

Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities

Abby Lippman*

This Article considers the influence and implications of the application of genetic technologies to definitions of disease and to the treatment of illness. The concept of "geneticization" is introduced to emphasize the dominant discourse in today's stories of health and disease and the social construction of biological phenomenon is described. The reassurance, choice and control supposedly provided by prenatal genetic testing and screening are critically examined, and their role in constructing the need for such technology is addressed. Using the stories told about prenatal diagnosis as a focus, the consequences of a genetic perspective for and on women and their health care needs are explored.

I. INTRODUCTION

During the past two decades, numerous techniques have been developed that allow geneticists to assess the physical status of the fetus during a woman's pregnancy. The variety of prenatal diagnostic techniques¹ and detectable/diagnosable fetal conditions continues to expand. These screening and testing procedures are already the most widespread application of genetic technology to humans.

This paper, part of an ongoing project, explores the genetic stories² told about health and disease today, the storytellers and the

* Associate Professor, Dep't of Epidemiology & Biostatistics, McGill University. Prenatal diagnosis, the focus of much of this paper, is troublesome for all women, users and critics alike. In no way do I intend my remarks about it to reflect on women who have considered or undergone testing; criticism of the technologies is not to be read as criticisms of them. Women considering childbearing today face agonizing issues I was fortunate enough not to have to confront, and I can only admire their resilience and strength.

¹ See *infra* notes 20-26 and accompanying text for a discussion of these techniques.

² In this Article, the word "stories" is not used to suggest that what is said is not true (this may or may not be the case). Rather it is used in a literary, not a legal, sense to capture the idea that how scientists present their observations and study results is no different from how novelists present *their* interpretations of the external world. "Raw" material is shaped and interpreted to convey a message by both groups, with their constructions reflecting the pre-

circumstances in which these stories are told. In this Article, I first discuss how disease categories and biomedical practices are constructed within their cultural context, and provide some technical information regarding prenatal diagnosis. I then examine the stories constructed about genetic testing and screening; the particular assumptions upon which they are grounded;³ and the necessarily problematic nature of applications of these genetic technologies with respect to perceptions of pregnancy and the health care needs of women considering childbearing. I demonstrate how the approach implicit in the use of genetic technology is as much a cultural and social activity as it is scientific. Specifically, I examine why prenatal diagnosis is made available, discussing some of the rationales usually presented for its use, and explore how a "need" for prenatal diagnosis is currently constructed. I then consider how existing health, health care beliefs and North American social stratifications situate prenatal technologies and how these activities may themselves influence health and health care inequities.

II. HEALTH AND DISEASE AND THE STORIES TOLD ABOUT THEM

In today's western world, biomedical and political systems largely define health and disease, as well as normality and abnormality.⁴ They also determine the individuals to whom each term will be applied. Western biomedicine does not just describe a pre-existing biological reality, but is grounded in particular social and cultural assumptions.⁵

vailing social/cultural context. Further, to the degree that the same story is repeated and becomes accepted and used, it will itself begin to shape this context.

³ I attempt, in this way, to enter "an old text from a new critical direction." A. RICH, *When We Dead Awaken*, in *ON LIES, SECRETS AND SILENCE* 35 (1979). I consider how stories about prenatal diagnosis both reflect and affect the social process of geneticization, how they emerge from existing cultural values at the same time as they interactively influence this very culture, altering our values, redefining our reality. See *infra* notes 101-40 and accompanying text. Using the biomedical and social science literature, and switching analogies, I want to create a "femmage," a "sister concept" to the collage, wherein a composite describing these stories is created from multiple sources. See S. PRICE, *PRIMITIVE ART IN CIVILIZED PLACES* 4 (1989) (quoting Meyer & Shapiro, *Waste Not, Want Not: An Inquiry into What Women Saved and Assembled*, 4 *HERESIES* 66-69 (1978)).

⁴ It should be emphasized that the priority given to matters of health is historically dependent and determined on a local level. These issues may not warrant political, economic or scientific attention in all places or at all times. A malady that is diagnosed and treated as a prevalent disease in one country may be diagnosed and treated completely differently in another country. See generally L. PAYER, *MEDICINE & CULTURE* (1988).

⁵ See *THE PROBLEM OF MEDICAL KNOWLEDGE: EXAMINING THE SOCIAL CONSTRUCTION OF MEDICINE* (P. Wright & A. Treacher eds. 1982) [hereinafter *THE PROBLEM OF MEDICAL KNOWLEDGE*]; M. LOCK & D. GORDON, *Relationship Between Society, Culture, and Biomedicine: Introduction to the Essays*, in *BIOMEDICINE EXAMINED* 11, 11-18 (M. Lock & D. Gordon eds. 1988); Taussig, *Reification and the Consciousness of the Patient*, 14 *SOC. SCI. & MED.* 3, 3 (through reification, "disease is recruited into serving the ideological needs of the social order"); Young, *The Anthropologies of Illness and Sickness*, 2 *ANN. REV. ANTHROPOLOGY* 257 (1982) [hereinafter *The*

No strictly objective and value-free view of the biological world exists. Any attempt to explain or order it will be shaped by the historical and cultural setting within which it occurs.⁶

Although there is a biological reality to disease, biological processes take on particular forms in different human groups and in different periods of time.⁷ Disorders and disabilities are not merely physiological or physical conditions with fixed contours. Rather, they are social products with variable shapes and distributions. Defining and studying these categories and the people assigned to them is necessarily subjective, reflecting how those with power at any particular historical time construct them as problems.

In studying the distribution of health and disease, any one of the factors influencing their occurrence (social and physical environments, economic conditions, heredity, personal behaviors, health services, etc.) may be chosen for attention and investment of resources. This choice and its subsequent expression in public policies and private practices reflect the assumptions, vested interests and ideologies of the investigators and those funding them.⁸ Because "disease is socially mutable" and medical responses are "maleable,"⁹ there is abundant raw material from which to create metaphors and stories describing health and disease. The same observations may be taken as evidence to construct very different hypotheses or stories.¹⁰

Today's stories about health and disease both in professional journals¹¹ and mass circulation magazines¹² are increasingly told in the lan-

Anthropologies of Illness and Sickness]; Young, *When Rational Men Fall Sick: An Inquiry into Some Assumptions Made by Medical Anthropologists*, 5 *CULTURE MED. & PSYCHOLOGY* 317 (1981) [hereinafter *When Rational Men Fall Sick*]; see also Young, *Rational Men and the Explanatory Model Approach*, 6 *CULTURE, MED. & PSYCHOLOGY* 57 (1982) [hereinafter *Rational Man and the Explanatory Model Approach*] (containing Young's replies to comments directed toward *When Rational Men Fall Sick*, *supra*).

⁶ See generally S. TESH, *HIDDEN ARGUMENTS: POLITICAL IDEOLOGY AND DISEASE PREVENTION POLICY* 3 (1988) ("there is an inextricable interrelationship between facts and values, both in the search for the causes of disease and in the process of developing the best preventive policy").

⁷ See Laurell, *Social Analysis of Collective Health in Latin America*, 28 *SOC. SCI. & MED.* 1183 (1989); M. LOCK, *Mind, Matter and Middle Age: Ideologies for the Second Sex*, to be published in *ANALYSIS IN MEDICAL ANTHROPOLOGY* (S. Lindenbaum & M. Lock eds.).

⁸ See Winner, *Is There Any Light Under Our Bushel? Three Modest Proposals for S.T.S.*, 10 *BULL. SCI. TECH. & SOC'Y* 12 (1990).

⁹ Woolhandler & Himmelstein, *Ideology in Medical Science: Class in the Clinic*, 28 *SOC. SCI. & MED.* 1205, 1206 (1989).

¹⁰ See generally H. LONGINO, *SCIENCE AS SOCIAL KNOWLEDGE: VALUES AND OBJECTIVITY IN SCIENTIFIC INQUIRY* (1990).

¹¹ E.g., Chui, Wong & Sriver, *The Thalassemias and Health Care in Canada: A Place for Genetics in Medicine*, 144 *CANADIAN MED. ASS'N J.* 21 (1991); Koshland, *The Rational Approach to the Irrational*, 250 *SCIENCE* 189 (1990); Stead, Senner, Reddick & Lofgren, *Racial Differences in Susceptibility to Infection by Mycobacterium Tuberculosis*, 322 *NEW ENG. J. MED.* 422, 426 (1990); Watson, *The Human Genome Project: Past, Present, and Future*, 248 *SCIENCE* 44 (1990).

guage of genetics. Using the metaphor of blueprints,¹³ with genes and DNA fragments presented as a set of instructions, the dominant discourse describing the human condition is reductionist, emphasizing genetic determination. It promotes scientific control of the body, individualizes health problems and situates individuals increasingly according to their genes. Through this discourse, which is beginning seriously to threaten other narratives, clinical and research geneticists and their colleagues are conditioning how we view, name and propose to manage a whole host of disorders and disabilities. Though it is only one conceptual model, "genetics" is increasingly identified as *the* way to reveal and explain health and disease, normality and abnormality. Baird, for example, sees the "major determinants" of disease as internal genetic factors.¹⁴

This conditioning directs how intellectual and financial resources are applied to resolve health problems.¹⁵ More critically, it profoundly influences our values and attitudes. To capture this process, I use the term "geneticization."¹⁶ Although most neologisms confuse rather

¹² E.g., Alexander, *The Gene Hunt*, TIME, Mar. 20, 1989, at 52; Beers, *The Gene Screen*, VOGUE, June 1990, at 236, 237; Montgomery, *The Ultimate Medicine*, DISCOVER, Mar. 1990, at 60; Schmeck, *Battling the Legacy of Illness*, N.Y. TIMES GOOD HEALTH MAGAZINE, Apr. 28, 1990, at 36.

¹³ See Council for Responsible Genetics, *Position Paper on Genetic Discrimination*, 3 ISSUES REPRODUCTIVE & GENETIC ENGINEERING 287 (1990) (criticizing the "blueprint" notion); Newman, *Idealist Biology*, 31 PERSPECTIVES BIOLOGY & MED. 353, 361 (1988) (DNA is one component of a "complex dynamical system," not a "command center" that is impervious to environmental input); Rose, *Human Perfectability*, 2 LANCET 1380, 1380-81 (1984) (emphasizing the effects of environment on DNA). See generally G. LAKOFF & M. JOHNSON, *METAPHORS WE LIVE BY* (1980).

¹⁴ Baird, *Genetics and Health Care: A Paradigm Shift*, 33 PERSPECTIVES BIOLOGY & MED. 203, 203-04 (1990).

¹⁵ See Lippman, *Genetics and Public Health: Means, Goals and Justices, to be published in* AM. J. HUM. GENETICS (1991) [hereinafter *Genetics and Public Health*]; Lippman, Messing & Mayer, *Is Genome Mapping the Way to Improve Canadians' Health?*, 81 CANADIAN J. PUB. HEALTH 397, 398 (1990) (noting that "undirected" studies of, for instance, "environmental protection against genotoxins or of nutritional supplementation during pregnancy," will suffer financially because funds are going to human genome mapping).

¹⁶ A. Lippman, La "Geneticization" de la Vie (unpublished manuscript presented at Seminaire, Lalonde-les-Maures, France, May, 1990). A few years ago, in an article only recently rediscovered, Edlin described a process he called "geneticizing" to refer to the tendency to label as "genetic" diseases and disorders "of possible polygenic-multifactorial origin" for which there was, in fact, "scant or no genetic evidence." Edlin, *Inappropriate Use of Genetic Terminology in Medical Research: A Public Health Issue*, 31 PERSPECTIVES BIOLOGY & MED. 47, 48 (1987). He argued that geneticizing led to premature categorization of diseases as genetic, and caused research funds to be allocated to genetic research to the detriment of other research. *Id.* at 48. I have deliberately chosen not to resurrect his term, since the processes I want to describe go beyond those that he emphasized. In this regard, too, the concept of geneticization goes beyond Yoxen's discussion of the "construction" of genetic disease. Yoxen, *Constructing Genetic Diseases*, in *THE PROBLEM OF MEDICAL KNOWLEDGE*, *supra* note 5, at 144. Apparently, the term "geneticism" was used even earlier in an essay by Sir Peter Medawar also to describe the inappropriate genetic labeling of variations between peo-

than clarify, enlarging our lexicon to interpret human genetics is appropriate. A new canon deserves a new vocabulary.

Geneticization refers to an ongoing process by which differences between individuals are reduced to their DNA codes, with most disorders, behaviors and physiological variations defined, at least in part, as genetic in origin. It refers as well to the process by which interventions employing genetic technologies are adopted to manage problems of health. Through this process, human biology is incorrectly equated with human genetics,¹⁷ implying that the latter acts alone to make us each the organism she or he is.

Duster captures much of this in describing how prevailing social concerns of our age are leading us to see things through a genetic "prism."¹⁸ "Geneticization" goes further, however, and poses genetics as the source of illumination itself, not merely one of the ways in which it might be refracted.

Prenatal diagnosis, already designated as a "ritual" of pregnancy, at least for white, middle-class women in North America, is the most widespread application of genetic technology to humans today.¹⁹ It provides a central activity around which to explore geneticization and the health stories told in its language.

III. PRENATAL DIAGNOSIS: A TECHNICAL AND A SOCIAL CONSTRUCTION

Of all applied genetic activities, prenatal diagnosis is probably most familiar to the general population and is also the most used. Prenatal diagnosis refers to all the technologies currently in use or under development to determine the physi(ologi)cal condition of a fetus

ple. Medawar, *The Genetic Improvements of Man*, 18 AUSTRALASIAN ANNALS MED. 317, 319 (1969).

¹⁷ See R. HUBBARD, *THE POLITICS OF WOMEN'S BIOLOGY* 52 (1990) (noting that in a less individualized society than ours, people might find many aspects of biology "more interesting than heredity, genes and . . . DNA"); Murphy, *The Logic of Medicine*, 66 AM. J. MED. 907, 908 (1979) (warning against a "narrow concern with single genes" that "destroys our vision of the human organism").

¹⁸ T. DUSTER, *BACKDOOR TO EUGENICS* 2 (1990). Duster defines the "prism of heritability" as a "way of perceiving traits and behaviors that attributes the major explanatory power to biological inheritance." *Id.* at 164. In this definition, he is very close to Edlin's "geneticizing." See *supra* note 16. However, only when Duster notes, but without detailed development of the theme, that labels will determine how we choose to respond to a problem, does he begin to incorporate all that I place under the rubric of geneticization. The concept of geneticization explicitly makes this an essential part of the process.

