The Genetic Construction of Prenatal Testing: 
Choice, Consent, or Conformity for Women?

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Biomedical researchers are currently redefining human geography. These modern explorers are elaborating a new human map, based on genes, that is likely to alter our views of the world—and our place in it—even more profoundly than did the maps generated by Columbus and other fifteenth- and sixteenth-century explorers. More important, this newest expression of territorial expansion and colonization, a process I call geneticization and describe more fully below, is likely also to alter our perceptions of self and other, of normality and abnormality, particularly in the area of procreation. This can be seen most clearly in the consideration of the impacts of prenatal genetic testing and screening on women.

The application of prenatal genetic screening and testing—and I use the terms generically, if imprecisely, to encompass the range of activities from amniocentesis through ultrasound to embryo analysis—raises a number of fundamental concerns related to women's health and health care simply because they are techniques applied to women. How, when, why, and to and by whom they are applied will be conditioned by prevailing attitudes about women, their bodies, and their roles. Although some concerns pertain especially to only certain groups of women, those that I will emphasize cut across color, ability, economic, and sexual orientation lines and are relevant to all women. Being developed in a world that is gendered, the ge-
netic and other reproductive technologies cannot escape gen-
dered use, use that reflects prevalent ideas about women.\(^1\) Thus,
even if the technologies have not been developed and used spe-
cifically to maintain gendered distinctions and increase patri-
archal power, as some have suggested (Rowland, 1984), pre-
natal testing cannot be considered as neutral in North America
or any other society in which inequality exists between the
sexes. Women remain politically and economically disadvan-
taged, have limited access to services, and are continually
challenged by prejudicial norms surrounding motherhood, in
addition to being delegated responsibility for family health.
Women experience testing, therefore, not merely as parents, but
as mothers. Applying prenatal technologies, when disability in
a child is viewed as a private problem for a family, is not only
a matter of testing a parent who will care for a child, but of
examining the woman who is to be a mother responsible for
avoiding, reducing, or managing disability in her offspring.

Let me emphasize that I am working under the assumption
that prenatal testing is problematic for all women, users and
nonusers, supporters and critics alike. In no way do I intend my
remarks about it to reflect negatively on women who have con-
sidered or undergone testing; criticism of the technologies is not
criticism of them. Women considering childbearing today face
agonizing issues that I was fortunate enough not to have to con-
front, and as I learn from them I can only admire and respect
their tremendous strength and resilience.

**Background of Prenatal Genetic Testing**

When first developed, prenatal diagnosis was employed for
conditions generally regarded by physicians as serious and for
which there were no treatments. It is now available for condi-
tions with little or uncertain impact on postnatal health and
functioning, conditions that will appear—if at all—only in
adulthood, and conditions for which effective treatments exist.
Clearly, the number of complications that can be discovered
with prenatal testing is expanding: the earliest time period when
attempts to detect problems are made is being moved back from
the 14–20 week period when amniocentesis is employed to the
10–12 week slot allotted to chorionic villi sampling (CVS). Indeed, a woman need not even be pregnant now to obtain “prenatal” diagnosis because embryos procured following in vitro fertilization can be examined before they are implanted.

The expansions being made in the definitions of the categories of subjects, objects, and timing of prenatal diagnosis are troubling. But even without those issues, many thousands of women, pregnant or not, are already confronted by the need to consider how much, if at all, they want to know about a fetus during pregnancy, what wanting or not wanting this information entails and implies, and how they feel about disability. The very availability of those technologies necessarily forces every woman at least to consider if she desires genetic testing—or if she even desires that testing be available for use by other women—and merely facing this choice is itself difficult, and often painful (cf. Lippman-Hand & Fraser, 1979a, 1979b).

Prenatal genetic testing is not just another improvement in obstetric care, despite the tendency of some to call it routine, or even banal (Dumez, 1989). Rather, deciding for or against testing makes many women feel they will be making a terrible mistake regardless of the path chosen. With the application of genetic testing earlier and earlier in fetal life, and with the growing number of variations now detectable (some of which may only increase susceptibility to the later development of a treatable medical problem), it seems urgent that we directly examine the real reasons we are testing women and fetuses, what it means to test them, how testing establishes boundaries for what we call normal, and how changes in us, our relationships, and the children we bear may be embedded in testing. To start this examination it is useful to look at some of the stories told about health, disease, and prenatal testing.

