His worry is about the abundance of genetic information being produced and the diffusion and marketing of such information. Kevles insists that we are creating the capacity for a “home-made eugenics,” and he assumes that people will want to use these technologies to try to produce, at the very least, healthy children (KEVLES D. 1992). In a similar vein, the philosopher Philip Kitcher (1996) insisted several years ago that we are already in an era of *laissez-faire* eugenics, one that depends upon decisions that individuals and families make on the basis of the results of genetic testing and screening programs. Kitcher’s concern is that although these new practices are designed to promote reproductive freedom, it is clear that the resources for such a freedom are not accessible to everyone. Furthermore, there is a real danger that social support for individuals born with disabilities and disorders that can now be detected by means of genetic testing may be cut back, thus indirectly imposing eugenic-like values on reproductive choice. Kitcher comments: «*Laissez-faire* eugenics is in danger of retaining the most disturbing aspect of its historical predecessors – the tendency...to reflect a set of [dominant] social values» (KITCHER P. 1996: 199).

The sociologist Dorothy Nelkin and historian of science Susan Lindee in their book *The DNA Mystique* (1995) expressed a worry that the United States is undergoing a revival of eugenics. In a later paper they point out that many publications in the 1990s, notable among them *The Bell Curve* by Richard Herrnstein and Charles Murray, promote the idea that “the genius pool” is shrinking due to excess reproduction among the immigrant poor

(NELCHIN D. - LINDEE S. 1997). Nelkin and Lindee demonstrate how this belief and others like it were very evident in American popular culture of the 1990s. Their conclusion is that eugenics in contemporary culture is less an ideology of the state than a set of ideals about a perfected and “healthy” human future (1997: 46) – a widely shared constellation of beliefs among the American public about «the importance of genetics in shaping human health and behavior» upon which, it is assumed, the economic, social, and political future of the nation depends (1997: 46). Highly critical of the genetic reductionism embedded in this discourse, Nelkin and Lindee’s view is fully supported by disability rights activists (ASCH A. 2001, PARENS E. - ASCH A. 1999) who note that the social cost of treating and caring for “defective” children is frequently used to justify the implementation of screening programs. Guidelines of the International Huntington Association make it clear, for example, that it is acceptable to refuse to test women who do not give a complete assurance that they will terminate a pregnancy if the Huntington gene is found. As Paul and Spencer (1995) point out, «Those who made this recommendation certainly did not think they were promoting eugenics. Assuming that eugenics is dead is one way to dispose of deep social, political and ethical questions. But it may not be the best one».

The comments by Habermas with which I started this essay are anchored in arguments that have been circulating in the world of Anglo-bioethics for several years now under the heading of “liberal eugenics.” Notions of individual autonomy are central in these debates primarily concerned with the ethics of genetic manipulation of embryos and fetuses (see PRUSAK B. G. 2005, for a summary). Supporters of liberal eugenics argue that provided fetal manipulations are limited to the reduction of suffering and do not interfere with the autonomy of the future person who must be free to create their own life in any way they please, then such manipulations are acceptable. Habermas, while he accepts these arguments up to a point, insists that liberal eugenics as it is currently outlined by Nikolas Agar and others «would not only affect the capacity of “being oneself”», but it would «create an interpersonal relationship for which there is no precedent as a result of an irreversible choice one person makes for the desired make-up of the genome of another person» (AGAR N. 2003: 83). In other words, the idea of an autonomous actor is put in jeopardy by what is proposed for liberal enhancement, or positive genetics.

In contrast to all of the above authors, Nikolas Rose argues strongly against use of word eugenics – neo-, flexible-, liberal-, or otherwise, to describe the present situation. His position is that nothing analogous to Nazi practices is taking place, and that «styles of biological and biomedical thinking that

inform ways of ways of governing others and ourselves in the advanced liberal polities of the West are no longer those concerning the quality of the race and the survival of the fittest» (ROSE N. 2007: 69). For Rose «letting die is not making die»; this new form of biopolitics, although death is very present, is a government of *life* (emphasis in the original, *ibidem*: 70). We are confronted today with calculations about probable futures based on estimations of risk, as the report on Predictive Medicine discussed above makes clear, and such calculations are entirely different from the coercive selection of certain people picked out as inferior and of poor quality for inhumane and genocidal treatment.

I agree with Rose that the neo-liberal environment in which genetic testing and screening has been carried out thus far in order to detect severely disabling and lethal single gene disorders is of a very different order than 20<sup>th</sup> century state-sponsored eugenics. For this reason I would not resort to an inflammatory term such as eugenics, even when prefixed, although it continues to be relatively easy to detect the kind of primitive eugenic thinking that Nelkin and Lindee note, thinly disguised in the comments of certain people, a few of them with political clout. However, the concerns of Kevles and Kitcher about inequities are clearly justified. Furthermore, not everywhere has government-supported eugenics died out (DIKOTTER F. 1998, KORHMAN M. 2005).

Lene Koch, in agreement with Rose, argues that although reductionistic thinking is present in both state orchestrated eugenics and contemporary molecular genetics, the idea of using genetic knowledge under the auspices of an “enabling state” to reduce suffering and disease represents a fundamental break with the past (KOCH L. 2004: 316). She also argues that the state should not be understood as inherently hegemonic, and that, in Scandinavia at least, in the past there was disagreement among politicians and scientists about the social benefits of sterilization. By the 1940s, sterilization practices were carried out only on “humanitarian grounds” for women considered to be “worn out” by child-bearing. And it is quite possible that many of these women cooperated willingly, especially when it is recalled how fashionable it was until just a few decades ago for middle aged women to beg their doctors for hysterectomies in order to avoid unwanted pregnancies (COULTER A. *et al.* 1988).