¹⁹ Rapp, *The Power of "Positive" Diagnosis: Medical and Maternal Discourses on Amniocentesis*, in *CHILDBIRTH IN AMERICA: ANTHROPOLOGICAL PERSPECTIVES* 103, 105 (K. Michaelson ed. 1988) [hereinafter *CHILDBIRTH IN AMERICA*]. See generally R. BLATT, *PRENATAL TESTS: WHAT THEY ARE, THEIR BENEFITS AND RISKS, AND HOW TO DECIDE WHETHER TO HAVE THEM OR NOT* (1988).

before birth. Until recently, prenatal diagnosis usually meant amniocentesis,²⁰ a second trimester procedure routinely available for women over a certain age (usually thirty-five years in North America),²¹ for Down syndrome detection. Amniocentesis is also used in selected circumstances where the identification of specific fetal genetic disorders is possible.²² Now, in addition to amniocentesis, there are chorionic villus sampling (CVS)²³ tests that screen maternal blood samples to detect a fetus with a neural tube defect or Down syndrome, and ultrasound screening.²⁴ Despite professional guidelines to the contrary,²⁵

²⁰ In amniocentesis, a hollow needle is inserted through a woman's abdomen and into the amniotic sac in order to remove a small sample of the fluid that surrounds the developing fetus. The procedure is usually preceded by an ultrasound examination to document the age of the fetus and its location so that an appropriate site for insertion of the amniocentesis needle can be chosen. The fluid that is removed — amniotic fluid — contains cells from the fetus that, if allowed to divide in the laboratory, can then be analyzed. In particular, one can count the number of chromosomes in the cells, determine fetal sex and carry out biochemical and specific genetic analyses on these cells. Amniocentesis is performed at about sixteen to twenty weeks' gestation, the second trimester of pregnancy: before this time not enough fluid or enough cells are available. Once a fluid sample has been obtained, there is a further three to four week wait for the analyses to be completed and results to be available, since it takes this long to grow a sufficient number of cells for study. Thus, if a fetus is found to be affected with the condition for which testing was done and the woman chooses to abort the pregnancy, the abortion is not induced until about the twentieth week, which is halfway through the pregnancy. See E. NIGHTINGALE & M. GOODMAN, *BEFORE BIRTH: PRENATAL TESTING FOR GENETIC DISEASE* 32-35 (1990) [hereinafter *BEFORE BIRTH*]. Recent technical developments that allow diagnoses to be made following amplification of the genetic material in a single cell can shorten considerably the time needed to obtain results. See *infra* note 23 and accompanying text.

²¹ See *infra* note 67 and accompanying text for a discussion of the social, rather than biological, bases for categorizing women over 35 as "at risk."

²² Over 150 "single gene" disorders can now be detected, and testing may be carried out for women who have a documented family history of one of these or who are otherwise known to be at increased risk. Testing is not carried out for these disorders without specific indications. See generally Antonarakis, *Diagnosis of Genetic Disorders at the DNA Level*, 320 NEW ENG. J. MED. 153 (1989) (reviewing recent progress in identifying single gene disorders).

²³ In chorionic villus sampling (CVS), a small tube (catheter) is inserted through the vagina and cervix. It is then advanced, under ultrasound guidance, until it reaches the placenta, from which a small amount of tissue (chorionic villi) is removed. Some obstetricians now obtain a sample through a needle inserted into the abdomen instead. Any chromosomal or biochemical disorder can, in theory, be diagnosed with tissues obtained by CVS, because the cells of the fetus and placenta (which are formed from chorionic villi) are genetically the same. See Vekemans & Perry, *Cytogenic Analysis of Chorionic Villi: A Technical Assessment*, 72 HUM. GENETICS 307 (1986). This procedure was first used successfully in China as early as 1975 to determine fetal sex. Tietung Hosp. Dep't of Obstetrics & Gynecology, *Fetal Sex Prediction by Sex Chromatin of Chorionic Villi Cells During Early Pregnancy*, 1 CHINESE MED. J. 117 (1975). CVS can be done as early as eight or nine weeks after a woman's last menstrual period and, while the results of tests carried out on the placental tissue can be available within hours, a two or three day waiting period is usually required. See *BEFORE BIRTH*, *supra* note 20, at 35-36. If a woman chooses to abort the pregnancy following CVS, the abortion can be carried out in the first trimester. Finally, CVS does not appear more likely to cause a spontaneous abortion than amniocentesis. Canadian Collaborative CVS - Amniocentesis Clinical Trial Group, *Multicentre Randomised Clinical Trial of Chorion Villus Sampling and Amniocentesis*, 1 LANCET 1, 4 (1989).

²⁴ During an ultrasound examination, high frequency sound waves are projected into the

ultrasound screening is performed routinely in North America on almost every pregnant woman appearing for prenatal care early enough in pregnancy. And although ultrasound is not usually labeled as "prenatal diagnosis," it not only belongs under this rubric but was, I suggest, the first form of prenatal diagnosis for which informed consent is not obtained.²⁶

Expansion of prenatal diagnosis techniques, ever widening lists of identifiable conditions and susceptibilities, changes in the timing of testing and the populations in which testing is occurring, and expanding professional definitions of what should be diagnosed *in utero*, attest to this technology's role in the process of geneticization.²⁷ But these operational characteristics alone circumscribe only some aspects of prenatal diagnosis. Prenatal diagnosis as a social activity is becoming

uterus; the sound waves that are reflected back are resolved visually to allow one to "see" the fetus on a television-like display screen. A. OAKLEY, *THE CAPTURED WOMB: A HISTORY OF THE MEDICAL CARE OF PREGNANT WOMEN* 155-68 (1984).

²⁵ See *BEFORE BIRTH*, *supra* note 20, at 31-32. A consensus development conference in the United States recently recommended reserving the use of ultrasound for pregnancies that may require it for specific medical reasons. PUB. HEALTH SERV., U.S. DEP'T OF HEALTH & HUM. SERVS., *CONSENSUS DEVELOPMENT CONFERENCE: DIAGNOSTIC ULTRASOUND IMAGING IN PREGNANCY* 11 (National Inst. of Health Publication No. 667, 1984). This recommendation is clearly not being followed and, at present, in many major North American teaching hospitals, almost all pregnant women are referred for two "routine" ultrasound examinations — one before the twentieth week and one in the third trimester — for purposes of dating the pregnancy, even though the benefits of such a policy have not been established. Even more frequent scans are considered routine in France. As a specific tool for prenatal diagnosis, ultrasound can be used to identify certain malformations such as neural tube defects, cleft lip, or limb shortening in fetuses known to be at risk for one of these abnormalities. It can also be used to identify fetal sex. Most subtle malformations will not be identified when ultrasound is applied routinely on a non-diagnostic basis, however; the detailed examination that would be necessary requires more than the time that is usually allowed (or the machinery that is employed) when the primary goal is pregnancy dating. Nevertheless, some fetal problems can be diagnosed and their recognition may influence subsequent decisions about how pregnancy is managed.

²⁶ See Chervenak, McCullough & Chervenak, *Prenatal Informed Consent for Sonogram*, 161 AM. J. OBSTETRICS & GYNECOLOGY 857, 860 (1989); Lippman, *Access to Prenatal Screening: Who Decides?*, 1 CANADIAN J. WOMEN L. 434 (1986) [hereinafter *Who Decides?*]. Chervenak and colleagues have recently called attention to the issue of informed consent for ultrasound, but their conclusions are troublesome. They consider the pregnant woman "the patient's fiduciary," the "patient" to them being the fetus. Chervenak, McCullough & Chervenak, *supra*, at 858. This suggests that the consent process they propose will be coercive.

It is also worth noting that ultrasound is no longer the only genetic technology applied without prior consent. Screening for carriers of hemoglobin disorders, for example, is also done unbeknownst to the individuals being tested in certain jurisdictions. See Rowley, Loader, Sutra & Walden, *Do Pregnant Women Benefit from Hemoglobinopathy Carrier Detection?*, 565 ANNALS N.Y. ACADEMY SCIENCES 152, 153 (1989) [hereinafter Rowley]. These authors noted that consent for sickle cell and other hemoglobinopathies was not obtained because: "Consent for screening was not routinely sought; providers agreed that obtaining timely informed consent required counseling approaching that to be provided to identified carriers and many providers declined to participate if they had to obtain it." Rowley, *supra*, at 153.

²⁷ See generally *Who Decides?*, *supra* note 26, at 434.

an element in our culture and this aspect, which has had minimal attention, will be examined in depth.

A. PRENATAL DIAGNOSIS AND THE DISCOURSE OF REASSURANCE

Contemporary stories about prenatal diagnosis contain several themes, but these generally reflect either of two somewhat different models.²⁸ In the "public health" model, prenatal diagnosis is presented as a way to reduce the frequency of selected birth defects.²⁹ In the other, which I will call the "reproductive autonomy" model, prenatal diagnosis is presented as a means of giving women information to expand their reproductive choices.³⁰ Unfortunately, neither model fully captures the essence of prenatal diagnosis. In addition, neither acknowledges the internal tension, revealed in the coexistence of quite contradictory constructions of testing that may be equally valid: 1) as an assembly line approach to the products of conception, separating out those products we wish to develop from those we wish to discontinue;³¹ 2) as a way to give women control over their pregnancies, respecting (increasing) their autonomy to choose the kinds of children they will bear;³² or 3) as a means of reassuring women that enhances their experience of pregnancy.³³

The dominant theme throughout the biomedical literature, as well as some feminist commentary, emphasizes the last two of these constructions.³⁴ A major variation on this theme suggests, further, that

²⁸ *Id.*

²⁹ See, e.g., Kolker, *Advances in Prenatal Diagnosis: Social-psychological and Policy Issues*, 5 INT'L J. TECH. ASSESSMENT HEALTH CARE 601 (1989); see also Dalgaard & Norby, *Autosomal Dominant Polycystic Kidney Disease in the 1980s*, 36 CLINICAL GENETICS 320, 324 (1989) (placing importance on "selective reproduction prevention").

³⁰ See PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICAL AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS: THE ETHICAL, SOCIAL, AND LEGAL IMPLICATIONS OF GENETIC SCREENING, COUNSELING, AND EDUCATION PROGRAMS 55 (1983) [hereinafter PRESIDENT'S COMM'N] ("In sum, the fundamental value of genetic screening and counseling is their ability to enhance the opportunities for the individual to obtain information about their personal health and childbearing risks and to make autonomous and noncoerced choices based on that information.").

³¹ See B. ROTHMAN, *RECREATING MOTHERHOOD: IDEOLOGY AND TECHNOLOGY IN A PATRIARCHAL SOCIETY* 21 (1989) (describing the "commodification of life, towards treating people and parts of people . . . as commodities We work hard, some of us, at making the perfect product, what one of the doctors in the childbirth movement calls a 'blue ribbon baby.'"). See also Ewing, *Australian Perspectives on Embryo Experimentation: An Update*, 3 ISSUES REPRODUCTIVE & GENETIC ENGINEERING 119 (1990); Rothman, *The Decision to Have or Not to Have Amniocentesis for Prenatal Diagnosis*, in *CHILDBIRTH IN AMERICA*, *supra* note 19, at 92, 92-98.

³² See Hill, *Your Morality or Mine? An Inquiry into the Ethics of Human Reproduction*, 154 AM. J. OBSTETRICS & GYNECOLOGY 1173, 1178-80 (1986).

³³ See generally ROYAL COLLEGE OF PHYSICIANS OF LONDON, *PRENATAL DIAGNOSIS AND GENETIC SCREENING: COMMUNITY AND SERVICE IMPLICATIONS* (1989).

³⁴ See, e.g., WOMEN'S RIGHTS LITIGATION CLINIC, *REPRODUCTIVE LAWS FOR THE 1990S: A BRIEFING HANDBOOK* (1987); *Who Decides?*, *supra* note 26, at 438.

through the use of prenatal diagnosis women can avoid the family distress and suffering associated with the unpredicted birth of babies with genetic disorders or congenital malformations, thus preventing disability while enhancing the experience of pregnancy.³⁵ Not unlike the approach used to justify caesarean sections,³⁶ prenatal diagnosis is constructed as a way of avoiding "disaster."

The language of control, choice and reassurance certainly makes prenatal diagnosis appear attractive. But while this discourse may be successful as a marketing strategy,³⁷ it relates a limited and highly selected story about prenatal diagnosis. Notwithstanding that even the most critical would probably agree prenatal diagnosis *can be* selectively reassuring³⁸ (for the vast majority of women who will learn that the fetus does not have Down syndrome or some other serious diagnosable disorder), this story alone is too simplistic. It does not take account of why reassurance is sought, how risk groups are generated and how eligibility for obtaining this kind of reassurance is determined. Whatever else, prenatal diagnosis is a means of separating fetuses we wish to develop from those we wish to discontinue. Prenatal diagnosis does approach children as consumer objects subject to quality control.

This is implicit in the general assumption that induced abortion will follow the diagnosis of fetal abnormality.³⁹ This assumption is reinforced by the rapid acceptance of CVS, which allows prenatal diagnosis to be carried out earlier and earlier in pregnancy when termination of a fetus found to be "affected" is taken for granted as less problematic.⁴⁰ The generally unquestioned assumption that pre-implantation diagno-

³⁵ McDonough, *Congenital Disability and Medical Research: The Development of Amniocentesis*, 16 WOMEN & HEALTH 137, 143-44 (1990). McDonough notes that three rationales for amniocentesis emerged from her survey: "The procedure offered those at risk the possibility of 'health' . . . [it] provided parents with reassurance and avoided abortion . . . [and it] prevent[ed] disease and disability." *Id.*

³⁶ See, e.g., McClain, *Perceived Risk and Choice of Childbirth Service*, 17 SOC. SCI. & MED. 1857, 1862 (1983).

³⁷ There is no evidence that control, autonomy and reassurance are actually enhanced and not merely assumed to occur. In fact, there have been very few in-depth studies in this area, and the conclusions of these investigations seem to vary with the orientation of the investigator. Studies reported in the social science and feminist literature suggest that prenatal diagnosis removes control; studies reported in the biomedical literature are interpreted to show how reassurance is provided. For an overview of these studies, see Lippman, *Research Studies in Applied Human Genetics: A Quantitative Analysis and Critical Review of Recent (Biomedical) Literature*, to be published in AM. J. MED. GENETICS (1991). Much more ethnographic work in this area is required.