Stories and Storytellers

In our contemporary Western culture, we tend to cling to the seemingly unproblematic belief that the pursuit of biomedical knowledge of health and disease is a sign of progress. We all too often forget that despite their biological reality, human diseases, disorders, and disabilities—the objects of prenatal screening—
are not just physical or physiological states with fixed contours. Rather than merely being "out there" awaiting our discovery, they are social products with variable shapes and distributions that we fashion, interpret, and give meaning to via our beliefs, attitudes, values, and interests. Western biomedicine is our ethnomedicine, and it does not describe a preexisting biological reality. Particular social and cultural assumptions (Wright & Treacher, 1982) influence the scientific researchers who give the biological processes of observed diseases particular forms through their diagnostic labels and causal attributions. Those forms vary across different human groups and at different periods of time. How the processes are counted, defined, and studied, and how people are assigned to the categories created, is necessarily context-specific, reflecting how those with power at any particular historical time construct a particular physiological or physical condition as a problem. These constructions are what I call "stories."

By using the word story I do not intend to suggest that what is said or written about health and disease is not true. This may or may not be the case, but that discussion is not relevant here. I use the word in a literary rather than a legal sense to capture the idea that scientists choose their subject matter and present their observations, their research, in the same way as novelists select some arbitrary slice of life to describe and interpret the external world. Both groups, both sets of authors, shape and interpret raw material to convey a message, reducing its complexity in order to tell a story. Their constructions reflect their personal views and the prevailing political, social, and cultural context.

Because the distribution of health and disease is influenced by many factors—social and physical environments, economic conditions, gender, racial identity, personal behaviors, and available health services, as well as heredity—biomedical scientists have a wealth of raw material from which to choose when they construct their explanations, their stories, for the conditions that interest them. The factors they choose to (re)create stories and metaphors about health and disease, and the subsequent expression of those choices in public policies and private practices, will reflect the background beliefs, the vested inter-
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ests, and the ideologies of both those studying such matters and those funding their studies.

Stories, in general, rearrange that which is complex into shapes that simplify and tame. This certainly characterizes the stories about health and disease in today's professional and popular media that are being told increasingly in the language of genetics. Using the metaphor of blueprints, with genes and DNA fragments presented as a set of instructions, the dominant discourse describing the human condition is reductionist, emphasizing a genetic determination for our various frailties and differences from one another, with the double helix employed as illustrative icon (Myers, 1990). In standard Cartesian tradition the body is viewed as a machine comprising replaceable parts, with genes and DNA sequences being the essential components of these parts. The author of a recent book about genetics selected for distribution by the Book-of-the-Month Club may have been extreme in enthusiastically describing human diseases as "typographical errors" (Shapiro, 1990), but his narrative was not out of line with today's best-selling stories telling how increased understanding of disease and the improvement of health can only be produced by studying (and mapping) genes and developing tests to establish our, and our children's, genetic status and chemical individuality.

I use the term "geneticization" to capture this single conceptual model that is increasingly elicited to reveal and explain health and disease, normality and abnormality, and that is directing the application of intellectual and financial resources for resolving health problems, profoundly affecting our values and attitudes (Lippman, 1991; Lippman, Messing, & Mayer, 1990). Geneticization refers to the ongoing process by which priority is given to searching for variations in DNA sequences that differentiate people from each other and to attributing some hereditary basis to most disorders, behaviors, and physiological variations (including such things as schizophrenia and high blood pressure as well as the ability of children to sit still while watching television and of adults to quit smoking). Whereas "energetic physicians" once "discerned microorganisms responsible for almost every ill known to mankind [sic]" (Rosenberg, 1992), their latter-day heirs discern genes. In this sense, geneti-
cization is a process of colonization with genetic technologies and approaches applied to areas not necessarily—or even apparently—genetic.

As geneticization becomes an ever louder theme in stories of health and disease, prenatal genetic screening and testing take on major roles in the search to find those who have certain genetic differences thought to be associated with what is considered biomedically abnormal. Indeed, applying these technologies increases the numbers of those with conditions labeled as genetic or with variations called abnormal, and establishes hierarchies among individuals based on their sought-after DNA differences. Carried out on women who experience unequal distributions of health that reflect class, race, and other social stratifications in North America, prenatal genetic screening and testing technologies have a vast shaping power likely to reinforce existing standards and power relationships. This alone makes an examination of those stories especially appropriate.

Stories about Prenatal Testing

As a major component of genetic stories of health and disease, prenatal diagnosis is given its own narrative shape. Attractively phrased, medically oriented arguments provide the key motifs in reports of prenatal testing, reports that serve largely to naturalize the activity by shaping it as a means for “reproductive autonomy,” a way of giving women information that will expand their reproductive choices (Lippman, 1986). As such, it is stated to be a response to the “needs” of pregnant women for reassurance, something women “choose.” (A subtext in contemporary biomedical stories about prenatal diagnosis presents it as a public health activity to reduce the frequency of selected birth defects, but this theme is usually considerably muted for reasons discussed elsewhere [Lippman, 1986, 1989]).