### *Screening for single gene disorders*

It is clear that among those families habitually afflicted by one or more rare disease that causes great suffering, genetic screening has almost without

exception been welcomed. The success of screening programs is measured in terms of the reduction in the incidence of the disease in question, and not in terms of the removal of the mutant gene from the susceptible population. In Montreal, for example, a program has been in place for nearly 30 years that screens volunteer teenagers from families believed to be “at risk” for the deadly Tays Sach’s or thalassemia genes, to determine if they are carriers. This program is monitored at arms length by the Québec government. Many people who have been screened, now adults, state that without these programs they would not have had children. Screening is voluntary, confidential, and makes use of individual informed consent. Not even the parents of the teenagers are informed of the genetic status of their children (although no doubt this does not stop some parents demanding that their children pass along the information). Only those relatively few couples where both individuals have tested positive for the mutation must make decisions about abortion and, since the time that the program has been in place, only one affected infant has been born (MITCHELL J. J. *et al.* 1997). A proposal to set up a program for screening sickle cell anemia in Montreal has been rejected by the involved community, largely of Caribbean origin. Without whole-hearted support of the community in question screening is entirely out of the question.

The doctor who organized these programs has been accused of practicing neo-eugenics but, in my opinion, this is an entirely inappropriate way to characterize these practices unless one believes that all voluntary selective abortions are eugenic. Furthermore, given that the genes themselves are not eliminated from the population this Montreal program falls far short in its implementation of the original “science” of eugenics. Dr. East, the Harvard doctor who called for monitoring of heterozygotes in the early 20<sup>th</sup> century, would have insisted that all detected carriers of unwanted genes be sterilized, thus slowly ridding the population of the gene.

Another program, Dor Yeshorim, based in New York, has tested more than 50,000 orthodox Jews in North America, Europe, and Israel. This program, unlike the one in Montreal, does not inform individuals about their status as a carrier for Tay Sachs’s disease or the other single gene disorders for which testing is available. This practice is justified, it is argued, because of the considerable stigma associated with genetic disease among the Orthodox community. When a marriage is being arranged between two families the young people are at liberty to contact a Rabbi about genetic testing, but only as individuals. Once the results are available the individual, or a designated proxy, is informed whether the potential union is or is not

“genetically compatible.” Test results are not made available to the potential partner or to extended family members. Almost without exception, when both individuals of the potential couple have tested positive for one or more specific genes, planned unions designated as incompatible are abandoned. The program, recognized by affected families as enormously successful, is designed expressly to facilitate religious observance in which procreation is obligatory and abortions can only be obtained when a mother’s life is at risk. Prainsack and Siegal point out that Dor Yeshorim is based on «a notion of genetic couplehood» and risk is not conceptualized individually (PRAINSACK B. - SIEGAL G. 2006). The program has been criticized as paternalistic (EKSTEIN J. - KATZENSTEIN H. 2001) but Prainsack and Siegal insist that to criticize this program because it compromises individual choice is inappropriate.

A third program in place for over 30 years is based in Cyprus, and screens individuals for beta-thalassemia. This program, initially sponsored by the WHO, is based on the idea of “collective risk management” and is compulsory. One in seven Cypriots is at risk for thalassemia, a rate that is said to be the highest in the world for inheritable single gene disorders. With the introduction of screening everyone in the reproductive age group must participate. Widespread education is carried out in schools and through the media. The Cypriot Orthodox Church routinely requires people to obtain a premarital certificate to testify that they have been screened and counseled (there is no civil marriage in Cyprus). However, the Church does not prohibit carriers from marrying one other, and only 3% of potential couples in which both are carriers of the gene abandon plans for marriage, although many resort quietly to abortion if fetal testing is positive. Turkish Cypriots are also legally required to present a screening certificate before marriage. In other words, screening is an “obligatory passage point” (BECK S. - NIEWÖHNER J. 2009). The number of babies born in Cyprus affected with thalassemia has decreased to virtually zero. This program has been criticized as unethical by people who live outside the country, although by far the majority of Cypriots are at ease with it (ANGASTINIOTIS M. 1990) and Cypriot health care practitioners are proud of what they have accomplished. Critics describe the program as authoritarian and paternalistic and are particularly critical because the Church is involved. Thalassemia is treated as a public health problem in Cyprus, one requiring systematic intervention, but no one is required to terminate a pregnancy, nor is anyone sterilized. The program is collectivist rather than individualistic (BECK S. - NIEWÖHNER J. 2009). Clearly some outsiders would rather that people of marriageable age be given the option of not being screened, a point in need of further debate.

Screening programs designed to bring about collective risk management inevitably target specific populations deemed at risk and involve governance implemented via the medical profession. The State is not always involved, as the Dor Yeshorim example makes clear. Concerted efforts are made to avoid abusive coercion, and many people no doubt participate willingly, but indirect pressure may well come from the extended family and the medical profession, and in the case of the Cyprus program, screening is mandatory.

Aside from religious fundamentalists, virtually no one voices opposition to voluntary screening programs set up to detect single gene disorders that cause terrible suffering. Even disability rights activists who are very sensitive about possible misuses of genetic testing are rarely in opposition to a technologically induced reduction in the incidence of these conditions (PARENS E. - ASCH A. 1999). An informal politics of "letting die," in Rabinow and Rose's idiom, is at work; alternatively the avoidance of conception of fetuses whose destiny is clearly one of pain and early death. The causative genes are not eliminated from the gene pool, so that even those who argue that clinicians are in danger of tinkering inappropriately with the human genome cannot be critical with any justification. But, as emerging technologies bring down the cost of individual genetic profiling and of screening programs, it may well be that proactive governance mandating genetic testing and screening may become increasingly common – with enormous social repercussions.

At least one publication in a technical journal encourages its readers to believe that the public is pushing scientists down a path of increased testing and screening (*Trends in Biotechnology* 1989). It is indeed the case that the Jewish community in Montreal first broached the idea of screening with local geneticists, but when such initiative is taken by members of the public it is most frequently in connection with single gene disorders that have devastating effects *in utero* and immediately after birth. Many involved families work together with clinicians and scientists to raise funding for research, and to elevate public awareness about the disease in question – activities that have been described as "genetic citizenship" (HEATH D. 1998, HEATH D. *et al.* 2004). These practices often have direct links to biocapital; the state is involved only in so far as political lobbying for recognition of the disease and funding for it are indispensable (RAPP R. *et al.* 2001, RAPP R. 2003).