³⁸ See *infra* text accompanying notes 48-51 for a reconstruction of the notion of reassurance.

³⁹ See *supra* notes 31-32 and accompanying text.

⁴⁰ This issue is discussed in A. Lippman, *Led Astray by Genetic Maps* (speech given, Ottawa, Canada, 1991). Treatment, often said to be a goal of early identification of affected fetuses, becomes even less likely with CVS. Pharmaceutical companies will not be motivated

sis is better than prenatal diagnosis also undermines a monotonic reassurance rhetoric.⁴¹ With pre-implantation (embryo) diagnosis, the selection objective is clear: only those embryos thought to be "normal" will be transferred and allowed to continue to develop.⁴² Thus, embryo destruction is equated with induced abortion.⁴³ In perhaps the most blatant example, Brambati and colleagues have proposed the combined use of *in vitro* fertilization, gamete intrafallopian transfer, chorionic villus sampling and fetal reduction to "avoid pregnancy termination among high risk couples" [sic], and have stated that the "fetus was reduced" when describing a situation in which this scenario actually occurred.⁴⁴

Thus, while no single storyline is inherently true or false, the reassurance discourse appears to mask essential features of genetic testing and screening that are troubling. Reassurance — for pregnant women or for geneticists⁴⁵ — notwithstanding, the story is more complex. Prenatal diagnosis necessarily involves systematic and systemic selection of fetuses, most frequently on genetic grounds.⁴⁶ Though the word

to invest in developing treatments for conditions that "need not occur." Rarely will they base business decisions on their social worth rather than on their financial value.

This situation contains elements of an unusual conflict. Increasingly, geneticists are promising to have treatments available for a wide range of disorders and, for some conditions, therapeutic developments have occurred which make them far more benign than previously. The promises, and the available examples, are likely to be sufficiently persuasive that women "at-risk" may either make use of prenatal diagnosis less frequently or see less reason to abort an affected fetus than today. Yet, at the same time, the very availability of prenatal diagnosis and abortion may be seen as justifications for *not* investing in the further development of these therapies that parents will have been led to expect. Cf. Varekamp, Suurmeijer, Bröcker-Vriends, Van Dijk, Smit, Rosendaal & Briët, *Carrier Testing and Prenatal Diagnosis for Hemophilia: Experiences and Attitudes of 549 Potential and Obligate Carriers*, 37 AM. J. MED. GENETICS 147, 153 (1990) [hereinafter Varekamp] (noting decrease in hemophilia screening as treatment capabilities increased).

⁴¹ See Bell, *Prenatal Diagnosis: Current Status and Future Trends*, in HUMAN GENETIC INFORMATION: SCIENCE, LAW & ETHICS 18-36 (Ciba Foundation Series 1990). See also Kolker, *supra* note 29, at 612 (prevention is "clearly cheaper than providing services for those with genetic disorders"); Modell, *Cystic Fibrosis Screening and Community Genetics*, 27 J. MED. GEN. 475, 476 (1990) ("undesirable [diseases] may be all but eradicated"); Dalgard & Norby, *supra* note 29, at 323-24 ("access to selective reproductive prevention" is important).

⁴² S. WYMELLENBERG, *SCIENCE AND BABIES: PRIVATE DECISIONS, PUBLIC DILEMMAS* 130 (1990).

⁴³ In fact, some consider the combined procedures of *in vitro* fertilization and embryo diagnosis to be "ethically better" than prenatal diagnosis for detecting problems because it "avoids" abortion. See Michael & Buckle, *Screening for Genetic Disorders: Therapeutic Abortion and IVF*, 16 J. MED. ETHICS 43 (1990). But see J. TESTART, *LE MONDE DIPLOMATIQUE* 24 (1990) (suggesting that it is the very need to consider abortion ("de terribles responsabilités") that is perhaps the best safeguard against ordinary eugenics ("l'eugenisme ordinaire")).

⁴⁴ Brambati, Formigli, Tului & Simoni, *Selective Reduction of Quadruplet Pregnancy at Risk of B-Thalassemia*, 336 LANCET 1325, 1326 (1990).

⁴⁵ If nothing else, it is certainly preferable for their public image if geneticists are seen as reassuring women, rather than selecting their offspring.

⁴⁶ Much of importance has been written about the link between prenatal diagnosis and

"eugenics" is scrupulously avoided in most biomedical reports about prenatal diagnosis, except when it is strongly disclaimed as a motive for intervention, this is disingenuous.⁴⁷ Prenatal diagnosis presupposes that certain fetal conditions are intrinsically not bearable. Increasing diagnostic capability means that such conditions, as well as a host of variations that can be detected *in utero*, are proliferating, necessarily broadening the range of what is not "bearable" and restricting concepts of what is "normal." It is, perhaps, not unreasonable to ask if the "imperfect" will become anything we can diagnose.⁴⁸

While the notion of reassurance has been successfully employed to justify prenatal testing and screening as responses to the problems of childhood disability, we need to question both the sufficiency and the necessity of its linkage to prenatal diagnosis. At best, reassurance is an acquired, not an inherent, characteristic of prenatal diagnosis. Even if testing provides "reassurance," it is of a particular and limited kind. For example, although the fetus can be shown not to have Down syndrome, most disabilities only manifest themselves after birth. Further, it is not the (only) way to achieve a global objective of "reassuring" pregnant women. Indeed, it may even be counterproductive. This becomes clear if one reconstructs the notion of reassurance. Assuming it is an acceptable objective of prenatal care, are there ways to reassure pregnant women desiring "healthy" children that do not lead to genetic testing and control?

Data from the United States Women, Infants and Children program leave little doubt that "low technology" approaches providing essential nutritional, social and other supportive services to pregnant women will reduce the low birth weight and prematurity responsible for most infant mortality and morbidity today.⁴⁹ Providing an adequate diet to the unacceptably large number of pregnant women living below the poverty line would clearly "reassure" them that their babies were developing as well as the babies of wealthier women. Similarly, alloca-

eugenics; this dialogue, despite its importance, will not be repeated here. See generally T. DUSTER, *supra* note 18; R. HUBBARD, *supra* note 17; Degener, *Female Self-determination Between Feminist Claims and "Voluntary" Eugenics, Between "Rights" and Ethics*, 3 ISSUES REPRODUCTIVE & GENETIC ENGINEERING 87 (1990); Hubbard, *Eugenics: New Tools, Old Ideas*, 13 WOMEN & HEALTH 225 (1987).

⁴⁷ This point is not merely an argument of critics of prenatal diagnosis. Shaw, a geneticist-lawyer who strongly defends the principle of fetal protection, has written that "any counselor who explains reproductive alternatives and offers a prenatal test to a counselee is a practicing eugenicist and any couple who chooses to avoid having babies with chromosome abnormalities or deleterious mutant genes is also practicing eugenics." Shaw, *Letter to the Editor: Response to Hayden: Presymptomatic and Prenatal Testing*, 28 AM. J. MED. GENETICS 765, 765-66 (1987).

⁴⁸ Rothschild, *Engineering Birth: Toward the Perfectability of Man?*, in 2 SCIENCE, TECHNOLOGY AND SOCIAL PROGRESS 93 (S. Goldman ed. 1989).

⁴⁹ See Anon, *WIC Program Shows Major Benefits*, NATION'S HEALTH, Dec. 1990, at 3.

tion of funds for home visitors, respite care and domestic alterations would "reassure" women that the resources required to help them manage their special needs were readily available without financial cost, should their child be born with a health problem. It would also be "reassuring" to know that effective medication and simplified treatment regimes were available or being developed for prevalent disorders. Reassurances such as these may be all that many pregnant women want. Not only would these alternative approaches provide "reassurance" with respect to (and *for*) fetal disability, they would diminish a woman's feeling of personal responsibility for a child's health, rather than "exacerbate" it as does prenatal diagnosis.⁵⁰

Genes may contribute to the distribution of low birth weight and prematurity in North America, and likely some investigators will seek their location and the order of their DNA base sequences on the human gene map. The social and economic inequalities among women with which they are associated,⁵¹ however, are already well "mapped"; the "location" of women who are at increased risk is well known; the "sequences" of events leading to excessively and unnecessarily high rates of these problems have been well described. From this perspective, *gene* mapping and sequencing may be irrelevant as a source of reassurance in view of the most pressing needs of pregnant women. Even if genes were shown to be related to these problems, it must be remembered that the individuals to whom reassurance will be provided, as well as the concerns chosen for alleviation, rest on social, political and economic decisions by those in power. Such choices require continued analysis and challenge.

B. CONSTRUCTING THE "NEED" FOR PRENATAL DIAGNOSIS

While reassurance has been constructed to justify health professionals' offers of prenatal diagnosis, genetic testing and screening have also been presented in the same biomedical literature as responses to the "needs" of pregnant women. They are seen as something they "choose." What does it mean, however, to "need" prenatal diagnosis, to "choose" to be tested?⁵² Once again, a closer look at what appear to

⁵⁰ See Farrant, *Who's for Amniocentesis? The Politics of Prenatal Screening*, in *THE SEXUAL POLITICS OF REPRODUCTION* 96, 120 (H. Homans ed. 1985) [hereinafter *THE SEXUAL POLITICS OF REPRODUCTION*].

⁵¹ See Yankauer, *What Infant Mortality Tells Us*, 80 AM. J. PUB. HEALTH 653 (1990).

⁵² While those in need are identified explicitly as (certain) pregnant women, it is worth noting that clinical geneticists, themselves, have a need for this technology, too. For instance, when a child is born with a malformation, geneticists likely feel most "helpful" when prenatal diagnosis, a technological palliative for the pains of etiologic ignorance, can be offered. Saying that the malformation is not likely to happen again, given the usually low empiric recurrence risks associated with most of these problems, is not nearly as comforting for genetic counselors as is offering *in utero* detection. Counselors "need" this technique for the satisfac-

be obvious terms may illuminate some otherwise hidden aspects of geneticization and the prenatal diagnosis stories told in its voice.

We must first identify the concept of need as itself a problem and acknowledge that needs do not have intrinsic reality. Rather, needs are socially constructed and culture bound, grounded in current history, dependent on context and, therefore, not universal.

With respect to prenatal diagnosis, "need" seems to have been conceptualized predominantly in terms of changes in capabilities for fetal diagnoses: women only come to "need" prenatal diagnosis after the test for some disorder has been developed. Moreover, the disorders to be sought are chosen exclusively by geneticists.⁵³ In addition, posing a "need" for testing to reduce the probability a woman will give birth to a child with some detectable characteristic rests on assumptions about the value of information, about which characteristics are or are not of value and about which risks should or should not be taken. These assumptions reflect almost exclusively a white, middle-class perspective.⁵⁴

This conceptualization of need is propelled by several features of contemporary childbearing.⁵⁵ First, given North American culture, where major responsibility for family health care in general, for the fetus she carries and for the child she births, is still allocated to a woman,⁵⁶ it is generally assumed that she must do all that is

tory performance of their jobs no less than they believe a family "needs" prenatal diagnosis to prevent the birth of a second affected child.

⁵³ See Lippman, *Prenatal Diagnosis: Reproductive Choice? Reproductive Control?*, [hereinafter *Reproductive Choice?*] in *THE FUTURE OF HUMAN REPRODUCTION* 182, 187 (C. Overall ed. 1989) [hereinafter *THE FUTURE OF HUMAN REPRODUCTION*] (consideration of prenatal diagnosis as a professional resource).

⁵⁴ See Nsiah-Jefferson, *Reproductive Laws, Women of Color and Low Income Women in REPRODUCTIVE LAWS FOR THE 1990s* 17, 17-58 (S. Cohen & N. Taub eds. 1988) [hereinafter *REPRODUCTIVE LAWS FOR THE 1990s*] (discussing potential areas of cultural conflict in genetic counseling).

⁵⁵ There is an extensive literature on "medicalization" in general and on the medicalization of pregnancy and childbirth *per se* in which this discussion is rooted and from which it derives guidance. See, e.g., A. OAKLEY, *supra* note 24, at 275. ("The medicalization of everyday life is a phenomenon described in many radical and liberal critiques of medicine."); *id.* at 276 ("For both birth and death normal signs have become neon lights flagging risks which demand and validate medical intervention."); Raymond, *Feminist Ethics, Ecology, and Vision*, in *TEST-TUBE WOMEN* 427, 427-37 (R. Arditti, R. Klein & S. Minden eds. 1984) [hereinafter *TEST-TUBE WOMEN*]; I. ZOLA, *Healthism and Disabling Medicalization*, in I. ILLICH, I. ZOLA, J. MCKNIGHT, J. CAPLAN & H. SHAIKEN, *DISABLING PROFESSIONS* 41 (1977); Zola, *In the Name of Health and Illness: On Some Socio-Political Consequences of Medical Influence*, 9 *SOC. SCI. & MED.* 83, 85-87 (1975) (noting that control by medical value not achieved through political means but by "medicalization"); Zola, *Medicine as an Institution of Social Control*, 20 *SOCIOLOGY REV.* 487 (1972); see also Lewin, *By Design: Reproductive Strategies and the Meaning of Motherhood*, in *SEXUAL POLITICS OF REPRODUCTION*, *supra* note 50, at 123, 123-38 (1985) (women "must adapt" to "motherhood" but can also approach it as "active strategists").

⁵⁶ See Oakley, *Smoking in Pregnancy: Smokescreen or Risk Factor? Towards a Materialist Analysis*, 11 *SOCIOLOGY HEALTH & ILLNESS* 311 (1989).

recommended or available to foster her child's health. At its extreme, this represents the pregnant woman as obligated to produce a healthy child. Prenatal diagnosis, as it is usually presented, falls into this category of behaviors recommended to pregnant women who would exercise their responsibilities as caregivers.⁵⁷ Consequently, to the extent that she is expected generally to do everything possible for the fetus/child, a woman may come to "need" prenatal diagnosis, and take testing for granted. Moreover, since an expert usually offers testing, and careseekers are habituated to follow through with tests ordered by physicians,⁵⁸ it is hardly surprising that they will perceive a need to be tested.⁵⁹ With prenatal diagnosis presented as a "way to avoid birth defects," to refuse testing, or perceive no need for it, becomes more difficult than to proceed with it.⁶⁰ This technology perversely creates a burden of not doing enough, a burden incurred when the technology is not used.⁶¹

A second feature, related to the first, is that women generally, and

⁵⁷ See Farrant, *supra* note 50, at 96; Oakley, *supra* note 56, at 311.