Unfortunately, the dominant (need/choice) presentation is incomplete because it fails to capture the internal tension of prenatal genetic testing. This tension arises because testing comprises at least two sets of conflicting activities. As supporters claim, it may be a way to give women some control over their pregnancies, respecting (and increasing) their autonomy to
choose the kinds of children they will bear (Hill, 1986). It may be a means of reassuring women that could enhance their experience of pregnancy (Royal College of Physicians, 1989) by providing a way to avoid the family distress and suffering associated with the unpredicted birth of babies with genetic disorders or congenital malformations. But, as critics claim, it is also an assembly line approach to the products of conception, separating out those products we wish to develop from those we wish to discontinue (Ewing, 1990; Rothman, 1989)—though biomedical authors continually reject any suggestion that testing may be eugenic.

The language of control, choice, and reassurance used by supporters, usually biomedical authors, certainly makes prenatal diagnosis appear attractive and is, at first reading, persuasive. (This discourse is also more likely to succeed as a colonizing strategy than one employing an image of selection.) But in reading the pleasing biomedical stories closely, several problems (beyond those of the absence of good empiric evidence to support the claim that control, autonomy, and reassurance are actually enhanced) are brought to the light.

First, these are but partial stories because they exclude the words of women who ignore their physicians’ urgings for amniocentesis and reject testing in order not to lose the assurances provided by their own bodies that they are healthy and normal. One particularly eloquent teller of such a story explained that she sought reassurance from what concerned her by refusing testing when pregnant at age 38. She perceived her risk as a pregnant woman not in terms of having a child with Down syndrome, but in terms of what might ensue if she entered a process of medical surveillance. She feared testing would enmesh her in a system that would produce problems and create experiences likely to undermine her pleasure of pregnancy, and she didn’t want to divert her energy from enjoying her pregnancy to fighting this system. Her story is not unique, and for a more complete description we need to situate prenatal testing and grapple with its contradictions; we must include such experiences told by women in their own ways. Reassurance comes from many sources, not all of which are linked to genetic testing.
Second, to tell the story of prenatal testing univocally, in the language of reassurance, is clearly too simplistic. Notwithstanding that genetic testing can be selectively reassuring for the vast majority of women in prenatal diagnosis programs who will learn that their fetuses do not have Down syndrome, the bold text offers rhetorical camouflage and evades questions about why reassurance is sought, how its provision is circumscribed, and how prenatal testing may actually threaten women's well-being and create dis-ease. It hides the iatrogenic nature of "need" by failing to ask whether reassurance would be sought if an outsider had not first decided that certain women were at risk and that the condition for which the risk existed warranted diagnosis before a baby with it was born. It hides the need to consider the possibility that reassurance is a biomedical fix disempowering women and increasing their dependency on technology.

The concept of risk dominates the process of becoming a mother in North America today (Quénéhat, 1988). Women are categorized from the time of a first prenatal visit into high- and low-risk groups, with membership in a "no-risk" group possible only in retrospect. By attaching a risk label to pregnancy, physicians reconstruct a normal experience, making it one that requires their supervision. This becomes especially clear in the context of the major application of prenatal genetic testing to date: here risk has been conceptualized strictly in terms of a woman's age, with those 35 years and older automatically and homogeneously labeled as belonging to a high-risk group warranting prenatal diagnosis because of their statistical probability of giving birth to a child with Down syndrome. While presented as a biomedical fact, however, this recommendation is actually more a social statement about the status of the woman and the quality of her fetus. For example, despite the biomedical classification, women 35 and older are not the only ones at risk for having a child with Down syndrome. In addition, the discontinuity imposed by this particular age cutoff is medically arbitrary, since the probability of fetal chromosome abnormality increases smoothly with a woman's age (Vekemans & Lippman, 1984). All women have some risk of having a child with Down syndrome. What defines one probability as high and another as low?
The location of a statistical boundary to separate high- or low-risk groups is historically and politically contingent. In France, for example, "risk" apparently begins only at 38 years, since this is when public funds first cover services (Moatti et al., 1989). Age 35 as the point of entry to a genetic risk group and as the criterion for prenatal testing probably replaced the initial threshold in North America—which was no less arbitrarily set at age 40—in response to cost-benefit analyses and service needs assessments undertaken as prenatal diagnosis was developed.  

Certainly, no new information was produced to indicate that women ages 35 to 39 were at greater risk than they had been a decade earlier when 40 was the magic threshold. Nor had women's biology changed. Rather, definitions and expectations of normal pregnancies intersected with developments in prenatal diagnosis and a growing "ideology of risk" surrounding pregnancy; the worries about Down syndrome and the quest for normal offspring turned into technical problems to be overcome, with prenatal testing being the response. The process, we should note, continues today with proposals to further lower, if not remove, the age limit for amniocentesis proliferating. Getting "older," it seems, is getting younger every day (Hubbard, 1984). And with more and more women being told that their age (thus, in effect they) create a risk for the fetus, the number wanting reassurance through testing to allay iatrogenic worries can only increase.