But it is equally clear, particularly in connection with diseases expressed later in life, or that are less than devastating, that many individuals are

reluctant to undergo genetic testing. Research has shown that only between 15 and 20 percent of adults designated at risk for a named genetic disease, or for carrying a fetus believed to be at risk for a genetic disease, have made use of testing, a finding that has held now for over ten years (these numbers vary from country to country and differ according to the disease in question – QUAID K. A. - MORRIS M. 1993, BEESON D. - DOKSUM T. 2001). Cox and McKellin have shown how people who come from families with Huntington's disease vacillate, sometimes for many years, about testing (1999). Further, it has been shown that a good number of people when they are tested ignore or challenge the results (HILL S. A. 1994, RAPP R. 1999).

Adding to the doubts that people hold about genetic testing are other problems associated with the unfolding of molecular knowledge. Current knowledge about Huntington Disease illustrates some of the unforeseen difficulties associated with estimating future risk, making "educated choice" much more difficult than previously was the case. Research has shown that there is no straightforward, unequivocal link between the presence of a Huntington gene and the expression of the actual disease, as was formerly believed to be the case. Today, when people from Huntington families are tested they are given one among three possible results: "No, you won't get the disease," or, "yes you will get the disease, but we don't know at what age it will start to affect you" or, alternatively, to a smaller number of tested people: "we simply don't know. You may or you may not get Huntington Disease" (LANGBEHN D. R. *et al.* 2004). As knowledge in molecular genetics increases it is ever more apparent that the absolute predictions made thus far about single gene disorders are fallible, with the result that some people have had to given new risk estimates at times entirely different from the previous estimate, with enormous social repercussions (ALMQVIST E. *et al.* 1997). Furthermore, for many diseases severity cannot, and perhaps never will be, predictable. The biopolitics of risk is itself riddled with risky estimations (LOCK M. 2005) and technological advances are raising the stakes.

### *Preimplantation genetic diagnosis*

I am going to turn now to pre-implantation genetic diagnosis (PGD) – a technology raising considerable concern among those activists who believe we are entering an era of neo-eugenics. Recently, the Human Fertilization and Embryology Authority of Great Britain passed a landmark ruling that permits thousands of women who carry the BRCA1 and BRCA2 genes asso-

ciated with breast cancer to make use of PGD to avoid giving birth to an infant who carries one of these genes (HENDERSON M. 2006). The ruling also applies to a third gene associated with bowel cancer. This announcement has revived extensive discussion about the “cherry-picking” of embryos, and the production of designer babies.

To elaborate, a woman carrying a BRCA gene who wishes to become pregnant, even if she can do so in the usual way, deliberately chooses to make use of IVF technology. She first undergoes hyper-stimulation of her reproductive system in a specialty clinic, and shortly thereafter up to 15 eggs are recovered and fertilized by her partner’s or donor sperm. If successful, several embryos will result, and a single cell is then removed from each embryo at a very early stage in development for testing for the BRCA genes. Only those embryos that do not have the BRCA genes are implanted into the woman’s body for further development.

Of course, genetic screening of pregnant women whose fetuses are assumed to be at high risk for disease is not new; such screening was first institutionalized in the 1960s when the technique of amniocentesis became widely available, and began to be used for detection of Down syndrome and diseases inherited in Mendelian fashion. But this new recommendation drastically changes the picture. Mutations of BRCA genes are *not* involved in by far the majority of cases of breast cancer and are implicated in only 5-10% of cases. And even when these mutations are found, this by no means *determines* that an individual will get breast cancer. It is estimated that on average BRCA mutations put people at an increased lifetime risk, as compared to a so-called normal population, of somewhere between 60 and 80%. Patient groups involved with the breast cancer movement support the new recommendation; their argument is that affected families will now be able to avoid this disease altogether and, further, that the mutation may well disappear entirely from the population as a result of the routinization of PGD. Both these claims are erroneous.

These advocates gloss over yet other difficulties: undergoing IVF treatment is not without risk, and it has still to be convincingly demonstrated that IVF children are not at increased risk for certain conditions in adult life. Recent research strongly indicates that the effects on an embryo of lying in a medium in a Petri dish may have life long epigenetic repercussions in connection with gene expression (DEBAUN M. *et al.* 2003, MAHER E. R. 2005). Moreover, both failure to conceive, and multiple births (inevitably involving cesarean sections) are common with IVF. What is more, IVF and PGD are expensive, somewhere between \$13,000 and \$17,000, so that many people would be hard pressed to make use of this technology, raising fundamental

questions about equal access for potential clients. Turning to the larger picture, preventive measures can be taken against breast cancer; early detection and treatment have improved dramatically over the past two decades, bringing down substantially both incidence and mortality rates. And, of course, breast cancer is an adult onset condition, and does not cause suffering or mortality in children or adolescents.

The British sociologist Nina Hallowell noted several years ago: «the new genetics not only positions individuals as responsible for their own health, but also for the health of others» and it is women in particular who are thought of as harboring genetic risks. She argues that it is likely that many women will increasingly develop a sense of “genetic responsibility,” that is, experience an obligation to undergo testing and reveal the results to kin. When Hallowell interviewed women in the UK who come from families where cancer is very common, and who were being tested for the BRCA genes at a specialty clinic, without exception she found that they believed it was their duty to themselves and to their children to be tested (HALLOWELL N. 1999). Moreover, many women who had already borne children believed that they were unknowingly responsible for having put their children at risk. As one woman put it:

«A large proportion of my concern is a responsibility to my daughter. And I think also it's sort of a helplessness... I've passed on the gene to my daughter. I must make sure now that I alert her to what might be in store for her, because I have that responsibility» (HALLOWELL N. 1999: 107).

Most women interviewed were frightened about subjecting themselves to the test, particularly so because it might affect their employment or health insurance, but nevertheless went through with it. Sometimes women were pushed to do so by their spouses or sisters:

«I said to my husband that I didn't want to know. I said, if I'm going to get cancer then I'm just going to get it. I don't want to go for this test. And my husband, he kept saying... you know, you should, because it's not just for you, but for the kids» (HALLOWELL N. 1999: 108).