⁵⁸ See R. HATCHER & H. THOMPSON, SATISFACTION WITH OBSTETRICAL CARE AMONG CANADIAN WOMEN (Health Servs. Res. Unit, Department of Community Health, Queen's Univ., Kingston, Ontario 1987) (results of a survey showing pregnant women's reluctance to question medical authority).

⁵⁹ See Lippman, *supra* note 53, at 182. Physicians may pressure women into being tested, even using false information to do so. Marteau, Kidd, Cook, Michie, Johnston, Slack & Shaw, *Perceived Risk not Actual Risk Predicts Uptake of Amniocentesis*, 96 BRIT. J. OBSTETRICS & GYNAECOLOGY 739 (1989).

⁶⁰ See Hubbard & Henifin, *Genetic Screening of Prospective Parents and of Workers: Some Scientific and Social Issues*, 15 INT'L J. HEALTH SERVS. 231 (1985); Rothman, *The Meaning of Choice in Reproductive Technology*, in TEST-TUBE WOMEN, *supra* note 55, at 23. I have previously discussed the "burden" of decisionmaking in the context of genetic counseling and a similar "burden" would seem to exist here. See Lippman-Hand & Fraser, *Genetic Counseling I: Parents' Perceptions of Uncertainty*, 4 AM. J. MED. GENETICS 51, 58-63 (1979) [hereinafter *Genetic Counseling I*]; Lippman-Hand & Fraser, *Genetic Counseling II: Making Reproductive Choices*, 4 AM. J. MED. GENETICS 73 (1978) [hereinafter *Genetic Counseling II*]. This theme is present in contemporary literature as demonstrated by Goldstein's reference to the "momentous decision" that childbearing now involves. R. GOLDSTEIN, *THE MIND-BODY PROBLEM* 200 (1983).

Hubbard and Henifin, in fact, identify a "new Catch-22" wherein participating in a genetic screening program may lead to a person's being identified as a "genetic deviant," but failure to participate (or to abort a fetus diagnosed with a disorder *in utero*) may lead to her being labeled as a "social deviant." Hubbard & Henifin, *supra*, at 231-48.

⁶¹ The degree of this burden is demonstrated by the frequency with which women queried about their reasons for having prenatal diagnosis say that they "had no choice." Sjögren & Uddenberg, *Decision Making During the Prenatal Diagnostic Procedure*, 8 PRENATAL DIAGNOSIS 263 (1988). See Kirejczyk, *A Question of Meaning? Controversies About the NRT's in the Netherlands*, 3 ISSUES REPRODUCTIVE & GENETIC ENGINEERING 23 (1990) (individuals often accept a medical technique because of fear that they might later regret not having done so); see also A. FINGER, *PAST DUE: A STORY OF DISABILITY, PREGNANCY AND BIRTH* (1990); Beck-Gernsheim, *From the Pill to Test-Tube Babies: New Options, New Pressures in Reproductive Behavior*, in HEALING TECHNOLOGY: FEMINIST PERSPECTIVES 23 (1988) [hereinafter *HEALING TECHNOLOGY*]; Rapp, *Moral Pioneers: Women, Men and Fetuses in a Frontier of Reproductive Technology*, 13 WOMEN & HEALTH 101 (1987).

pregnant women specifically, are bombarded with behavioral directives⁶² that are at least as likely to foster a sense of incompetence as to nourish a feeling of control.⁶³ It is therefore not surprising that a search for proof of competence is translated into a "need" for testing; external verification takes precedence over the pregnant woman's sense of herself. Evidence that the fetus is developing as expected may provide some women with a sense that all is under control (although this suggestion has not been studied empirically to the best of my understanding). Personal experience is set aside in favor of external and measured evidence.⁶⁴ Moreover, given that a pregnant woman is more and more frequently reduced to a "uterine environment,"⁶⁵ and looked upon as herself presenting dangers to the fetus (especially if she eats improperly, smokes, drinks alcoholic beverages, takes medications, etc.), being tested becomes an early warning system to identify whether this "environment" is adequate. Women who share these suspicions and doubt that they can have a healthy baby without professional aid are likely to subject themselves to tests that are offered.⁶⁶

Third, prenatal diagnosis will necessarily be perceived as a "need" in a context, such as ours, that automatically labels pregnant women thirty-five years and over a "high risk" group.⁶⁷ Although this risk la-

⁶² B. ROTHMAN, *supra* note 31, at 92-97. Women are expected to behave in accordance with norms set up by those in power. See Rodgers, *Pregnancy as Justifications for Loss of Judicial Autonomy*, in *THE FUTURE OF HUMAN REPRODUCTION*, *supra* note 53, at 174.

⁶³ See, e.g., Fleischer, *Ready for Any Sacrifice? Women in IVF Programmes*, 3 *ISSUES REPRODUCTIVE & GENETIC ENGINEERING* 1 (1990) (referring to a "code of good conduct" pregnant women ought to follow); see also M. DE KONINCK & F. SAILLANT, *ESSAI SUR LA SANTÉ DES FEMMES* (Conseil du Statut de la femme 1981); A. QUÉNIART, *LE CORPS PARADOXAL: REGARDS DE FEMMES SUR LA MATERNITÉ* (1988); Simkin, *Childbearing in Social Context*, 15 *WOMEN & HEALTH* 5 (1989) (all discussing the ideology of risk and behavioral expectations in pregnancy).

⁶⁴ See B. ROTHMAN, *supra* note 31, at 92; Leuzinger & Rambert, "I Can Feel It — My Baby Is Healthy," *Women's Experiences with Prenatal Diagnosis in Switzerland*, 1 *ISSUES REPRODUCTIVE & GENETIC ENGINEERING* 1153 (1988).

⁶⁵ Cf. Levran, Dor, Rudak, Nebel, Ben-Shlomo, Ben-Rafael & Mashiach, *Pregnancy Potential of Human Oocytes — The Effect of Cryopreservation*, 323 *NEW ENG. J. MED.* 1153, 1154 (1990) [hereinafter Levran]; Sauer, Paulson & Lobo, *A Preliminary Report on Oocyte Donation Extending Reproductive Potential to Women Over 40*, 323 *NEW ENG. J. MED.* 1157, 1159 (1990).

⁶⁶ See generally R. BLATT, *supra* note 19; A. Lippman, *supra* note 40.

⁶⁷ See Fuhrmann, *Impact, Logistics and Prospects of Traditional Prenatal Diagnosis*, 36 *CLINICAL GENETICS* 378, 380 (1988). This categorization is more a cultural than biological creation. See Bourret, *Le temps, l'espace en Génétique: Intervention Médicale et Géographique Sociale du gène*, 6 *SCIENCES SOCIALES ET SANTÉ* 171 (1988); A. Lippman, *The Geneticization of Health and Illness: Implications for Social Practice* (manuscript in preparation based on presentation at National Ass'n for Science, Tech. & Soc'y, Washington, D.C., Feb. 2, 1991). It reflects prevailing ideas about the kinds of children women should have and when the probability for them is or is not diminished. See Finkelstein, *Biomedicine and Technocratic Power*, *HASTINGS CENTER REP.* 1990, at 13, 14-16; see also *infra* note 86 for a discussion of the role of genetics in creating these ideas.

Age has thus become more than an event, a birthday; it has been redefined as a marker, a risk, although nothing inherent in it makes it so. See Fuhrmann, *supra*, at 380 (35 is the crucial age in North America); J. Moatti, J. Lanoë, C. LeGalés, H. Gardent, C. Julian & S. Aymé,

belonging is, itself, socially rather than biologically determined,⁶⁸ women informed that they are "at-risk" may find it hard to refuse prenatal diagnosis or other measures that are advertised to be risk-reducing. Once again, however, this "need" does not exist apart from the current context that created it by categorizing homogeneously those thirty-five and older who are pregnant as "at-risk." Mere identification of one's self as a member of a "high risk" group may influence the interpretation of an absolute risk figure⁶⁹ and the acceptance of a test. In this light, the additional screening and testing possibilities generated by genome projects are likely to expand greatly the ranks of those deemed "needy."⁷⁰ As the number of factors or people labeled as risks or at-risk increases, so, too, will offers of intervention.⁷¹

Fourth, as prenatal diagnosis becomes more and more routine for women thirty-five years and older in North America, the risks it seems to avoid (the birth of a child with Down syndrome) appear to be more ominous,⁷² although the frequency of Down syndrome has not

Economic Assessment of Prenatal Diagnosis in France (unpublished manuscript presented at Joint Meeting of European Health Economic Societies, Barcelona, Spain, Sept. 21-23, 1989) (age 38 in France); Sjögren & Uddenberg, *supra* note 61, at 263 (age 37 in Sweden). This age marker may even serve to stigmatize the "older" woman. See Hubbard & Henifin, *supra* note 60, at 238 (1985). Further discussion of the arbitrariness of age 35 as a criterion for access to prenatal diagnosis can be found in *Who Decides?*, *supra* note 26, at 434; Vekemans & Lippman, *Letter to the Editor: Eligibility Criteria for Amniocentesis*, 17 AM. J. MED. GENETICS 531 (1986).

⁶⁸ The many ways in which the concept of "risk" is itself a cultural creation, unfortunately, cannot be given the attention they deserve here. However, it is useful to recall that the data used to assign people to risk categories reflects the information we choose to collect, and the problems that interest the collector. Alexander & Keirse, *Formal Risk Scoring*, in 1 EFFECTIVE CARE IN PREGNANCY AND CHILDBIRTH 345, 346-47 (I. Chalmers & M. Keirse eds. 1989). It is also important to note that changes in the nature and number of things counted as risks are more prevalent than changes in the actual number of people "at-risk"; and that even using the term "risk" to describe an event or experience is politically and socially dependent. Cf. L. WINNER, *THE WHALE AND THE REACTOR: A SEARCH FOR LIMITS IN AN AGE OF HIGH TECHNOLOGY* 142 (1986) (discussing risks versus hazards).

⁶⁹ See Botkin, *Prenatal Screening: Professional Standards and the Limits of Parental Choice*, 75 OBSTETRICS & GYNECOLOGY 875 (1990); Shiloh & Sagi, *Effect of Framing on the Perception of Genetic Recurrence Risks*, 33 AM. J. MED. GENETICS 130 (1989).

⁷⁰ A. Lippman, *supra* note 40. Human genome projects comprise the organized and directed international and national programs to map and sequence all human genes. Some of these genes will be associated with recognizable disorders; others will be associated with biological variations of varying and mostly unknown consequence. See generally McKusick, *Mapping and Sequencing the Human Genome*, 320 NEW ENG. J. MED. 910 (1989); Watson, *supra* note 11 at 44. Differences between people will be identified, and while knowing the location and composition of human genes will add to our information about the latter, it will not reveal how the person with these genes will "turn out." See *supra* notes 13-14 and accompanying text for a critical discussion of the limits of the genetic model.

⁷¹ Cf. Vallgarda, *Increased Obstetric Activity: A New Meaning to "Induced Labor?"*, 43 J. EPIDEMIOLOGY & COMMUNITY HEALTH 48, 51 (1989) (hypothesizing that, among other factors, the availability of new technologies such as electronic fetal monitoring leads to an increased number of interventions by practitioners).

⁷² This may be an example of what Tversky and Kahnemann have called the "availability" heuristic. Tversky & Kahneman, *Availability: A Heuristic for Judging Frequency and Probability*, 5

changed. This, too, may have a framing effect, generating a "need" for prenatal testing among women in this age group. Interestingly, however, this perception may inadvertently influence both the implementation and efficiency of proposed screening programs designed to supplement risk estimates based on maternal age with information from maternal blood samples.⁷³ Having been socialized during the past fifteen to twenty years to view age thirty-five and over as the entry card to prenatal diagnosis, and convinced that once past this birthday they are "at risk," how will women beyond this age respond when blood test results remove them statistically from those in "need" of prenatal diagnosis? Will there be lingering doubts, and their sequelae, or will it be as easy to remove a risk label as it has been to affix one? What about the younger women who will have become prematurely aged (that is, eligible "by age" for prenatal diagnosis though not yet thirty-five)? As the title of a recent book phrases it, are pregnancy screening and fetal diagnosis *Calming or Harming*?⁷⁴ We neither have the data necessary to answer this question, nor do we give priority to studies that would be informative.⁷⁵ Instead, we proceed as if calming were a foregone conclusion. Programmatic changes such as these, no less than those subsequent to developments in genomics, underline how risk groups and needs are generated and constructed.

Fifth, on the collective level, prenatal diagnosis is generally presented as a response to the public health "need" to reduce unacceptably high levels of perinatal mortality and morbidity associated with perceived increases in "genetic" disorders. This reduction is of a special kind, in that prenatal diagnosis does not *prevent* the disease, as is

COGNITIVE PSYCHOLOGY 207 (1973). That is, having become familiar through constant reference to it and to prenatal diagnosis, Down syndrome may be perceived by the general population as "worse" and as more frequent than it is statistically.

⁷³ Until recently, the frequency of births of children with Down syndrome to women of different ages was the sole basis for estimating individual risks. Within the past few years, investigators have identified certain substances in blood samples from pregnant women that show a statistical association with the chromosomal status of the fetus. This additional information is now beginning to be used in conjunction with maternal age to estimate risks for Down syndrome. In some cases these data will increase a woman's putative risk above that associated with her age alone; in others, it will decrease it. When the numerical value of this risk equals or surpasses that associated with maternal age 35 alone, ("35-equivalent"), prenatal diagnosis is generally offered. See Wald & Cuckle, *AFP and Age Screening for Down Syndrome*, 31 AM. J. MED. GENETICS 197 (1988).

⁷⁴ J. GREEN, *CALMING OR HARMING? A CRITICAL REVIEW OF PSYCHOLOGICAL EFFECTS OF FETAL DIAGNOSIS ON PREGNANT WOMEN* (Galton Inst. 2d Series 1990). In this context, the notion of "iatrogenic anxiety" would seem pertinent. This anxiety may develop when laboratory analyses reveal chromosomal variations never before reported whose significance is unknown. The prevalence of iatrogenic anxiety among women being tested may be substantial, but its extent is currently unknown.