Moreover, having a prenatal screening test specifically oriented to detect a particular condition—and Down syndrome provides a compelling example—expresses a social statement about the quality or the value of fetuses and children based solely on their genetic or chromosomal material. Through these programs we are saying it is okay if children with certain chromosomes are not born, and that having the condition detected is, in effect, worse than being alive (Asch, 1988). And we underscore this by invariably considering the abortion of a fetus with some disorder as a core benefit, not a worrisome cost (Clarke, in press), when economic analyses of screening programs are carried out.

Further, the power to set boundaries for who may or may not be born remains with those university researchers and for-profit laboratories who develop and deploy the technologies of
testing. Only the conditions for which they make tests available can be sought, with what is available determined by their agendas for professional recognition or financial profit—by their social values. Here, as elsewhere, individuals may seem to choose, but it is only from options constrained by the limitations of possibilities created by others (Lippman, 1989).

Thus, for a complete understanding of how reassurance relates to prenatal testing programs for women 35 and older and to their acceptance of these procedures, we need to situate the biomedical stories in the historical and cultural context in which notions of risk and attitudes toward normality are constructed. When we remember that in North America today, pregnancy has largely come to be seen as baby production (Martin, 1987) with the laborer, the pregnant woman who will produce the baby, being held to certain standards (Rothman, 1989), it is not unreasonable to call stories about testing incomplete if they fail to take into account its use to ensure the quality of both mother and child. Prenatal testing provides “reassuring” quality control and consumer protection, necessarily involving systematic and systemic selection of fetuses, most frequently on genetic grounds. Biomedicine can’t directly change the risk to the quality of the “product” stemming from a woman’s age, the probability of chromosomal nondisjunction leading to Down syndrome. But rereading the reassurance text reveals that biomedicine claims it will control its impact by providing testing to identify “products” of lesser quality—fetuses with Down syndrome—and prevent the birth of those that are “abnormal.” If, then, reassurance is produced following prenatal diagnosis, it is, at best, an acquired rather than inherent characteristic of testing, tranquilizing women who have first been made fearful.

So, before screening or testing for Down syndrome is further extended to reassure women of all chronological ages, let us reclaim the term and consider alternative stories about reassurance that respond to the desire of all pregnant women for healthy children and do not rely on prenatal testing and genetic control. For instance, the unacceptably large number of pregnant women living below the poverty line would probably like reassurance that their babies could develop as well as the babies of wealthier women and not be at increased risk for the childhood mortality and morbidity associated with low birth weight
and prematurity. Why not reassure them by providing the ade­quate diet required to prevent low birth weight? Why not allo­cate public funds for home visitors, respite care, and domestic alterations that would permit women to manage their special needs should their children be born with (or as is more likely, later develop), a health problem? These and other alternative approaches would provide reassurance to many women, would provide this reassurance with respect to (and for) fetal disabil­ity, and would diminish a woman’s feeling of personal re­sponsibility for a child’s health (Farrant, 1985). Furthermore, they would not require women to select fetuses based on their characteristics.

Stories about prenatal testing that imply that the testing is really only a response to the needs of pregnant women for re­assurance, something women choose, may seem sensible in a society that still allocates major responsibility for family health care to women and assumes that they must do all that is rec­ommended or available to foster their children’s health. But is there really choice? Is a full range of options truly available? Continuing a pregnancy when the fetus has been found to have Down syndrome cannot be considered a real option when so­ciety does not truly accept children with disabilities or provide assistance for their nurturance (cf. Retsinas, 1991). It is not sur­prising that a woman offered ultrasound by an expert—who implies that she really wants to have a healthy child, doesn’t she?—perceives a need to be tested, a need to do all that is rec­ommended (for her peace of mind, if nothing else). Is her agree­ment, then, to testing an expression of choice or an instance of conformity? When prenatal testing is presented as giving nature a helping hand because most fetuses with malformations are spontaneously aborted (for example, about 80% of fetuses with Down syndrome), is induced abortion perceived as a choice or as an automatic (natural) component of testing? And when those of us who are not pregnant repeatedly hear or read stories about the increasing frequency of genetic disorders and their further strain on already overextended medical systems, how can supporting the extension of testing programs not seem an appropriate social “choice” to deal with this so-called public health problem (Rowland, 1984).³

To no one’s surprise, a woman may need some extra help to
raise a child with a disability. If society does not respect and meet her needs appropriately, she will, as is understandable, seek a way to avoid the problem. If prenatal testing and abortion of fetuses with the disability constitute the only solution offered, a need for screening gets created. But without real options that respect a woman for herself, not for her role as producer, choice may be a misnomer.