Now that PGD is available, women and their doctors can select “good” embryos for implantation and leave the “bad” ones in storage or donate them for research. Should this practice be understood as a form of neo-eugenics? With respect to bringing about an imbalance in human genetic variation, the answer is a definitive “no.” Nor can use of PGD as it is practiced in Europe and North America be described as state-enforced disposal of unwanted life. However, regulations vary enormously from country to country. There is no regulation of any kind in the United States and Italy, and virtually no monitoring of what happens in private clinics. Regulations are

pending in Canada and Denmark, whereas clear guidelines exist in Sweden, the United Kingdom and France. In the United Kingdom and France only a very limited number of trained clinicians are allowed to carry out PGD. Among those countries with guidelines, there is considerable variation as to what conditions may be tested for, with the United Kingdom being the most flexible. Links among politics, local values, and private enterprise (notably in the United States) and the form that control (or lack of it) takes in connection with PGD are evident, resulting at times in “reproductive tourism” (SPAR D. 1995).

In light of these varied government responses, it is clearly not appropriate to posit that unfettered neo-liberal values are equally at work everywhere enabling a laissez-faire eugenics; but can this cherry picking of unwanted fetuses perhaps be described as a negative eugenics because coercion is involved? For example, Rayna Rapp has shown that, despite training in non-directive counseling, genetic counselors on occasion indirectly or inadvertently encourage women whom they perceive to be poor, uneducated, or as having sufficient children already, to terminate pregnancies when a fetus tests positive for a specific medical condition (RAPP R. 2000). Hallowell's findings strongly suggest that there is some evidence that medical practitioners and family members on occasion coerce or pressure women into undergoing genetic testing in attempts to determine what the future has in store for them, and with the advent of PGD people are able act on genetic knowledge and select the embryos they are led to believe are not at risk for a named disease. These practices are exceedingly troubling. Clearly governments are not directly involved, but unequal power relationships are very often at work and unexamined prejudices are implicated. Overt coercion is no doubt rare, but pressures, subtle and not so subtle, are exerted in households and clinics, and indirectly via medical and government supported guidelines.

Legitimate concerns about IVF and PGD do not stop here. Rapidly growing knowledge about molecular genomics makes it clear that there are reasons to consider carefully if it is *ever* a reasonable decision to abort a *wanted* pregnancy because a fetus is shown to carry a susceptibility gene for a complex disorder such as breast cancer, heart disease, or Alzheimer's disease. Probability estimates in connection complex disorders are unreliable, and one can never predict who among those who carry susceptibility genes will or will not get the disease in question (LOCK M. *et al.* 2006). Estimates of increased lifetime risk as compared to a baseline population are usually around 50% at the most, and often much lower. Furthermore, and most important in calculating risk estimates, epigenetics is ignored entirely. In

other words, the significance of the relationships among macro environments, social and physical, the micro-environment of the body, and gene expression is bracketed out. In making individualized risk estimates for susceptibility genes biostatisticians in effect continue to assume that genes cause disease directly, unless an assortment of serendipitous, under-researched factors get in the way (LOCK M. *et al.* 2007). And yet it is now well known that knowledge of what brings about or inhibits gene expression is crucial, rather than the mere presence or absence of a gene – making the usual types of probabilistic risk modeling highly questionable (JABLONKA E. - LAMB M. J. 1995, MATTICK J. 2004).

Obviously if one's mother and several sisters have died of breast and/or ovarian cancer, PGD may well appear to be the best choice. Both practitioners and involved patients firmly believe that what they are combating is miserable suffering. But the ethnographic research by Zeiler (2004) and by Franklin and Roberts (2006) make it very clear that although most people are positive about the advantages of PGD, as opposed to fetal testing accompanied by abortion, they nevertheless do not approach this technology lightly, or without hesitation, and many consult clinicians but then decide to go no further. Even involved doctors evidence considerable caution (ROBERTS C. - FRANKLIN S. 2004, FRANKLIN S. - ROBERTS C. 2006). Creating "perfect," disease-free babies is simply not on the agenda in the clinics that carry out these technologies, in contrast to the rhetorical hype that appears all too often in the media and in comments such as those made by Daniel Koshland, James Watson, and others. However, even though the majority of clinicians are cautious, I believe they can nevertheless be faulted for not making very clear to government, advocacy groups, GPs, the media, and the public the obvious dangers and limitations of these technologies and, further, fully acknowledge the rudimentary state of molecular genomic knowledge. Perhaps "willful ignorance" is the best descriptor of some clinician attitudes when they assist with embryo selection.

The reality of genomic complexity and the low success rates associated with IVF technologies is likely to hamstring all efforts at creating babies to order, perhaps indefinitely. This will be the case even if the mapping of personal genomes comes down to \$ 1000 per individual, as promised by James Watson and Affymetrix (WADE N. 2006). When this happens, the uses to which PDF will be put will no doubt continue to be limited primarily to testing embryos for genes associated with specific diseases. In the United States, perhaps more so than in other countries, where aggressive direct to consumer advertising combined with virtually no federal or state control over the application of reproductive technologies is the situation, con-

sumers are particularly vulnerable to exploitation. But these laissez-faire practices, with all the usual attendant problems of economic gain, duplicities, and inequities, are not designed to intentionally “breed” a superior population of people.

Sandel, a philosopher, has other, troubling concerns: «A *Gattica*-like world, in which parents become accustomed to specifying the sex and genetic traits of their children, would be a world inhospitable to the unbidden, a gated community writ large» (SANDEL M. 2007: 86). In common with Habermas, Sandel believes that we are transforming our “moral landscape” by making “enhancement” technologies available. Of particular concern to Sandel is, as less is left to “chance” and more rests on “choice,” parents «become responsible for choosing, or failing to choose, the right traits for their children» (*ibidem*: 87). Like Kitcher, Asch, and many others, Sandel believes that with increased use of genetic testing parents may be held directly responsible for producing “imperfect” children. What is more, he believes that human solidarity and humility are likely to be reduced as a result of these practices. These are valid concerns, and Sandel recognizes that widely shared values are at work in how we choose to apply these technologies. He is particularly critical of the tendency towards “hyperparenting” in contemporary society – a clear expression, in his opinion, of the “anxious excess of mastery and dominion” that we now live with (2007: 62).