⁷⁵ See Lippman, *supra* note 37.

usually claimed.⁷⁶ Yet, even this "need," ostensibly based on "hard" data demonstrating the size of these problems, is constructed. For example, geneticists say "their" kinds of diseases are increasing as the prevalence of infectious diseases decreases, making genetic intervention seem appropriate. But others construe the same data as evidence of an increase in the "new morbidity" of pediatrics (developmental delays, learning difficulties, chronic disease, emotional and behavioral problems, etc.), the problems of concern in *their* specialty.⁷⁷ Clearly, what one counts, emphasizes and treats as "evidence,"⁷⁸ depends on what one seeks as well as on the background beliefs generating the search. The numbers are then tallied, justifying a "need" to do something.⁷⁹

Moreover, unacceptably high rates of morbidity generate all sorts of "needs."⁸⁰ Reducing these solely to biomedical problems hides the range of potential responses that might be considered.

Viewing needs and demands as cultural creations within a social context leads to doubts that assumptions of "free choice" with respect to the actual use of prenatal diagnosis are appropriate. It also clarifies why it is not fruitful to think that there may be a conflict between women who want prenatal diagnosis and critics who do not want them to have it. Not only does this polarization misinterpret the critics' position, it fails to recognize, for example, that prenatal diagnosis cannot really be a choice when other alternatives are not available,⁸¹ or that accepting testing as "needed" may be a way for a woman to justify going through what is a problematic experience for her. Society does not truly accept children with disabilities or provide assistance for their nurturance. Thus, a woman may see no realistic alternative to diagnosing and aborting a fetus likely to be affected.

⁷⁶ See, e.g., Modell, *Cystic Fibrosis Screening and Community Genetics*, 27 J. MED. GENETICS 475 ("Cystic fibrosis . . . is fast becoming preventable . . . [because] [t]he gene in which mutation can lead to CF . . . has recently been identified . . . [This creates] an imminent need to set up population screening for CF carriers.").

⁷⁷ See, e.g., N. ZILL & C. SCHOENBORN, *DEVELOPMENTAL, LEARNING, AND EMOTIONAL PROBLEMS: HEALTH OF OUR NATION'S CHILDREN* 190 (National Center for Health Statistics, Nov., 1990).

⁷⁸ See H. LONGINO, *SCIENCE AS SOCIAL KNOWLEDGE: VALUES AND OBJECTIVITY IN SCIENTIFIC INQUIRY* 38, 38-48 (1990).

⁷⁹ See ARMSTRONG, *The Invention of Infant Mortality*, 8 SOCIOLOGY HEALTH & ILLNESS 211 (1986) (the idea of infant mortality was created by new measuring tools in statistics); ARMSTRONG, *Use of the Genealogical Method in the Exploration of Chronic Illness: A Research Note*, 30 SOC. SCI. & MED. 1225 (1990) (how increases in chronic disease are constructed).

⁸⁰ Children with malformations and medical disorders will always be born, and avoiding their birth via prenatal diagnosis does not address the issue of preventing these problems or of ameliorating their effects on the child or the family. The former will require interventions that reduce environmental mutagens and teratogens, for example; the latter elicits interventions which have already been discussed. See *supra* text accompanying notes 42-44.

⁸¹ See R. HUBBARD, *supra* note 17, at 198.

Parallel to the creation of a woman's "need" for prenatal diagnosis is the development of health professionals' "need" for technological solutions to problems of malformation. Thus, geneticists increasingly choose to use and develop prenatal diagnosis to deal with problems of malformation excluding, if not precluding, consideration of other approaches. They "need" to employ these technologies, and in doing so they establish professional norms about how much is needed. Individual decisions about when a woman needs testing accumulate, and rapidly establish new standards for the profession.⁸² The routine use of ultrasound to monitor all pregnancies is probably the most obvious example. Regardless of the driving forces for dependency on this technology, the result is the construction of a particular "need": the basic "need" to know the gestational age of the fetus; the additional "need" to demonstrate that the pregnancy is progressing "normally." And the "needs" grow.

"Needs" for prenatal diagnosis are being created simultaneously with refinements and extensions of testing techniques themselves.⁸³ In popular discourse — and with geneticists generally silent witnesses — genetic variations are being increasingly defined not just as problems, but, I suggest, as problems for which there is, or will be, a medical/technical solution. With but slight slippage these "problems" come to be seen as *requiring* a medical solution. This again hides the extent to which even "genetic" disease is a social/psychological experience as much as it is a biomedical one.⁸⁴ This process is likely to accelerate as gene mapping enlarges the numbers of individuals declared eligible for genetic testing and screening. Given the extent of human variation, the possibilities for constructing "needs" are enormous.

C. PRENATAL DIAGNOSIS AND THE SOCIAL CONTROL OF ABORTION AND PREGNANCY

The third element in the prenatal discourse that I will consider here stems from the often told story that testing is an option that increases women's reproductive choices and control. This claim has had

⁸² See Beck-Gernsheim, *supra* note 61, at 28-29 ("It is characteristic that new technologies, once available, produce new standards of what we ought to have."); Lippman, *supra* note 53, at 182 (discussing professional establishment of criteria for testing and physicians' desires to comply with perceived medical standards).

⁸³ These techniques are likely to be driven by financial considerations of the pharmaceutical companies developing them. See, e.g., D. NELKIN & L. TANCREDI, DANGEROUS DIAGNOSTICS: THE SOCIAL POWER OF BIOLOGICAL INFORMATION 33-36 (1989); A. Lippman, *supra* note 40; cf. Note, *Patents for Critical Pharmaceuticals: The AZT Case*, 17 AM. J.L. & MED. 145 (1991) (analyzing the validity of pharmaceutical companies' claims that without a federally-granted monopoly, they would not have the incentive to research and develop orphan drugs).

⁸⁴ See Shiloh, Waisbren & Levy, *A Psychosocial Model of a Medical Problem: Maternal PKU*, 10 J. PRIMARY PREVENTION 51 (1989).

much attention in the literature and I will examine it only with respect to how some features of prenatal diagnosis do increase control, but allocate it to someone other than a pregnant woman herself. This is most apparent in the context of abortion.⁸⁵

Without doubt, prenatal diagnosis has (re)defined the grounds for abortion⁸⁶ — who is justified in having a pregnancy terminated and why — and is a clear expression of the social control⁸⁷ inherent in this most powerful example of geneticization. Geneticists and their obstetrician colleagues are deciding which fetuses are healthy, what healthy means and who should be born, thus gaining power over decisions to continue or terminate pregnancies that pregnant women themselves may not always be permitted to make.

To the extent that specialists' knowledge determines who uses prenatal diagnosis and for what reasons, geneticists determine conditions that will be marginalized, objects of treatment or grounds for abortion.⁸⁸ Prenatal diagnosis is thus revealed as a biopolitical as well as a biomedical activity.⁸⁹ For example, an abortion may only be "legal" in some countries if the fetus has some recognized disorder,⁹⁰ and the justifying disorder only becomes "recognizable" because geneticists first decide to screen for it. Fuhrmann suggests that in Europe, in fact, geneticists significantly influenced legislators establishing limits within which abortion would be at all permissible, by arguing that access to abortion be maintained through a gestational age that reflected when results from amniocentesis might be available.⁹¹ One wonders where

⁸⁵ For thorough analyses of the question of women's control, see generally Rapp, *Chromosomes and Communication: The Discourse of Genetic Counseling*, 2 MED. ANTHROPOLOGY Q. 143 (1988).

⁸⁶ In fact, the availability of amniocentesis "influenced legislation so that the upper limit of gestational age for legally tolerated termination of pregnancy was adjusted to the requirements of second trimester prenatal diagnosis in several countries." Fuhrmann, *supra* note 67, at 378. Evidently, geneticists can accomplish what women's groups cannot: a revisioning of abortion.

⁸⁷ The term "social control" is used in accord with its original use to embrace "the widest range of influence and regulation imposed by society upon the individual." D. GORDON, *Clinical Science and Clinical Expertise: Changing Boundaries Between Art and Science in Medicine*, in BIOMEDICINE EXAMINED, *supra* note 5, at 257.

⁸⁸ *Reproductive Choice?*, *supra* note 53, at 187-192.

⁸⁹ Finkelstein, *supra* note 65, at 14-16.

⁹⁰ Fetal abnormality as grounds for abortion is of fairly recent vintage, having first become "legal" in the United States in 1967 in response to a rubella epidemic. The Canadian Medical Association gave its approval the same year. Beck, *Eugenic Abortion: An Ethical Critique*, 143 CANADIAN MED. ASS'N J. 181, 181-84 (1990). Today, members of the general population as well as physicians regularly and strongly agree that fetal abnormality is a justification for abortion. See Annas, *The Supreme Court, Privacy and Abortion*, 321 NEW ENG. J. MED. 1200 (1989); Breslau, *Abortion of Defective Fetuses: Attitudes of Mothers of Congenitally Impaired Children*, 49 J. MARRIAGE FAMILY 839 (1987); Varekamp, *supra* note 40, at 147.

⁹¹ See Fuhrmann, *supra* note 67, at 383-84. A recent example of the use of genetics to set social policy in this area is the position taken by the American Society of Human Genetics with

limits might have been placed had first trimester chorionic villus sampling been available *before* amniocentesis? Would they have been more restrictive?

Other potential participants in what should be an intensely personal matter for "control" include insurance companies and governments.⁹² If either funds genetic screening programs or covers the cost of treatment for conditions diagnosable *in utero*, they may claim a say in determining which tests are carried out and what action the results entail.⁹³ Recently circulated reports about a health maintenance organization planning to withdraw medical coverage for a woman who could have avoided the birth of a child with cystic fibrosis if she had "chosen" to abort the pregnancy after the prenatal diagnosis was made, gives substance to concerns about changes in the locus of control.⁹⁴ While this kind of abuse of power grabs headlines — and gets discounted as something regulations can prevent — there are more subtle forms of control that achieve the same ends and actually result from seemingly benevolent regulations and public policies. For example, newborn screening for Phenylketonuria (PKU) is carried out in the United States with universal approval. However, in only four states are health insurers required to cover the cost of the special foods children with PKU need.⁹⁵ What choices/control does a woman have in this context? What are her options if prenatal diagnosis for PKU is offered? It would not be unreasonable to believe that a pregnant woman who learns that the fetus has the genes for PKU and does not see this as a reason for abortion may feel compelled to terminate her pregnancy because she could not herself finance the special diet her child would require after

respect to possible restrictions on abortion under consideration in various parts of the United States. This professional group has proposed as model legislation

that any pregnant female whose pregnancy has not reached the point of viability and who has been informed by a licensed or certified health care professional that her fetus (or fetuses) is/are likely to have a serious genetic or congenital disorder shall have the right, among other options, to choose to terminate her pregnancy. This right shall extend to situations where the female is at significantly increased risk for bearing a child with a serious disorder for which precise prenatal diagnosis is not available.

Letter from Phillip J. Riley to the author. The merits for/against this position aside, it certainly demonstrates how geneticists seek to influence the resolution of fundamentally political, legal (and ethical) problems.

⁹² Nsiah-Jefferson, *supra* note 54, at 31-37, 39-41.

⁹³ Billings, *Genetic Discrimination: An Ongoing Survey*, GENEWATCH, May 1990, at 7-15.

⁹⁴ See Billings, Kohn, de Cuevas & Beckwith, *Genetic Discrimination As a Consequence of Genetic Screening*, to be published in AM. J. HUM. GENETICS (1991); see also Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109 (1991).

⁹⁵ Brody, *A Search to Ban Retardation in a New Generation*, N.Y. Times, June 7, 1990, at B9, col. 1 (citing Carol Kaufman) (the four states are Massachusetts, Montana, Texas and Washington). PKU reflects an inability to metabolize phenylalanine properly. It can be controlled by dietary restrictions.

birth. Such pressures (explicit and implicit) exerted on a woman to abort a pregnancy following the prenatal diagnosis of some problem that makes her unable to keep a pregnancy she wants reveals another way in which social control over abortion may be genetically based.

Policy decisions establish control, too, in the guise of guidelines for seemingly straightforward features of prenatal screening and testing programs. For example, it has been shown that parents' decisions about pregnancy termination for the same chromosome abnormality are influenced by whether or not fetal anomalies are visualized on ultrasound.⁹⁶ Even *who* does the counseling associated with prenatal diagnosis can influence what a woman does after learning of a fetal chromosome abnormality;⁹⁷ rates of induced abortion are higher when obstetricians relate the results of testing than when geneticists do.⁹⁸ Similarly, the interval between prenatal diagnosis counseling and testing is of consequence. This is demonstrated clearly in the reported association between the rates of amniocentesis utilization and the interval between counseling and testing: the shorter the interval, the greater the use.⁹⁹ Pressure from state policies establishing when (as well as how)¹⁰⁰ genetic counseling will be provided to screening program participants may be covert, but this does not prevent it from being controlling. In sum, prenatal testing and screening may provide control. But for whom? To what ends? For whose benefit?

IV. THE CONTEXT OF GENETICIZATION

I now turn from the specific stories being told about prenatal diag-

⁹⁶ Drugen, Greb, Johnson & Krivchenia, *Determinants of Parental Decisions to Abort for Chromosomal Abnormalities*, 10 *PRENATAL DIAGNOSIS* 483 (1990).

⁹⁷ See *Genetic Counseling I*, *supra* note 60, at 51; *Genetic Counseling II*, *supra* note 60, at 73; Harper & Harris, *Editorial: Medical Genetics in China: A Western View*, 23 *J. MED. GENETICS* 385, 386-388 (1986) (noting role of "genetic counselor as arbiter for permission to have additional children in China" or to abort child); Rapp, *supra* note 85, at 143 (analyzing messages conveyed in genetic counseling discourse); see also Puck, *Some Considerations Bearing on the Doctrine of Self-Fulfilling Prophecy in Sex Chromosome Aneuploidy*, 9 *AM. J. MED. GENETICS* 129 (1981) (noting use of term "syndrome" in prenatal diagnosis).

⁹⁸ Holmes-Seidle, Ryynanen & Lindenbaum, *Parental Decisions Regarding Termination of Pregnancy Following Prenatal Detection of Sex Chromosome Abnormality*, 7 *PRENATAL DIAGNOSIS* 239, 241-243 (1987). See also Robinson, Bender & Linden, *Decisions Following the Intrauterine Diagnosis of Sex Chromosome Aneuploidy*, 34 *AM. J. MED. GENETICS* 552 (1989). This raises an interesting question for the future as screening is further routinized and moves increasingly from geneticists to obstetricians.