Legitimate efforts to avoid unnecessary harm to a fetus or a woman in a continuing pregnancy and to protect both from avoidable death or disability are essential. But if healthy children really matter to us, as we say they do, is prenatal testing the best way to express our concern? All—or even most—that interferes with this idealized health status is not obviously genetic. And if healthy children really matter to us, their mothers must matter first. The well-being of children and the well-being of women are inseparable. Social, political, and economic neglect of women interferes with the physical and mental development of their children more than does the genetic variation they inherit. The physical violence experienced by 10% of women during their pregnancies cannot but affect their children's health too. If we value the mother and not only the birth of a healthy child, we must attend to this violence and neglect and not just attend to their genes. To ensure a woman's agency, we must create the conditions in which agency can be fully exercised without limits on her options.

Thus, we should resist relying on prenatal genetic testing to ensure our children's health when employing it threatens to displace attention from society's role in creating illness and seriously risks women's general well-being. Prenatal genetic testing, already called a ritual for (white, middle-class) women older than 35 (Rapp, 1988), may actually threaten women's well-being with the circumstances of its use making it resemble an addiction: the practice is socially determined, it satisfies a need to feel good with a fix, it creates dependency, and it provides substitute gratification. Evidence of this addiction appears in stories that describe testing as a way to release a woman to enjoy her pregnancy, high with the reassurance that the fetus does not have Down syndrome. It appears when women come to depend on testing because they are told it will provide a
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healthy baby. And it appears in the photograph or videotape of her ultrasound scan proudly displayed by a pregnant woman that functions as a technological substitute for the changes in her body and feelings that might once have satisfied her about her pregnancy. Extending the parallel just a bit further suggests that regulation of prenatal testing will not preclude the dependence on technology that disempowers women any more than the regulation of drugs will preclude addiction. Detoxification requires a change in the circumstances that present use (of drugs and of testing) as a solution, especially when the technology (as drug use) creates a “lifestyle” among and for users that is troublesome.

Prenatal Testing as “Lifestyle”

Prenatal genetic testing creates a lifestyle for pregnant women to the extent that the use, if not the mere availability, of the technology inevitably shapes the experiences of maternity and, in some ways, even becomes an end in itself. Prenatal testing, like other technologies, creates a lifestyle because it shapes issues in new ways, translates everyday life, transforms definitions of natural, and determines how pregnant women ought to live. For example, data from ongoing studies by myself and others (Green, Statham, & Snowdon, 1992; Press & Browner, 1993) indicate that having all the prenatal tests offered, along with giving up alcohol and smoking, going to prenatal classes, and eating properly have already become established behaviors that “responsible” (white, middle-class) women say they do “for the baby’s good” once pregnancy begins (cf. Green et al., 1992). In addition, the mere possibility that women can avoid the birth of a child with some malformation makes the occurrence of such a birth “regrettable” and not just unfortunate.

Further transformations result from other features intrinsic to the use and experience of prenatal testing:

1. Most obvious, and as Beeson (1984) first showed, prenatal testing shapes the experience and progression of pregnancy. It divides what is unique, and unitary, into two not always compatible experiences—a social pregnancy and a biological pregnancy—and requires a woman to adapt to the testing process
and to a physician's schedule. When she tells others about her pregnancy, when she visits her physician, where she receives her care, and what she acknowledges as evidence that things are going well all occur on "testing time" rather than "women's time" (Beeson, 1984). Rothman's term, the "tentative pregnancy," captures some of that notion (Rothman, 1986).

Moreover, because prenatal screening and diagnosis have come to be seen by providers as part of the taken-for-granted package of services for pregnant women, part of the lifestyle of maternity, the normative has been inverted; only women who decline screening are referred for genetic counseling in some jurisdictions (Green et al., 1992); only women who reject parts of the antenatal care package (if they are white and well-educated) are treated as somehow abnormal. There seems to be more room for maneuver for African-American and Asian-American women, interestingly enough, perhaps because their rejection of testing is taken (ethnocentrically?) as an expression of "difference" (cf. Clarke, in press).