But just how many of us are indeed captivated by this particular value of mastery? Setting aside devastating single gene disorders that affect infants, the numbers of people who choose not to undergo genetic testing when it is freely offered to them suggest that “mastery and dominion” might not be a widely shared ideology. Activities of certain middle class Americans and Europeans, widely reported in the media, are presumed to be evidence of values shared by us all. Moreover, to confound the entire spectrum of genetic engineering and the wide range of individualized choices it makes possible (some practices of which are indeed very troubling – non-medical sex selection and inappropriate use of growth hormone – to give just two examples) with state orchestrated 20<sup>th</sup> century eugenics, as do Sandel and others, is to conflate authoritarian brutality and unfettered coercion of ideologically created populations of outcasts with present day governmentality. We are indeed in possession of technologies that have the potential to enable massive transformations in moral landscapes; this does not mean that they should be ruled entirely out of order. Apart from anything else, limits to manipulation imposed by the material world itself, vast lacunae in scientific knowledge, the ability of people living in democratic societies to monitor and prohibit certain technological practices, and the

apparent lack of desire on the part of many people to try to master their futures by means of genetic manipulation, will proscribe these transformations for a long time to come. I am going to turn in closing to a very troubling topic, one that on superficial investigation apparently justifies the moniker of neo-eugenics (see, for example KITCHER P. 1996), but when examined in context, as with the other examples cited thus far, forces second thoughts.

### *Situating sex selection*

The routinization of ultra-sound screening (sonography) for pregnant women that commenced in Europe and the United States in the 1960s made it possible to inform women about the sex of the fetus they are carrying. This relatively simple piece of technology is now made use of in many parts of the world, allowing people to practice what is euphemistically described by some experts as “family balancing” by terminating a pregnancy on the basis of the sex of the fetus alone (VAN BALEN F. - INHORN M. C. 2003). It is common knowledge that such activities are frequent in India and China, but survey research of clinics in the United States, where no legal prohibitions against sex selection are in place, has shown that “non-medical sex selection” is practiced in that country as well. Among the reproductive medicine clinics surveyed in the US, 42% offer sex selection when a client requests it (BARUCH *et al.* 2006). Researchers believe that they have uncovered the tip of an iceberg. They note that there is little government support for adopting regulations; in contrast they found that among IVF clinic practitioners there is strong support for the introduction of professional guidelines. In other countries where sex selection is clearly prohibited it may well be that “family balancing” is at work as well. In Canada, for example, where abortion on demand is a woman’s right with no questions asked, it is likely that some women are in fact undergoing sex-linked abortions to bring about their desired “balanced” family. It is virtually impossible to investigate these practices due to the way in which statistics are collected.

One specialist at a US clinic reports that his clients come from all over the world and the largest numbers are from Canada followed by China. He also states that his Chinese customers want boys but the Canadians want girls, thereby suggesting that the majority of the Canadian clients are not of Indian or Chinese origin (Toronto.ctv.ca 2006). Marcia Inhorn reports that non-medical sex selection for males is increasingly being made use of

in the Middle East, where not only are local clients served, but efforts are being made to encourage a reproductive tourism industry designed to suit South Asian customers. The demographer Caroline Bledsoe has recently found a startling discrepancy in Spain in the sex ratio at birth among Chinese immigrants living there (personal communication), strongly supporting the idea that such practices are carried out in Europe as well.

For less wealthy clients, including a very large number of women in India and China, ultrasound followed by abortion of fetuses of the unwanted sex continues to be the most common practice. Although there is widespread condemnation by both internal and external commentators about the extent to which sex-selection is apparently taking place in these two countries, the shortcomings of the technology is rarely noted. On the basis of ethnographic work with physicians living in California whose specialty is reproductive medicine, Sunita Puri, herself a doctor, notes that there is agreement among her informants that the sex of a fetus cannot be determined by ultrasound with unfailing accuracy in the early states of gestation (PURI S. ms) and ultrasound specialists with whom I have spoken in Montreal state that only from about 17 weeks can the sex be determined with reasonable confidence, although in some cases this can never be done due to the position of the fetus. These specialists know of cases referred from other clinics where the sex had been wrongly determined. It is probable, then, that some women in India and China are opting for abortions based on inaccurate ultrasound information and are at times aborting male fetuses. On occasion too, they must give birth to female babies when they expected a male. Given the very imbalanced sex ratio in these countries, it seems likely that many must be having late abortions once the sex can be determined with reasonable accuracy; such abortions are more likely to interfere with future reproductive success. The question arises as to why these technological uncertainties are so little discussed.

Assertive efforts to plan family size and composition has not sprung up as a result of the existence of reproductive technologies, as perhaps some commentators who decry such practices as a form of neo-eugenics mistakenly believe. Infanticide and selective neglect of young children have very long histories and evidence of it persists until the present day. Such practices had little if anything to do with individual desire, nor with state orchestrated degrees, but were most often carried out to benefit the welfare, continuity, and economy of the extended family. In Japan, for example, infanticide was practiced from medieval times or earlier, and the idea of something akin to family planning, including selective reduction in family size, commenced well before the 19<sup>th</sup> century (HANLEY S. 1985, LA FLEUR W.

1992). The Japanese word for infanticide – *mabiki* – is a euphemism, the prime referent of which is to rice cultivation and the thinning of spindly, weak seedlings; the midwife was the one usually enjoined to carry out *mabiki* shortly after birth, but such practices were contrary to state edicts and had to be carried out in the utmost secrecy. The National Eugenic Law implemented in the early part of the 20<sup>th</sup> century in Japan had direct links to these earlier practices (LOCK M. 1998).