⁹⁹ Lorenz, Botti, Schmidt & Ladda, *Encouraging Patients to Undergo Prenatal Genetic Testing Before the Day of Amniocentesis*, 30 *J. REPRODUCTIVE MED.* 933 (1985).

¹⁰⁰ As possibilities for screening and testing expand, so, too, will the need to provide genetic counseling services to participants. The size of the resources required to do this appropriately may be enormous, if existing models for genetic counseling are to be followed. See Fraser, *Genetic Counseling*, 26 *AM. J. HUM. GENETICS* 636 (1974). The consequences may also be enormous — however the programs are designed.

nosis to the circumstances in which they are being told, attempting to show the interactions between content and context. The links are numerous and the required analysis substantial. I shall concentrate here on the existence of the connections rather than on their critique. My overall thesis is that characteristics (political, economic, social) of the North American society in which prenatal diagnostic technologies have been developed determine how these techniques will influence how we define individual health, health care and the health care system. The same technology will have different consequences in different societies, so that exploring the characteristics of the system in which it is introduced is important.¹⁰¹ The critical characteristics derive from current stratifications of North American society and the inequities with which they are associated.¹⁰² These influence (and are influenced by) the use of prenatal technology in ways that laws, regulations or even ethical codes for screening and testing alone do not — and probably cannot — address.

A. IS THE "PLAYING FIELD" LEVEL?

Access to, a perceived need for and the use of either health care providers or the health care system vary markedly between people. The outcomes of these encounters (or of their non-occurrence) also are quite variable. A person with certain signs, characteristics or features may be referred to different people/services/systems for help.¹⁰³ Variations in the perspective and nature of the "help," along with variations in people's approach to and use of these different services, mean that disease and illness are labeled and socialized differentially according to where one becomes situated.¹⁰⁴ The definition of and help offered for

¹⁰¹ Kranzberg, *The Uses of History in Studies of Science, Technology and Society*, 10 BULL. SCI. TECH. & SOC. 6 (1990). These technologies are not neutral objects waiting for us to make good or evil use of them. Rather, the "politics embodied in material things" from the very start, Winner, *supra* note 8, at 12, give them "valence" and make it essential to understand the social context in which a new device or practice is offered. Bush, *Women and the Assessment of Technology: To Think, To Be; To Unthink, To Free*, in MACHINA EX DEA: FEMINIST PERSPECTIVES ON TECHNOLOGY 154, 154-56 (J. Rothschild ed. 1983) [hereinafter MACHINA EX DEA]. The context, itself, not only influences the technologies we choose to develop but also presupposes certain approaches to their use. In turn, the use of any given technology will change the context, will change us. Technology is like a "new organism insinuating itself and altering us irrevocably." Boone, *Bad Axioms in Genetic Engineering*, HASTINGS CENTER REP., Aug.-Sept. 1988, at 9.

¹⁰² This issue is presented in fairly general terms here without the in-depth consideration that is being (and will be) developed elsewhere in the context of my larger project.

¹⁰³ Waxler, *The Social Labeling Perspective on Illness and Medical Practices*, in THE RELEVANCE OF SOCIAL SCIENCE TO MEDICINE 283 (L. Eisenberg & A. Kleinman eds. 1980); *The Anthropologies of Illness and Sickness*, *supra* note 5, at 257; *Rational Men and The Explanatory Model Approach*, *supra* note 5, at 57.

¹⁰⁴ A recent example is the differential in rates of substance abuse reporting during pregnancy to public health authorities in Florida, with poor women being reported more often

the same "sickness" or characteristic will vary according to an individual's economic and social power. This variability distributes inequities in health problems and their resolution.

Moreover, since health-related naming and helping activities occur in a cultural/political context where restraints on options vary with a person's place in the society, "life choices,"¹⁰⁵ presented as ways to manage or avert health problems, will not be randomly distributed.¹⁰⁶ This certainly includes a "choice" of asking for or accepting information obtainable through genetic screening tests. Again, societal differences, no less than individual psychological ones, underlie these differential behaviors.

Life circumstances, broadly defined, establish an individual's place in society. They act, therefore, as powerful restraints on health options from identification of a problem to approaches, by self or others, to its resolution, and they influence possible options, expectations and responses.¹⁰⁷ These dynamics establish the inequities, the contours/terrain of the society (the so-called "playing field"), that will modulate the impact of genetic screening and testing just as the latter may themselves landscape the "playing field" and its inequities. To illustrate this, I shall consider in very broad terms how two stratifications — gender and class — shape and are shaped by genetic testing and screening.¹⁰⁸ Although these are inseparably linked, I shall arbitrarily isolate each one to clarify the discussion.

B. GENDER

Prenatal testing and screening represent techniques applied to women. How, when, why and by whom they are applied will be condi-

than others. Chasnoff, Landress & Barrett, *The Prevalence of Illicit Drug or Alcohol Use During Pregnancy and Discrepancies in Mandatory Reporting in Pinellas County, Florida*, 322 NEW ENG. J. MED. 1202 (1990). See also L. WHITEFORD & M. POLAND, *Introduction*, in NEW APPROACHES TO HUMAN REPRODUCTION I (L. Whiteford & M. Poland eds. 1989).

¹⁰⁵ See Townsend, *Individual or Social Responsibility for Premature Death? Current Controversies in the British Debate About Health*, 20 INT'L J. HEALTH SERVS. 373, 382-84 (1990) (noting that life style is not just a matter of choice, and presenting an analysis of the many forces that shape what we too easily call choice); cf. Rosén, Hanning & Wall, *Changing Smoking Habits in Sweden: Towards Better Health, But Not for All*, 19 INT'L J. EPIDEMIOLOGY 316 (1990) (providing example of where education contributes to increased inequities in health).

¹⁰⁶ *Rational Men and the Explanatory Model Approach*, *supra* note 5, at 57.

¹⁰⁷ See Kickbusch, *Self-Care in Health Promotion*, 29 SOC. SCI. & MED. 125 (1989).

¹⁰⁸ Other stratifications of consequence here based on ability, race, etc. are considered elsewhere. See generally A. Lippman, *supra* note 40; T. DUSTER, *supra* note 18 (emphasizing racial and ethnic strata). In addition, inequities attached to genetic screening and testing relating to employment discrimination, insurance refusals and racial prejudice, for example, have been considered in detail elsewhere and these situations will not be reviewed specifically here. See, e.g., T. DUSTER, *supra* note 18; N. HOLTZMAN, *PROCEED WITH CAUTION: PREDICTING GENETIC RISKS IN THE RECOMBINANT DNA ERA* (1989); Billings, *supra* note 93, at 7, 15; Council for Responsible Genetics, *supra* note 13, at 287.

tioned by prevailing attitudes about women, their bodies and their roles. Because the world in which genetic and other reproductive technologies are developing is gendered, it would be naive to think that these technologies can escape gendered use.¹⁰⁹ In this world, women are disadvantaged, generally powerless, and frequently socialized to follow authority and acquiesce in certain norms surrounding maternity and motherhood.¹¹⁰ Furthermore, because a child's disability is viewed as a private problem for the family, the gendered attribution of responsibilities for family health to women obligates them to deal with it alone whether by avoiding, reducing or managing disability. Prenatal diagnosis in such a context can hardly be "neutral."

Perhaps the most dramatic consequence of gender stratification for prenatal diagnosis is the (potential) use of genetic screening and testing to identify and select fetuses on the basis of their sex alone. Being female is of less value than being male, and the fetuses that are least valued are those most likely to be aborted.¹¹¹ Though generally condemned by North American geneticists,¹¹² and commonly considered unlikely when "selection" entails a second trimester abortion, the availability of chorionic villus sampling resurrects the problem anew, as if the timing of abortion were the (only) problematic aspect.¹¹³ Because this use of prenatal diagnosis as a tool *against* women has had much attention in the literature, with one commentator calling it "previctimization,"¹¹⁴ it will not be considered further here other than to emphasize that "sex selection" is problematic no matter when it is carried out, whether or not it requires some technological assistance, and that preconceptional selection differs from postconceptional selection only with respect to process, not principles.¹¹⁵ However done, it

¹⁰⁹ Some even suggest that they have been developed and used specifically to maintain gendered distinctions and increase patriarchal power. See, e.g., Morgan, *Of Woman Born? How Old Fashioned! — New Reproductive Technologies and Women's Oppression*, in *THE FUTURE OF HUMAN REPRODUCTION*, *supra* note 53, at 60; Rowland, *Reproductive Technologies: The Final Solution to the Woman Question?*, in *TEST-TUBE WOMEN*, *supra* note 55, at 356.

¹¹⁰ See L. WHITEFORD & M. POLAND, *NEW APPROACHES TO HUMAN REPRODUCTION* 1, 8-9 (1989); Raymond, *Reproductive Gifts and Gift Giving: The Altruistic Woman*, *HASTINGS CENTER REP.*, Nov.-Dec., 1990 at 7; see also *supra* note 61.

¹¹¹ See, e.g., M. WARREN, *GENDERCIDE: THE IMPLICATIONS OF SEX SELECTION* (1985); Hoskins & Holmes, *Technology and Prenatal Femicide*, in *TEST-TUBE WOMEN*, *supra* note 55, at 237; Rothschild, *supra* note 48, at 107.

¹¹² E.g., Fletcher, *Is Sex Selection Ethical?*, in *RESEARCH ETHICS* 333 (K. Berg & K. Tranoy eds. 1983); Wertz & Fletcher, *Ethics and Medical Genetics in the United States: A National Survey*, 29 *AM. J. MED. GENETICS* 815, 821 (1988) (Table V).

¹¹³ *Who Decides?*, *supra* note 26, at 434; *Reproductive Choice?*, *supra* note 53, at 182.

¹¹⁴ Raymond, *Introduction*, in *THE CUSTOM-MADE CHILD? WOMEN CENTERED PERSPECTIVES* 177 (H. Holmes, B. Hoskins & M. Gross eds. 1981) (defining previctimization as "the spectre of women being destroyed and sacrificed before even being born").

¹¹⁵ See generally G. COREA, R. KLEIN, J. HANMER, H. HOLMES, B. HOSKINS, M. KISHWAR, J. RAYMOND, R. ROWLAND & R. STEINBACHER, *MAN-MADE WOMEN: HOW NEW REPRODUCTIVE*

can only reinforce gender-based inequities.

Another consequence, less immediately obvious, is how the current applications of prenatal diagnosis are subtly entangled with another long-standing problematic for women: aging.¹¹⁶ Not only has the availability of prenatal diagnosis and professionally imposed limits on access to testing created the "social category"¹¹⁷ of "the older woman at risk," considered above,¹¹⁸ but, not unlike cosmetic surgery or estrogen replacement regimens, testing has been presented as another way for women to circumvent features of aging,¹¹⁹ with prenatal diagnosis supposedly a tool for women. The increasing probability of chromosomal nondisjunction associated with increases in a woman's age¹²⁰ can be managed, just as can other bodily changes associated with "getting older." The biological "failure" causing Down syndrome can be controlled and "older" women need not be "less fit"¹²¹ for childbearing, just as wrinkles of the skin or hot flashes can be controlled. "Old enough" to warrant control is getting younger all the time.¹²² When age, whether chronological or "equivalent,"¹²³ is used as a principal criterion for prenatal diagnosis, it appears to be essential for defining a woman (and women in general). Age-based strata come to be seen strictly as fixed "facts" of life, camouflaging the extent of their social production.¹²⁴

TECHNOLOGIES AFFECT WOMEN (1987); Hanmer, *Reproductive Technology: The Future for Women?*, in MACHINA EX DEA, *supra* note 101, at 183, 191 ("The questions of social scientists imply that sex predetermination is an accepted and acceptable idea. It is just a matter of finding out which method is preferred and when and how many children are desired."); Rowland, *Technology and Motherhood: Reproductive Choice Reconsidered*, 12 SIGNS 512 (1987).

¹¹⁶ Cf. E. MARTIN, *THE WOMAN IN THE BODY: A CULTURAL ANALYSIS OF REPRODUCTION* (1987).

¹¹⁷ D. NELKIN & L. TANCREDI, *supra* note 83, at 17 (testing creates social categories "in order to preserve existing social arrangements and to enhance the control of certain groups over others").

¹¹⁸ See *supra* notes 67-71 and accompanying text.

¹¹⁹ These circumventions pale in comparison to the variety of pharmaceutical and surgical methods that can be applied to remove all age limits on the possibility of pregnancy for a woman. See, e.g., Levran, *supra* note 65, at 1153; Sauer, Paulson & Lobo, *supra* note 63, at 1157.

¹²⁰ Hook, Cross & Schreinemachers, *Chromosomal Abnormality Rates at Amniocentesis and in Live-Born Infants*, 249 J. A.M.A. 2034 (1983).

¹²¹ Hubbard & Henifin, *supra* note 60, at 238.

¹²² R. HUBBARD, *supra* note 17; Hubbard, *Personal Courage Is Not Enough: Some Hazards of Childbearing in the 1980s*, in TEST-TUBE WOMEN, *supra* note 55, at 331, 339.

When amniocentesis was first introduced, 40 years was the age cut-off. This has dropped to 35 in North America, and recommendations that it be lowered further have been made. PRESIDENT'S COMM'N, *supra* note 30, at 81; Crandell, Lebherz & Tabsh, *Maternal Age and Amniocentesis: Should This Be Lowered to 30 Years?*, 6 PRENATAL DIAGNOSIS 237, 241 (1986).

¹²³ See *supra* note 73.

¹²⁴ See Rindfuss & Bumpass, *Age and the Sociology of Fertility: How Old Is Too Old?*, in SOCIAL DEMOGRAPHY 43 (K. Taueber, L. Bumpass & J. Severt eds. 1978) (providing an overview of social definitions of childbearing age).