2. Prenatal testing, by another process of division, separates a single entity, a pregnant woman, into two: herself and her fetus. And by shaping the fetus as separate and separable from the woman, an opportunity is provided to assign independent interests (and/or rights) to it—interests not just attached through the mother. Suddenly "fetal abuse" becomes a thinkable concept, and a pregnant woman can be subjected to rules, regulations, and duties established by those seeking to protect fetal interests. With this division, a responsible mother becomes one who does everything—takes all tests—to ensure fetal health (Robertson, 1983; Shaw, 1980). So while a woman may have no control over or responsibility for the chromosomal occurrence of Down syndrome, she can control the birth of a child with this condition by being tested. Thus, if a child with Down syndrome is born to a woman who has refused testing, this becomes an event for which the child's mother is responsible because she could have prevented its occurrence. The individual is made into an agent of the state. This is made explicit when a 38-year-old gives birth to a baby with Down syndrome and several professionals ask: Why didn't she get tested (Thomson, personal communication, 1992)? Given that prevention is in-
creasingly the goal of biomedicine, with what speed will the
disabilities and variations that can be prevented because prenatal
tests for them exist become those that should be prevented, with
testing thereby reshaping eugenics into a private process of “se-
lection by prevention” (Kuitert, 1988)?

3. Prenatal testing as a lifestyle shapes general attitudes to-
ward disability in multiple ways. Most generally, testing pre-
sents disability as if it were simply a medical problem, hides the
social roots of handicaps, and distracts attention from prevailing
social, economic, and political policies whose failure to account
for a wide distribution of abilities convert impairments into
handicaps. Testing reshapes the problem of disability so that it
need not be ours collectively to solve (what will we do to em-
brace and accommodate those among us with disabilities?), but
becomes, as noted above, one for the individual woman to pre-
vent (what will she do to avoid having a baby with a disability?).

Perhaps more troubling, however, prenatal testing implicitly
assumes some norm of ability. Not only has testing clearly
shaped attitudes toward Down syndrome, making it a privi-
leged reason for abortion, but it gives social endorsement—if
not active encouragement—to the abortion of a fetus on the
basis of its potential ability.

Women have abortions for many reasons. No matter what
one’s commitment to women’s reproductive freedom may be,
however, some abortions seem more troubling than others. In
this more problematic group are abortions that occur because
society has created implicit expectations about the kinds of ba-
bies women should have. In so doing, society fails to provide
women with what they require to be able to continue a wanted
pregnancy to term, whether or not a disability has been identi-
fied. Unfortunately, prenatal testing contributes to this failure.

4. Prenatal testing further shapes the experience of abortion
in ways beyond the models on which we usually rely to guar-
antee women’s privacy and control. As suggested earlier, pre-
natal testing may not only reduce a woman’s liberty to refuse
an abortion, but it allows geneticists and their obstetrician
colleagues to impose a “choice” for abortion covertly, if not
overtly, when they decide which fetuses are healthy, what de-
fines healthy, and who should be born. They do this merely by
offering tests for certain conditions and not others, as well as by what they tell parents about such conditions. (For a summary of these “twice-told” tales see Lippman & Wilfond, 1992.) That the birth of certain babies should be avoided is announced merely by making testing available. And as specialists in prenatal screening programs determine, more and more, whether a condition will be marginalized, an object of treatment, or grounds for abortion, the more power they gain over decisions to continue or terminate pregnancies—power that pregnant women themselves may not always have.

Prenatal testing shapes control over abortion, too, by legitimizing a role for insurance companies and governments in what should be an intensely personal matter for the individual woman. Whoever funds genetic testing programs or covers the cost of treatment for conditions diagnosable in utero may claim a say in determining which tests are carried out and what action the results must entail (Billings, 1990). Recent reports of the plan of a health maintenance organization in the United States to withdraw medical coverage if a child with cystic fibrosis was born whose birth could have been avoided by a “choice” to abort the pregnancy after the prenatal diagnosis was made (Billings et al., 1992) give substance to concerns about the power of testing to shape control of abortion.

However dramatic, such gross abuses should not distract us from the seemingly straightforward and everyday policies for testing programs that also reshape abortion choices. For example, women’s decisions about pregnancy termination for the same chromosome abnormality are influenced by whether or not fetal anomalies are visualized on ultrasound (Drugan, Greb, Johnson, & Krivchenia, 1990). They are influenced too by the person who announces that an abnormality has been found, with rates of abortion reported as higher when the information is related by obstetricians than by geneticists (Holmes-Siedle, Ryynanen, & Lindenbaum, 1987). Even replacing amniocentesis by the earlier CVS reshapes control because geneticists generally view first trimester terminations as less problematic than the possibility of a second trimester termination and, thereby, a less legitimate reason to refuse prenatal testing.

No policy may have yet been formulated explicitly to reshape
control over abortion, but shifts in control are embedded in the very process of testing (only some conditions are tested for, some person must provide counseling, some method must be used), and it is insufficient merely to consider the change in the locus of control as a "side effect" subject to regulation or ethical review. We can draft and enforce regulations that establish who shall do counseling, when and whether ultrasound scans will be shown, and so on, to avoid misuse, but every use will have some effect on abortion. And these effects will reflect the values of those with power and position to establish the policies.