Research over the past two decades has made it clear that in many countries it is female fetuses and infants who are most likely to be disposed of (HILL K. - UPCHURCH D. M. 1995); this practice of “son preference” is particularly evident today in India, China, and Taiwan and, until very recently, in South Korea (CROLL E. 2000, GREENHALGH S. - WINCKLER E. 2005, GUPTA M. *et al.* 2004, SEN A. 1990). However, none of these states condones sex selection. In India, for example, in an effort to stop this practice, in 1994 it was made illegal to carry out sex selection in fertility clinics, either before or after conception. Even so, despite the establishment of supervisory boards; monitoring of the situation at local and national levels; demands that medical records be available for inspection; potential and on occasion actual punishment of practitioners who break the law, and media campaigns against sex selection, the practice continues unabated, appears to be on the increase, and is actively encouraged openly by widespread advertising. Three hundred Indian doctors have been prosecuted for aborting fetuses on the basis of sex, but only a few have been convicted, and even fewer jailed. It is estimated that one out of every 25 female fetuses are aborted each year in India, resulting in a total loss of 500,000 (JHA P. *et al.* 2006). The sex ratio in India is currently 1000 boys to 927 girls up to the age of 6, and the ratio drops to 614 for second daughters. Many authors stress that second daughters are particularly vulnerable to abuse (CROLL E. 2000, GUPTA M. 1987).

Numerous reports suggest that fertility clinics in India discretely generate a multi-million dollar black market through sex selection practices, and it is thought that doctors, together with many women activists who believe, no doubt rightly, that women will be subject to abuse if they produce several daughters and no sons, work together in ensuring that such clinics continue their practices. Despite a cost of about \$ 18,000, the demand for ultrasound is apparently enormous. Two physicians who run an infertility clinic in Mumbai state that their use of the technology is limited to “family balancing,” thus enabling women to have children of both sexes in a timely manner; they argue that in the West use of reproductive technologies, including the selection of fetuses making use of PGD is ethically acceptable,

and insist that it is patronizing to point a finger at Indian practices (MALPANI A. - MALPANI A. 2001). In contrast, some feminist groups in India argue that the government is complicit in the increase of sex-selection practices by placing no tariffs on the importation of ultra sound and IVF technologies – however, these technologies have a well validated medical use and to ban them would be inappropriate.

Social science research makes it clear that sex-selection in India is much more complex than the simple availability of reproductive technologies, profitability, and poorly enforced government policies. Ultra sound technology apparently makes it possible for people to achieve less crudely what has long been established practice in many parts of India, notably the northern and western provinces (PATEL V. 1989, MILLER B. 1981). Prior to the 1990s, over and above infanticide, selective neglect and abuse of female children of all ages resulting in malnutrition, and high mortality rates accounted for the “100,000 missing women” Amartya Sen documented in India and China (SEN A. 1990). Today the number is estimated to be 100 million. On the basis of recent interviews with Indian families residing in the Bay Area, California, Sunita Puri found that negative sentiment and even outright discrimination towards female children persists among a good number of families, a situation of enormous concern to local pediatricians (PURI S. ms).

In India itself, it is particularly in regions where there is entrenched patriarchy; family obligations and rituals that can only be performed by the eldest son; a large gender gap in literacy rates; low participation by women in the labor force; customary neglect of female children, and a dramatic separation of women from their natal families after marriage that sex-selection, practiced with or without the assistance of technology, is highly evident (RUSTAGI P. 2006: 16). Recent studies claim that son preference is on the increase as a result of an overall reduction in family size. This trend can be traced back to the introduction of state orchestrated family planning initiatives in the 1930s (CHATTERJEE N. - RILEY N. E. 2001) culminating in the sterilization of millions, mostly very poor citizens, in the campaigns of the 1970s set in motion by Indira Ghandi under emergency rule. The Green Revolution, followed more recently by further economic and land reforms have also contributed substantially to smaller families (SUDHA S. - RAJAN S. I. 1999) resulting in added pressure to ensure family continuity and security in old age by the survival of at least one boy and preferably two to adulthood.

Despite serious efforts from before the time of partition 40 years ago to integrate Indian women fully into mainstream public life, including the

establishment of female suffrage, results have been, at best, mixed (GUPTA M. *et al.* 2004: 250). With respect to education and health, elite segments of society have been successful in diverting money away from the poor, exacerbating already existing disparities. Laws passed to improve the status of women, including the banning of infanticide and child marriage, have not brought about significant changes in practice. Drèze and Sen conclude, in contrast to many other countries where lowered mortality rates resulted in an improved status for women, anti-female discrimination has if anything actually increased in India with declining mortality (2002, see also AGNIHOTRI S.B. 2000). Bandyopadhyay, working in villages in West Bengal, encountered flat denial among women and midwives, whether Hindu, Moslem, or tribal peoples, living in these villages, that sex-selective abortions were being performed. However, she concluded on the basis of statistics on sex ratios at birth that in these villages the practice was undeniably taking place in the easily accessible private clinics. She also noted that in these villages, in nearly half of the families, senior women or men decide and enforce what should be the ideal family size and composition (2003). Prenatal sex selection using ultrasound is thought of as scientific and neutral – a practice performed by professionals – thus relieving all but the very poor of direct responsibility for their actions.

In Bijnor, a town in northern India of just over 100,000 people, the sociologist Patricia Jeffrey finds that son preference is still very evident among Hindu families, and that with consumerism there has been an escalation in dowry expectations, making young women an ever greater financial liability. Furthermore, over 20 kiosks and clinics offer ultrasound in Bijnor. Most of the owners of these clinics proclaim that they do not practice sex selection, but they often state that their neighbors do so (JEFFREY P. personal communication). In contrast to the enforced sterilization campaigns of the 1970s that usually targeted poor areas, the government remains at arms length from private medical clinics, making only desultory efforts to rectify matters by passing laws that are infrequently enforced, although one or two Indian doctors who have aborted fetuses on the basis of gender alone have recently been prosecuted (RAMESH R. 2006).

It is abundantly clear that the forces of modernization *per se* do not necessarily bring about changes in gender discrimination and that in India, for structural, cultural, and economic reasons, women and female children are considered secondary to males in very many Indian families, one result of which is female feticide. There is a perceived urgency by many people, including members of the Indian government, to bring about an end to these practices that ultrasound enables so efficiently. Accumulated research

of years strongly suggests that changes will only be brought about by actions of both men and women at local and national levels in which recognition of the importance of social security in old age, changes in inheritance patterns, and an end to illegal dowry practices are key features. But the findings from California suggest that structural changes and economic wellbeing alone may not be sufficient. Unexamined stereotyped assumptions about female inferiority are proving to be extraordinarily resistant among certain populations, despite legislation to the contrary, and loopholes in governmentality, notably in the United States, India, and now the Middle East, foster this gendered discrimination in which doctors are complicit and from which they profit enormously. This is not state orchestrated eugenics but neo-liberal profiteering at its worst.