Existing gender (and age) strata mean that procreation-linked testing and screening cannot but be of major consequence to women (irrespective of any consequences it may have for them).¹²⁵ Thus, the *geneticization* of pregnancy is following a trajectory similar to — but perhaps even more alienating than — that described and analyzed eloquently by others studying the medicalization of pregnancy.¹²⁶ Once again, those with great power — physicians — control powerful technologies to monitor, regulate and even obliterate the female body when they situate a fetus in conflict with a pregnant woman in the provision of obstetric care.¹²⁷ With dramatic images obtained by ultrasound, a presentation of the pregnant woman as a fetal container,¹²⁸ a uterine environment,¹²⁹ perhaps even a “fetal abuser”¹³⁰ gains force. Once again, an underlying ideological premise that women’s inadequacy can threaten the success of reproduction justifies some technological intervention, and this time the “inadequacy” is innate. Purposefully or not, prenatal testing and screening reinforce stereotyped gender definitions of women and traditional values regarding their behavior. It would be particularly unfortunate, therefore, if realistic and serious concerns about increasing threats to women’s already fragile abortion rights were to silence no less realistic and serious concerns about the place of prenatal diagnosis in a gendered society.

C. ECONOMIC CLASS

Morbidity patterns associated with all aspects of procreation (fertility, abortion, pregnancy or birthing, for example) have repeatedly been

¹²⁵ Its impact on their experience of pregnancy is enormous but will not be considered here. See Beeson, *Technological Rhythms in Pregnancy*, in CULTURAL PERSPECTIVES ON BIOLOGICAL KNOWLEDGE 145 (T. Duster & K. Garrett eds. 1984); A. Lippman, *supra* note 40; see also B. ROTHMAN, *THE TENTATIVE PREGNANCY: PRENATAL DIAGNOSIS AND THE FUTURE OF MOTHERHOOD* (1986).

¹²⁶ See generally K. MICHAELSON, *Childbirth in America: A Brief History and Contemporary Issues*, in *CHILDBIRTH IN AMERICA*, *supra* note 19, at 1; A. OAKLEY, *supra* note 24; Fraser, *Selected Perinatal Procedures: Scientific Bases for Use and Psycho-social Effects. A Literature Review*, 117 ACTA OBSTETRIC ET GYNECOLOGICA SCANDANAVIA 6, 6 (Supp. 1983); O'Reilly, *Small "p" Politics: The Midwifery Example*, in *THE FUTURE OF HUMAN REPRODUCTION*, *supra* note 53, at 159.

¹²⁷ Board of Trustees, American Med. Ass'n, *Legal Interventions During Pregnancy. Court-Ordered Medical Treatments and Legal Penalties for Potentially Harmful Behavior by Pregnant Women*, 264 J. A.M.A. 2663 (1990); Landwirth, *Fetal Abuse and Neglect: An Emerging Controversy*, 79 PEDIATRICS 508 (1987) (discussing tension between fetal interests and maternal rights to privacy and self-determination).

¹²⁸ Petchesky, *Fetal Images: The Power of Visual Culture in the Politics of Abortion*, in *REPRODUCTIVE TECHNOLOGIES: GENDER, MOTHERHOOD AND MEDICINE* 57 (M. Stanworth, ed. 1987).

¹²⁹ Morgan, *supra* note 109, at 65. For recent use of this term in the context of scientific studies, see *supra* note 65 and accompanying text.

¹³⁰ See Robertson, *Procreative Liberty and the Control of Conception, Pregnancy, and Childbirth*, 69 VA. L. REV. 405, 438-43 (1983); Shaw, *The Potential Plaintiff: Preconceptional and Prenatal Torts*, in 2 GENETICS AND THE LAW 225 (A. Milunsky & G. Annas eds. 1980).

shown to be influenced by a woman's economic circumstances.¹³¹ As previously noted, these circumstances are created and result from general class- and power-based inequities that determine how illness is named and treated (by self or others).¹³² A woman's social (political) status will also lead inescapably to "classist" effects in the use of genetic testing, screening and the resulting information. Most simply, varying circumstances (and psychological differences) cause individuals to react to offers of testing and screening unequally, and differentials in the use of genetic services have repeatedly been observed.¹³³ For example, from the time amniocentesis first became available, utilization rates of prenatal diagnosis among women thirty-five and over have been associated with a woman's socioeconomic status: those with more education or wealth undergo amniocentesis more often than women with less schooling or income. This is true even in Canada where there is no direct financial charge for testing.¹³⁴ Whatever the exact reason,¹³⁵ the potential consequences of this distribution are similar. One is the possibility of a substantial socially-created alteration in the epidemiology of chromosomal disorders: Down syndrome, which heretofore was generally unrelated to sociodemographic factors might no longer be so in the future. To the extent that use of prenatal diagnosis is class-specific, and abortion of fetuses with trisomy 21 the general pattern, so, too, will be the prevalence of this condition among births. Similarly, with "routine" prenatal care automatically including an ultrasound examination of a woman early in her pregnancy, children with neural tube defects may be born increasingly out of proportion to women whose circumstances prevent early prenatal care — the poor and the powerless.¹³⁶

¹³¹ E.g., Lazarus, *Poor Women, Poor Outcomes: Social Class and Reproductive Health*, in *CHILD-BIRTH IN AMERICA*, *supra* note 19, at 39; Silins, Semenciw, Morrison, Lindsay, Sherman, Mao & Wigle, *Risk Factors for Perinatal Mortality in Canada*, 133 *CANADIAN MED. ASS'N J.* 1214 (1985) (listing social class as risk factor in stillbirths and infant deaths up to seven years of age); Yankauer, *Editorial: What Infant Mortality Tells Us*, 80 *AM. J. PUB. HEALTH* 653 (1990).

¹³² See *supra* text accompanying notes 104-07.

¹³³ Beeson, *supra* note 125, at 145; Roghmann, Doherty, Robinson, Nitzkin & Sell, *The Selective Utilization of Prenatal Genetic Diagnosis: Experiences of a Regional Program in Upstate New York During the 1970s*, 21 *MED. CARE* 1111, 1122 (1983) (concluding that in use of prenatal genetic testing, "[t]he primary factor appears to be emotional acceptance by the patient . . . [but] [l]ack of knowledge, financial barriers, earlier prenatal care, and cooperation from the primary care sector are important"); Sokal, Byrd, Chen, Goldberg & Oakley, *Prenatal Chromosomal Diagnosis: Racial and Geographic Variation for Older Women in Georgia*, 244 *J. A.M.A.* 1355 (1980) (study showing that 15% of Georgia women 40 years and older underwent prenatal chromosomal diagnosis; use ranged from 60% among whites in two large urban counties to 0.5% among blacks outside Augusta and Atlanta health districts).

¹³⁴ Lippman-Hand & Piper, *Prenatal Diagnosis for the Detection of Down Syndrome: Why Are So Few Eligible Women Tested?*, 1 *PRENATAL DIAGNOSIS* 249, 250 (1981).

¹³⁵ Professional underreferral seems to be a factor in underutilization of prenatal diagnosis. *Id.* at 255.

¹³⁶ I do not suggest that all women *should* have an ultrasound exam early in a "normal" pregnancy but merely point out what one of the effects of such a policy might be.

Leaving aside important questions about the priority to assign to this or any other sophisticated prenatal genetic screening program in a society that does not guarantee access to adequate prenatal care for all women, establishing such programs on today's "playing field" may be more likely to reinforce than to reduce existing inequalities in the distribution of health problems.¹³⁷ The failure to reduce inequalities in health among social groups during the past forty years, despite the proliferation of other biomedical developments during this interval,¹³⁸ strengthens this concern.

The conditions of this playing field also, and unfortunately, mean that posing "access" as an *isolated* problem of prenatal diagnosis may produce failure to grapple fully with the issue of who is (or can get) tested. If access is defined merely as having sufficiently affordable and geographically available services, class-based inequities will likely persist. Comparable availability does not automatically lead to equity, especially when individuals start off unequally. If nothing else, inequities in the distribution of information will keep the poor excluded in a class-stratified society.¹³⁹ "Access" may not even be a meaningful feature when the allocation of resources and services is controlled by those who develop and employ them, rather than by those on whom they are used.

With respect to genetic screening, particularly those programs likely to follow gene mapping, the "bumps" in the playing field deriving from class strata based on occupation may be of special pertinence, especially for women. The unequal distribution of workplace hazards by type of activity and the continued existence of female employment ghettos, combined with persisting racial discrimination, mean that some women will be seen as "more" eligible for certain genetic screening tests than others. To the extent that one finds what one is looking for, the identification of only certain groups of workers as "susceptible" to some putative workplace hazard might be used as a supposedly sci-

¹³⁷ Bowman, *Legal and Ethical Issues in Newborn Screening*, 83 PEDIATRICS 894, 895 (Supp. 1989) ("If we ask poor mothers to participate in newborn screening programs and do not fight for universal prenatal care, equitable health care delivery, education, and adequate housing and food, then we are coconspirators in health deception."); Lippman, Messing & Mayer, *supra* note 15, at 398; Lippman, *supra* note 15; Lippman, *supra* note 67.

¹³⁸ Acheson, *Public Health — Edwin Chadwick and the World We Live In*, 336 LANCET 1482, 1483 (1990) (United Kingdom study suggesting that inequalities in health are present everywhere).

¹³⁹ Cf. Stewart, *Access to Health Care for Economically Disadvantaged Canadians: A Model*, 81 CANADIAN J. PUB. HEALTH 450, 452-53 (1990) (advocating education as one of four strategies to increase health care access for the poor). Omitted from discussion here, since it is being treated in detail elsewhere, is the marketing of susceptibility screening as a form of preventive medicine and its failure to acknowledge the historical, political and economic determinants of health (by its focus on individuals) or the constraints on behavioral choice created by class (and other) stratifications. Lippman, *supra* note 67.

entific justification for workplace discrimination.¹⁴⁰ Occupational segregation, no less than racial or residential segregation, is entangled with differential perceptions of the acceptability and "appropriate" applicability of genetic testing. Will testing level — or build up further — "bumps"?

V. CONCLUSION

There are an unlimited number of ways to tell stories about health and disease, and an extensive vocabulary exists for telling them. Yet today, an increasing number of these stories are being told in the same way and with the same language: genetics, genes and genetic technologies. These genetic presentations of health, disease and ways to deal with them are grounded in the political and social context of the storytellers. My concern has been to decipher some of the stories about prenatal genetic screening and testing, and to reveal alternative constructions and interpretations to those already written.

Prenatal testing and screening, as has been repeated throughout this text, are most often presented as ways to decrease disease, to spare families the pain of having a disabled child and to enhance women's choice. The best-selling stories about them speak of reassurance, choice and control. As has also been suggested, this discourse presents a child born with some disorder requiring medical or surgical care as (exhibiting) a "failure."¹⁴¹ This failed pregnancy theme is reinforced in counseling provided to these families when counselors emphasize how most fetuses with an abnormality abort spontaneously during pregnancy, are "naturally selected," as it were, and how prenatal testing is merely an improvement on nature.

Just as there are several ways to construe reassurance, choice and control, the birth of a child with a structural malformation or other problem, "genetic" or otherwise, can be presented in other than biomedical terms. Is the story claiming that the pregnancy has malfunctioned (by not spontaneously aborting),¹⁴² resulting in a baby with a malformation, any "truer" than the story suggesting that *society* has malfunctioned because it cannot accommodate the disabled in its midst?¹⁴³

¹⁴⁰ See Andrews & Jaeger, *Confidentiality of Genetic Information in the Workplace*, 17 AM. J.L. & MED. 75 (1991).

¹⁴¹ Dunstan, *Screening for Fetal and Genetic Abnormality: Social and Ethical Issues*, 25 J. MED. GENETICS 290 (1988).

¹⁴² Dunstan thus sees genetic screening and "selective abortion" as a "rationalized adjunct to natural processes" in which "defective products" (babies) are "discard[ed] spontaneously." *Id.* at 292.

¹⁴³ For a full development of these ideas, see Asch, *Reproductive Technology and Disability*, in REPRODUCTIVE LAWS FOR THE 1990S, *supra* note 54, at 69; Asch & Fine, *Shared Dreams: A Left Perspective on Disability Rights and Reproductive Rights*, in WOMEN WITH DISABILITIES 297 (M. Fine & A. Asch eds. 1988).

Social conditions are as enabling or disabling as biological conditions. Why are biological variations that create differences between individuals seen as preventable or avoidable while social conditions that create similar distinctions are likely to be perceived as intractable givens?¹⁴⁴

While "many people don't believe society has an obligation to adjust to the disabled individual,"¹⁴⁵ there is nothing inherent in malformation that makes this so. Consequently, arguing that social changes are "needed" to enable those with malformations to have rich lives is not an inherently less appropriate approach. Actually, it may be more appropriate, since malformation, a biomedical phenomenon, requires a social translation to become a "problem." Expanding prenatal diagnostic services may circumvent but will not solve the "problem" of birth defects; they focus on disability, not on society's discriminatory practices.¹⁴⁶ They can, at best, make only a limited contribution to help women have offspring free of disabilities, despite recent articles proposing prenatal diagnosis and abortion as ways to "improve" infant mortality and morbidity statistics.¹⁴⁷ Thus, as sociopolitical decisions about the place of genetic testing and screening in the health care system are made, it will be important to consider how problems are named and constructed so that we don't mistakenly assume the story told in the loudest voice is the only one — or that the "best seller" is best.

Unarguably, illness and disability are "hard" (difficult) issues,¹⁴⁸

¹⁴⁴ There would seem to be similar assumptions beneath the transformation of problems with dirty workplaces into problems with women workers who may become pregnant. See, e.g., Bertin, *Women's Health and Women's Rights: Reproductive Health Hazards in the Workplace*, in *HEALING TECHNOLOGY*, *supra* note 61, at 289, 297 (advocating legislation requiring safe workplaces and prohibiting sterility requirements); Woolhandler & Himmelstein, *supra* note 9, at 1205.

¹⁴⁵ Levin, *International Perspectives on Treatment Choice in Neonatal Intensive Care Units*, 30 *SOC. SCI. & MED.* 901, 903 (1990) (citation omitted).

¹⁴⁶ For a further discussion on this, see McDonough, *supra* note 35, at 149.

¹⁴⁷ Powell-Griner & Woolbright, *Trends in Infant Deaths from Congenital Anomalies: Results from England and Wales, Scotland, Sweden and the United States*, 19 *INT'L J. EPIDEMIOLOGY* 391, 397 (1990) (probable that level of infant mortality will be influenced by prenatal screening and selective abortion); Saari-Kemppainen, Karjalainen, Ylostalo & Heinonen, *Ultrasound Screening and Perinatal Mortality: Controlled Trial of Systematic One-Stage Screening in Pregnancy*, 336 *LANCET* 387, 391 (1990) (Researchers of ultrasound screening in Helsinki, Finland concluded that "[t]he decrease in perinatal mortality of about half in this trial can be explained mainly by the detection of major fetal anomalies by ultrasound screening and the subsequent termination of these pregnancies.").