5. Prenatal testing reshapes our perspective on a woman's life cycle. This stems from the subtle entanglement between prenatal diagnosis and another long-standing problematic issue for women—aging (Martin, 1987)—and from the ways in which development of testing around maternal age 35 has reflected and reinforced existing attitudes toward women and their adequacy. At the least, the availability of prenatal diagnosis and professionally imposed age limits on access to testing have created the social category of "the older woman" (Nelkin & Tancredi, 1989). More troublesome, however, is how testing is portrayed as a tool for the already negatively stereotyped woman in her middle years who wants or needs to circumvent features of aging. With this tool, the increasing probability of chromosomal nondisjunction associated with increases in a woman's age can be managed, just as cosmetic surgery and estrogen replacement regimens can manage her other bodily changes associated with getting older. The biological "failure" causing Down syndrome can be controlled and older women need not be "less fit" (Hubbard & Henifin, 1985) for childbearing, just as wrinkles of the skin or hot flashes that also make her "less fit" can be controlled. Against this background, the enthusiasm of medical researchers who have recently begun to create pregnancies in women well beyond menopause using eggs from younger women should certainly trouble us (Sauer, Paulson, & Lobo, 1990).

Prenatal testing for women 35 and older may not be as transparently age-ist as the use of donated or purchased ova to create a pregnancy in a postmenopausal woman, but it also reshapes the "older woman" by its reliance on chronological age or its
equivalent as a principal criterion for fetal diagnosis. It implies that this sole feature is all that matters about a woman and conveys the message that after some arbitrary age she is a failure.

Given how prenatal genetic testing involves these various transformations—of pregnancy, of the fetus, of disability, of abortion as a choice, and of age—and the adaptations it demands of women, it becomes appropriate to see it as a lifestyle. Moreover, it is a lifestyle that takes for granted a very limited, class-biased, norm. How else would finding every fetus with Down syndrome become so important that universal triple screening is entering recommended medical practice while guaranteeing sufficient income and nutrition to all pregnant women to decrease their probability of having a premature or growth-retarded baby is not. The lifestyle of prenatal testing seems fashioned from a middle-class pattern that highlights the problems biomedical professionals themselves may experience. Women in this group are far more likely to have pregnancies when they are in their mid-30s and older than are poorer women, but they are much less likely to give birth to babies with growth problems.

**Making Mothers Matter**

When amniocentesis was introduced, abortion subsequent to the diagnosis of a fetal abnormality was presented as a temporary necessity until treatment for the detected condition could be devised. Advocates assumed that this would soon be forthcoming. With time, however, the gap between characterization and treatment of disease has widened. New information from efforts at gene mapping will certainly increase the ability to detect, diagnose, and screen, but not necessarily to treat. In fact, in the current sociopolitical climate of North America, where individual responsibility to prevent health problems takes precedence over social responsibility to support policies that promote the general well-being of all, developing remedies is probably far less likely than developing ways to prevent the birth of those who may have such problems.

The human gene map currently under construction will identify variations in DNA patterns. Genes alleged to cause specific disease, as well as those associated only with increased suscep-
tibility to some disorder, will be found. All the variations that will be mapped could potentially become targets of prenatal testing. Which physical, mental, and aesthetic characteristics of our children do we want to select? Why? Do we want others to do this selection for us, as necessarily occurs when choices and needs are constructed by them?

Prenatal screening and testing are evolving in a climate that favors a genetic approach to personal and public health, an approach that is fundamentally expensive, individualized, and eugenic (Lippman, 1991, 1992a, 1992b). Giving that approach priority diminishes incentives to challenge the existing system that handicaps those with disabilities and makes it next to impossible for a woman to refuse an offer of testing or to choose to give birth to a child after in utero testing has indicated it may develop some medical problem. Recently, a genetic variation said to be associated with increased susceptibility to lead poisoning was described in the literature, with the authors implying this might be a useful objective of a screening program (Wetmur, Kaya, Plewinska, & Desnick, 1991). Do we really want to screen for genes rather than clean out lead to prevent the avoidable damage known to affect the millions of children unnecessarily exposed annually to this toxic agent (Lippman, 1992a)?

Although it is more than 20 years since the first fetal diagnosis of Down syndrome by amniocentesis, we still do not know the full impact of prenatal testing on women's total health, power, or social standing (Lippman, 1992c). For this reason alone, defining a place for prenatal screening and testing in our lives and in our health systems is not easy. Unfortunately, nor have we really grappled with the economic and eugenic forces propelling testing activities.

It would be naive to believe we can—or even would want to—dis-invent the technologies (though we might want to isolate rather than institutionalize them), but it might be an informative exercise to ask some fresh questions about how we might live without further extensions in the use of prenatal testing instead of examining only how we might implement them. Why not consider alternatives to geneticization before remediation (fixing it up) or regulation (keeping it ethical and legal) become our only demands?