State involvement in population control has a very long history in China consolidated from the late 19<sup>th</sup> century by European thinking. Sterilization eugenics were systematically practiced on disabled and other individuals labeled as burdens on society because they contributed to the “degeneracy” of the race, a practice that continued until the end of the 20<sup>th</sup> century (DIKÖTTER F. 1998) and that sporadically persists to the present day when people blatantly do not comply with the one-child policy. The one-child policy, established in the late 1970s, represents a break from earlier eugenic practices. The best-known example of government-orchestrated population control today, this policy was initially applied across virtually all the population (only people designated as ethnic minorities were exempt). The explicit goal was not improvement of the “race,” but a slowing of the birth rate to bring about China’s plan for accelerated modernization and economic growth – a plan that would be thwarted, it was believed, if the population continued to balloon out of control. The anthropologist/demographer Susan Greenhalgh argues that this situation came about in large part as the result of a fetishization of numbers that accompanied Chinese-style population demographics in which an ideology of population reduction was adopted in order to catapult the entire country into a modernized economy (GREENHALGH S. 2005).

Many doctors in the employ of the state are made extremely uncomfortable enforcing this policy (GREENHALGH S. - WINCKLER E. A. 2005) and Greenhalgh has documented the ways in which baby girls are often quietly hidden after birth, never registered, placed in orphanages, or passed along to childless couples (GREENHALGH S. 2003). Thus, political cadres, doctors, and families collude in various ways to circumvent the sex selection that the one child policy indirectly encourages. Even so, Greenhalgh and Winkler argue that “birth planning, in conjunction with China’s male-centered

culture and market economy, has masculinized the social order, making a large gender gap ... a constitutive feature of Chinese modernity" (GREENHALGH S. - WINCKLER E. A. 2005: 266, see also ANAGNOST A. 1995).

The Chinese communist party explicitly made women the equal of men in law, and female infanticide, abandonment, and mistreatment of female children were all made illegal in the early 1990s. Measures were taken to rectify an emerging sex imbalance by institutionalizing a national program to subsidize school fees for girls; provide housing and employment privileges to one-daughter families; by waiving the one-child policy in several locations and making use of pro-daughter media campaigns. With evidence of continued son preference, the Deng government reformed the one child policy in the mid 1990s to allow those families whose child proved to be a girl to have a second child. At the time the one-child policy had been implemented it was wrongly assumed, due decades of socialist egalitarian education, that "outmoded" cultural beliefs would quickly die out. The persistence of a strong desire for boy children, particularly in rural areas, came as a surprise to many population policy makers whose initial reaction was to ridicule it as a remnant of "feudal culture." However, Greenhalgh is of the opinion that these reforms inadvertently re-enforced son preference by acknowledging officially that if the progeny of the first pregnancy is a girl, the result is less than satisfactory (GREENHALGH S. 2001).

Recently laws have been enacted in China against sex-selection based on the results of sonography, but it has also been reiterated by the government that a woman has a right to know the sex of her unborn child, and ultra sound machines are present in even the smallest rural clinics; as in other countries, a Chinese woman can go to one clinic for an ultrasound and, when informed that the fetus is female, present herself at another clinic for an abortion, freely given with no questions asked.

Despite efforts on the part of the government to remedy the situation, it is clear that the sex ratio continues to worsen, although the degree to which this happens varies greatly depending upon geographical location. A 2007 report in *China Daily* notes that in the city Lianyungang in Jiangsu province the ratio currently stands at 163.5 boys to 100 girls, and a total of 99 cities have sex ratios higher than 125 ([www.chinadaily.com.cn/china/2007-08/content](http://www.chinadaily.com.cn/china/2007-08/content)). A professor cited in the report states that the sex imbalance will affect "stability and harmony," and the National Population and Family Planning Commission is very concerned given that it is estimated that there are now 18 million more men than women of marriageable age in China (WATTS J. 2007a). Evidence is beginning to accumulate in both India and China that the sex imbalance has contributed to an increased

demand for the services of sex workers, and a further spread of HIV/AIDS. Rising violence against women is also documented (AGNIHOTRI S. B. 2000).

Das Gupta *et al.* (2004) have noted strong commonalities among China, northern India, and the Republic of Korea with respect to powerful, patriarchal, lineage-based systems of kinship and inheritance patterns. The Korean case is of great interest because census data suggests that throughout the early 1990s an imbalanced sex ratio in favor of males was even more pronounced in South Korea than in either China or India. This situation apparently came about as a result of a state-sponsored program for population control implemented in the 1960s designed to reduce overall family size. In contrast to China and India, this program was set up during a time of rapid urbanization and relative rise in wealth, accompanied by easy access to ultrasound and a widespread desire for at least one son.

Between 1995 and 2005 a rather dramatic change then took place, bringing about a declining trend in the sex ratio at birth, returning it to what is assumed to be the “natural” range. The figures make it clear that in the latter part of the 1990s sex selection was practiced almost exclusively in connection with second daughters and that by 2005 this practice had essentially ceased altogether (<http://www.nso.go.kr/>). During this time, new laws and policies were implemented so that women could become household heads (a change in part spurred on by a rising divorce rate and a tendency for the courts to award custody of children to women). Educational policies became less discriminatory toward women than they were formerly; gender equality in the work place increased, and use of ultrasound to determine the sex of fetuses was banned. Clearly structural changes, including recognition of the substantial economic contribution of women to households, were central to restoration of the sex ratio imbalance. Policies making indiscriminate use of ultrasound illegal would not alone have had the same effect (OUM Y. R. 2003, WILLIAMS H.: personal communication). Instead of withdrawing investment in a population, as would be the case if eugenic intention were at work, the Korean government selected to invest in a population it perceived to be at risk<sup>(1)</sup>.