¹⁴⁸ Lippman, *supra* note 15. See A. FINGER, *supra* note 61; P. Kaufert, *The Production of Medical Knowledge: Genes, Embryos and Public Policy* (paper presented at *Gender, Science and Medicine II* conference, Toronto, Ontario, Nov. 2, 1990). Moreover, illness and disability are hard (i.e., difficult) issues partly because society defines them as such, in its decisions about how (not) to allocate resources to deal with them. Unfortunately, since resources are always "scarce," the programs or projects that do (not) get supported will merely be those which policymakers choose (not) to fund. No specific choice is inherent in the limited budgets available, although the requirement that choices be made is. In choosing how to deal with health problems, budget limitations may sometimes be secondary to limitations in our visions about

and no one wants to add to the unnecessary suffering of any individual. But being "hard" neither makes illness or disability totally negative experiences,¹⁴⁹ nor does it mean they must all be eliminated or otherwise managed exclusively within the medical system. Women's desire for children without disability warrants complete public and private support. The question is how to provide this support in a way that does no harm.

To date, support has been constructed to comprise genetic screening and testing. This construction is, in many ways, a result of the current system of health-care delivery in North America and the economic pressures on it. At a time when cost-containment is a dominant theme and a primary goal of policy makers, identifying those with, or susceptible to, some condition and preventing the occurrence of the anticipated condition seem to "make sense." It coincides, too, with the risk-benefit approach currently applied to most social and environmental problems.¹⁵⁰ It corresponds with middle-class attitudes toward planning, consumers' rights and quality. But while this approach seems to "make sense," it does not suffice as a justification for the use of these technologies. Though it is more than twenty years since the first fetal diagnosis of Down syndrome by amniocentesis, we do not yet know the full impact of prenatal testing and screening on women's total health, power and social standing.

When amniocentesis was introduced, abortion subsequent to a diagnosis of fetal abnormality was presented as a temporary necessity until treatment for the detected condition could be devised.¹⁵¹ Advocates assumed that this would soon be forthcoming. With time, however, the gap between characterization and treatment of disease has widened.¹⁵² New information from efforts at gene mapping will certainly increase the ability to detect, diagnose and screen, but not to treat. A human gene map will identify variations in DNA patterns. Genes that "cause" specific disease, as well as those associated with increased susceptibility to specific disorders, will be found. Simultaneously, prenatal screening and testing are evolving in a context where a "genetic approach" to public health is gaining great favor.¹⁵³ All the variations that will be mapped can become targets of prenatal testing. Which targets will be selected in the quest for improved public health? And who will deter-

what to do. And, in choosing how to approach (even) "hard" issues, genetic prevention is but one possibility.

¹⁴⁹ Asch, *Reproductive Technology and Disability*, *supra* note 143, at 70.

¹⁵⁰ Cf. L. WINNER, *supra* note 68.

¹⁵¹ See Friedmann, *Opinion: The Human Genome Project — Some Implications of Extensive "Reverse Genetic" Medicine*, 46 AM. J. HUM. GENETICS 407, 412 (1990).

¹⁵² *Id.* at 411.

¹⁵³ Lippman, Messing & Mayer, *supra* note 15, at 397.

mine that they have been reached? Given the extraordinary degree of genetic variability within groups of people, what does "genetic health" actually mean — and does it matter?

For society, genetic approaches to health problems are fundamentally expensive, individualized and private. Giving them priority diminishes incentives to challenge the existing system that creates illness no less than do genes. With prenatal screening and testing in particular, the genetic approach seems to provide a "quick fix" to what is posed as a biological problem, directing attention away from society's construction of a biological reality as a problem and leaving the "conditions that create social disadvantage or handicap . . . largely unchallenged."¹⁵⁴

Justice in the domain of health care has several definitions, but only one is generally employed in contemporary choice-and-control stories of genetic screening and testing. In these stories, justice is defined by the extent to which testing and screening programs are available and accessible to all women.¹⁵⁵ Distributive justice is the goal: fair treatment requires access for all.

This definition seems insufficient. Access involves more than availability, even broadly defined. Not all individuals can respond similarly even to universally "available" services and, even if they can, unfairness and injustice may continue. Thus, perhaps we need to introduce other concepts of justice when thinking about prenatal testing and how these programs contribute to, or diminish, fairness in health and health care for women (and others). Do they ensure good for the greatest number (social justice)¹⁵⁶ given all the causes of perinatal morbidity and mortality? Do they recognize and seek to correct past discrimination (corrective justice) given current and historically-based inequities in health? Will they level the playing field for women, for the poor?

One approach to justice is not necessarily better than another. In fact, depending on the circumstances, each one might be seen as "better." We need to keep these multiple routes to fairness in mind as we determine those to whom we wish to be fair and that for which fairness will be sought. For instance, human relationality may be as worthy of guarantees and respect as human autonomy;¹⁵⁷ "individual good" is not always synonymous with "common good," though social responsi-

¹⁵⁴ McDonough, *supra* note 35, at 149.

¹⁵⁵ See, e.g., Cunningham & Kizer, *Maternal Serum Alpha-Fetoprotein Screening: Activities of State Health Agencies: A Survey*, 47 AM. J. HUM. GENETICS 899 (1990) (arguing that state health agencies must accept that genetic services constitute a public health responsibility).

¹⁵⁶ Lippman, *supra* note 15. Cf. Shannon, *Public Health's Promise for the Future: 1989 Presidential Address*, 80 AM. J. PUB. HEALTH 909 (1990) (need for public health programs to promote social justice).

¹⁵⁷ Ryan, *The Argument for Unlimited Procreative Liberty: A Feminist Critique*, HASTINGS CENTER REP., July-Aug. 1990, at 6 (cautioning that human relationships must not be overlooked in the argument for an unlimited right to procreate).

bility need not become paternalism. There are choices to be made and the choices will reflect our values and ideology. How we choose our culture (by the routes we take) is no less problematic than how we choose our children, and consequences from both will be among our legacies.¹⁵⁸

Addressing these choices will itself be "hard," and will require we recognize and grapple with disjunction¹⁵⁹ between goals and needs — perhaps even "rights" — on the social and on the individual levels. What seems to be appropriate or best for the individual may not be so for the collectives to which we all belong.¹⁶⁰ We need urgently to address these contradictions now, using our energies to situate, understand and maybe even in some way resolve them, rather than keep them at the periphery of our vision. We must confront the possible need to choose between what is unfortunate and what is unfair in the distribution and reduction of risks to health and well-being. We must also acknowledge how our compassion for an individual's situation may harm women's health in general if addressing private needs dislocates provisions required for the public or solidifies existing inequities in women's position. This disjunction is not unique to genetic screening and testing,¹⁶¹ but is certainly echoed with force in this area.

This disjunction will make dialogue about the place of prenatal diagnosis in women's health care especially difficult (and, on occasion, tense). However, this only underscores the need to avoid premature closure of discussion and to avoid reducing it to sterile debates be-

¹⁵⁸ See R. CHADWICK, *Having Children*, in ETHICS, REPRODUCTION AND GENETIC CONTROL 3 (R. Chadwick ed. 1987) (prenatal diagnosis is not only a private matter); see also Edwards, *The Importance of Genetic Disease and the Need for Prevention*, 319 PHIL. TRANSACTIONS ROYAL SOC'Y LONDON 211 (1988). Edwards identifies the "conveyance of our genetic material from one generation to the next with the minimum of damage" as the "biggest public health problem facing our species." *Id.* at 112. I adapt his comments as a further reminder of the essential interconnections between genes and culture: mutations cause genetic damage and we do make social and political choices that influence the rate of mutation.

¹⁵⁹ I thank Margrit Eichler for suggesting this term and apologize if my use distorts her concept inappropriately.

¹⁶⁰ Cf. Danis & Churchill, *Autonomy and the Commonweal*, HASTINGS CENTER REP., Jan.-Feb. 1991, at 25 (suggesting we can no longer avoid the conflict between individual wishes and societal needs and proposing, though with respect to other technologies, that we consider the concept of "citizenship" in attempting to accommodate both levels); see also Fox, *The Organization, Outlook and Evolution of American Bioethics: A Sociological Perspective*, in SOCIAL SCIENCE PERSPECTIVES ON MEDICAL ETHICS 201 (G. Weisz ed. 1990) [hereinafter SOCIAL SCIENCE PERSPECTIVES].

¹⁶¹ Given that even viewing private and public as alternatives reflects our prior western beliefs that these are necessarily distinct spheres, it is of interest that the notion of disjuncture seems to echo the lingering historical debate between "healers" and "hygienists" about the best way to deal with health problems. Generally, heroism in healing has had more appeal than the supposedly less glamorous work of the hygienist. See Loomis & Wing, *Is Molecular Epidemiology a Germ Theory for the End of the Twentieth Century?*, 19 INT'L J. EPIDEMIOLOGY 1 (1990).

tween "pros" and "cons." The issue is *not* between experts promoting technology and Luddites trying to retard science. It is not between women who "want" prenatal diagnosis and women who don't want "them" to have it. It is not a dispute between advocates of prenatal diagnosis who are seen as defending women's already fragile rights to abortion and critics who are said to be fueling "right to life" supporters seeking to impose limits on women (and their choices).¹⁶² All of these themes are being played out, but to focus on them is to create false polarities and to trivialize the possible advantages and disadvantages of these technologies when trying to deal with women's health concerns. Moreover, it incorrectly decontextualizes these technologies, severing their essential relatedness to time and place and isolating them from the broader health and social policy agenda of which they are a part.

Consequently, it is imperative that we continue to listen to the stories being told about prenatal testing and screening with a critical ear, situate them in time and place, question their assumptions, demystify their language and metaphors and determine whether, and to what extent, they can empower women. These technologies warrant social analysis.¹⁶³ Not to examine repeatedly the tales and their tellers will be to abdicate responsibility to the generations that present and future genetic screening and testing programs will, or will not, allow to be born. A perspective that makes us responsible for the future effects of our current activities, the well-intentioned and the unintended, may stimulate the imaginative re-vision required so that we consider not just "where in the world" we are going with the new genetics,¹⁶⁴ but where we want to go and whether we in fact want genetics to lead us there.†

¹⁶² Important to understanding this idea is the distinction between "fetalists" and "feminists." Raymond, *Fetalists and Feminists: They are Not the Same*, in *MADE TO ORDER: THE MYTH OF REPRODUCTIVE AND GENETIC PROGRESS* 58 (P. Spallone & D. Steinberg eds. 1987). "Feminist positions on the NRTs [new reproductive technologies] highlight the explicit subordination and manipulation of women and their bodies that are involved in these reproductive procedures . . . [while] fetalists are concerned with what they express as the 'violence' done to the conceptus, embryo, or fetus in procedures such as IVF." *Id.* at 60-61.

¹⁶³ In fact, we must be careful not to assume that all the social implications are ethical ones and to acknowledge that even deciding *what* the moral/ethical questions are is not "value free." This is especially important because bioethical analyses tend to emphasize individual rights rather than the "mutual obligations and interdependence" that may be critical determinants. G. WEISZ, *Introduction*, in *SOCIAL SCIENCE PERSPECTIVES*, *supra* note 160, at 1, 3.

¹⁶⁴ Fletcher, *Where in the World Are We Going with the New Genetics?*, 5 J. CONTEMP. HEALTH L. POL'Y 33 (1989).

† This paper, and the larger project from which it derives, would have been impossible without the support (emotional and intellectual) of an especially generous and thoughtful number of friends and colleagues who have nurtured my work and ideas (and, not infrequently, me) during the past several years. Some of these individuals are personal friends; others I've either met only recently or know only through their writing because of our common interests in and concern about the impact on women or reproductive and genetic technologies. Among the latter, Peggy McDonough, Christine Overall, Rayna Rapp, Janice Raymond and Barbara Katz Rothman have been of particular influence. In many ways, this

paper represents a synthesis of much of what they and I have said or written on various occasions in our interconnecting and overlapping commentaries. I have tried to disentangle who said/wrote what first so as to give credit where it is due, but I fear I have not always been successful. This means that the initiator of some argument or the coiner of some phrase may not be appropriately acknowledged in what follows. I request forgiveness for these citational lapses and count on those whose work I have unconsciously adopted and adapted without credit to point them out.

I extend special gratitude, too, to Louise Bouchard, Myriam Marrache and Marc Renaud, colleagues at the Université du Montréal who helped me think through some aspects of this project during its earliest stages in its — and their — mother tongue.

I have benefitted in many ways from my friends Gwynne Basen, Margrit Eichler, Patricia Kaufert, Karen Messing and Louise Vandelac. Their insightful ideas and comments have given depth and breadth to my own thinking about the issues discussed here, and their constant support has kept me going. Friendship with these very special women has enriched my life enormously.

The same is true of Ruth Hubbard, who graciously and thoughtfully shared her wisdom and provided encouragement. She was first to introduce many of the issues and concerns I address and her presence is apparent throughout this text. Her proposal that I use the opportunity of this paper to pull together several partial manuscripts I had been carrying around, on paper and in my head, was, moreover, just the stimulus needed to get me going at a time when this project was stalled and likely to remain so forever. But, while she is responsible for the process, any shortcomings in the product are mine alone.

There are others whom I would also like to thank: Marion Kaplan, the "best friend" everyone should have who, with Irwin, was an extravagant donor of bed and board during my sojourn in New York; the staff at the Hastings Center for their hospitality and the occasion to get carried away in their library during my month there as a visiting international scholar in 1989; Ryk Edelman and Bill Swetland, who made emergency house calls when my limited word processing skills made manuscript drafts mysteriously disappear; Zeba Hashmi who put up with multiple document conversions trying to harmonize her WP 5.0 with my 4.2 as we created the text and its multiple annotations; the Social Sciences and Humanities Research Council of Canada for providing funds to support research assistants for project-related studies that allowed me to meet and work with Fern Brunger, a graduate student who held my hand during my first steps in the world of critical medical anthropology, and provided clear evidence of how the best learning is a two-way street; the National Health Research Development Program of Health and Welfare Canada for a Scholar Award that provides my personal support; and finally, but perhaps most of all and with much love, Christopher and Jessica for being in my life.