The governments of India and China have both actively attempted to bring about similar changes, but thus far are thwarted by their respective checkered histories in connection with population management, national and local, and by a “persistence of the local,” as Veena Das puts it. In certain localities in India deeply embedded discriminatory practices against women of very long standing appear to be particularly entrenched among some families. Most troubling is the increased incidence of sex selection for sons among urbanized middle class families in India, and the documentation

of the persistence of these practices among both Chinese and Indian families after immigration. Today, wealthy Chinese and Indians have the freedom today to travel to clinics in the United States to achieve their desire for boy babies in privacy making use of PGD and thus avoiding abortion. The most famous of these clinics in Las Vegas receives over 140,000 hits a month from China on its inter-net site (CHINA DAILY 2006) and over 12,000 hits per month from India inquiring about PGD (GOKHALE K. 2006). The sperm sorting technique known as Microsort is also gaining popularity. For a cost of \$ 23,000 interested couples can send a semen sample to the United States from anywhere in the world to select for male producing sperm.

### *Conclusions*

In efforts to improve the quality of their populations, coercive intrusion into reproduction on the part of the governments of Britain and the United States in the early part of the 20<sup>th</sup> century was justified by means of an ideology grounded in the late 19<sup>th</sup> century concept of degeneracy. Emulated by other countries, the science of eugenics and its associated practices were thoroughly discredited by the mid 20<sup>th</sup> century, although authoritarian states continue to exist, and there is evidence of the persistence of eugenics in these countries.

Genetic testing and screening technologies have come about in an era in which it is commonly believed that eugenics is dead and gone. However, the majority of the screening programs discussed above rely on state funding, and the sociologist Troy Duster described the early sickle cell screening programs in the United States as a “backdoor to eugenics” (DUSTER T. 1990). As a result of increasing racialization of molecular genetics and the exponential increase in DNA forensics, Duster’s current fears are that genetic discrimination and racial profiling may worsen quite dramatically (2007). This is a worrying development not limited to the United States. As Henry Porter observed when writing in *The Guardian Weekly*, Britain is now in a “crisis of liberty” and well on the way to becoming a police state as a result of remarkable national surveillance practices involving the storage of a massive DNA database for all offenses including minor misdemeanors (PORTER H. 2007). These are early signs of how rapidly expanding, increasingly affordable DNA technologies, including individual genetic profiling, are being inserted into society for daily use. Disability rights activists and others are rightfully concerned that for certain medical conditions the *laissez-faire* conditions under which much genetic testing currently takes place

may gradually shift, similar to emerging DNA forensics, to a more coercive practice with tacit government support, so that once again those lives deemed as burdensome to society may be subject to elimination before birth, or else given little or no financial support after birth, thereby forcing families into impossible positions. To characterize what takes place in the clinic as neo-eugenics is to distract from the social and political import of what may happen in the not too distant future.

Similarly to describe the practice of non-medical sex-selection as neo-eugenics is a disservice, even though it clearly presents a major, very visible problem in India and China. No country, whatever form its governance takes, wishes for or benefits by widespread extermination of female fetuses. Son preference is of long-standing in parts of Asia and elsewhere but, as the discussion above makes clear, this custom has been exacerbated in recent years by government-supported initiatives and policies designed to reduce family size, bring about economic reforms, accompanied by access to ultrasound screening. However, it appears that the outcome of a sex-imbalanced population was not foreseen by the respective governments of India, China, and Korea, bent as they were on modernization and economic development, and Korea alone has been able to redress this situation.

The Indian and Chinese cases make it clear that legislation in favor of women and at the same time against the use of ultrasound for sex selection is not sufficient to depose deeply embedded values of long standing. In the end, such change may be driven by the severe shortage of women in some areas, leaving young men with no one to marry. The problem is magnified by increasing disparities between rich and poor in both India and China, coupled with less social security than was formerly the case – a major side effect of “millennial capitalism” (COMAROFF J. - COMAROFF J. L. 2001) accompanied by a “retreat of the state” in the face of neoliberalism (HARVEY D. 1989) resulting in an increased preference for sons. Practices of sex selection do not for the moment affect national economies or trade imbalances, but they most certainly will do in the not too distant future. It is a matter of speculation as to whether the governments of India and China will be willing to intrude directly into the reproductive lives of families in order to restore a “natural” sex ratio. Recent reports from China make it clear that such interventions are likely to incite rioting and enormous unrest (WATTS J. 2007b). And in India the government must also discipline the medical profession if it is to achieve its goal. But by no means does everyone resort to sex selection, even in those parts of India and China where it is most prevalent, and it may be that gradually the voices and arguments of these people will be more widely disseminated.

In the West, the practice of “family balancing” remains essentially hidden, but choosing a desirable fetus on the basis of its sex alone, whether male or female, is nevertheless a moral problem, one that is possibly more troubling than the situation in India and China. Decisions made in the West are based, we assume, on personal desire alone (a culturally infused sentiment pervasive in contemporary society); such decisions that have few if any significant economic and social ramifications. More than any other kind of medical technology, those that affect reproduction bring to the fore an inherent tension among individual desire, family interests, and what is deemed appropriate for the nation, and indeed the world as a whole. As genetic engineering, including germ-line manipulation, advanced stem-cell technologies, and other innovations become available, these tensions will be exacerbated, particularly when discussion turns to future generations and to what extent we are willing to create our descendents using technological assistance. Debate about these matters should not be reduced to assertions about neo-eugenics and self-indulgent people; it must be contextualized, paying due attention to the long, dreary history of repression of women, and the manipulation of reproduction everywhere for a variety of pragmatic ends.

The looming question is one of governance, and if and how this will be accomplished in an era when matters relating to health are increasingly managed as part of the globalized market. Should genetic manipulations of all kinds, including sex selection, be made a public health matter? A related concern is about the limitations and uncertainties inherent to the technologies and the knowledge associated with them, and if and when practitioners will be obliged to discuss such shortcomings frankly with clients, and how clients will then respond. Increasing public awareness of these matters is one small step in the right direction.

## Notes

- <sup>(1)</sup> I am indebted to Nicholas Harkness for the formulation of this idea.

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