Seeking such alternatives may be facilitated if we recall that
variations in the distribution of wealth and power have far greater impact on the distribution of health than do variations in the distribution of genes. And both are inherited within families. Why do we construe childhood poverty as a “problem too big for ordinary mortals to tackle” (Heagarty, 1991), but consider mapping and sequencing all of the 50,000 to 100,000 human genes we have no big deal? Is children’s development disrupted more by genetic loci than by ghetto lead? Do guns or genes alone cause more premature deaths in North America (cf. Novello, 1991)?

Health problems all have multiple causes, and to prevent ill health we must eliminate some cause—but it appears that any cause will do (Hesslow, 1984). We have social and medical options for dealing with genetic or any other disorders. Why do we segregate, for high priority, genetic services and programs to prevent the birth of those with potential for developing health problems?

Medical technology, prenatal genetic testing included, is especially seductive with its stories of human triumph. But unfortunately, the triumph for the individual who learns that her fetus does not have Down syndrome or some other detectable condition may not be a triumph for the collectives to which she and we all belong. We must never lose our compassion for an individual’s situation, including her desire for reassurance, but we must also never forget that addressing often elastic private needs—needs that geneticists and obstetricians help to create—may dislocate provisions required for our collective health or solidify existing inequities in women’s positions. And we might seriously consider that individual rights only have meaning within the relationships and collectivities of our lives.

Unfortunately, in considering issues of health and disease, some disjunction between individual wishes and societal needs will persist. The disjunction is being reinforced by genetic stories that more and more constrain notions of health and normality; that promote reliance on biomedical technology as a replacement for social and environmental change; and that privatize and individualize health problems. The disjunction is being played out in sterile debates too quickly (and falsely) polarized between pros and cons that trivialize the possible ad-
vantages and disadvantages of prenatal testing in response to women's valid health concerns. These debates incorrectly de-contextualize testing, sever its essential relatedness to time and place, ignore the imbalances in power between the providers and users, and isolate it from the broader health and social policy agenda of which it is a part. 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).

Feminists concerned with how prenatal testing technology creates a coercive lifestyle for women and how the technology may be used to manipulate them are not “fetalists” (Raymond, 1987)—or fatalists. Recognizing the power imbalances between the providers and the users of testing, they are concerned about potential violence to women from the use of technology. They are seeking not to limit women's options but to ensure and expand them by exposing the structures that now constrain women's choices. To these critics—and I am among them—choice in prenatal testing means that it can be rejected by a woman without someone questioning her motives. It means that a woman could, if she wished, continue her pregnancy after a fetal diagnosis is made because we have guaranteed her help to support a child with a disability. And it means that personal actions are completely severed from public agendas so that a decrease in uptake rates from current levels might be seen to measure the effectiveness, not the failure, of prenatal screening (cf. Clarke, in press).

Prenatal testing is developed and applied with inherent expectations of how, when, and why it will be used that are tied to attitudes about women and about disability. It is currently expanding in a society that is deeply fractured along lines of gender, race, class, and ability. Its promotion and application can only reflect and, in turn, reinforce those divisions.

We need urgently, therefore, to question that technology not because of nostalgia for some seemingly simpler past, but be-
cause we recognize how political systems, cultural beliefs, and complex patterns of human relationships overlap, alter, and are altered by the application of screening. We need to question its power over us and its ways of controlling how we live without confusing the modern with the good, the newer with the better, or science with the objective, so as to grapple effectively with the extensive social modeling that testing tools allow.

Consequently, it is imperative that we continue to read the stories being told about prenatal genetic testing with a critical eye, situate them in time and place, question their assumptions, and demystify their language and metaphors. A healthy child is a matter of concern for all of us, mothers or not. But so is the world in which these children will live.

Women’s desire for children without disability warrants complete public and private support. The question is how to provide support for women in a way that does no harm, that does not measure its effectiveness by the short-term profit from money saved when the lives of those with present or future disabilities are prevented, that does not view the birth of a child with a disability as a technological failure. Does support for expanded fetal screening programs improve how we welcome those with all kinds of abilities to our communities? Does the allocation of resources to genetic services correct gendered inequities and injustices in the health care system that endanger women’s health? Is placing fetal screening in the routine prenatal care package part of the solution or part of the problem? Is its use liberating or oppressive or both—and for whom? Because we have a responsibility to mothers today as well as to the generations of those who present and future genetic testing programs will, or will not, allow to be born, and because the values and beliefs we transmit by engaging in the practice of prenatal genetic testing and selection will influence the possibilities for the next generation no less than will transmitted genes, we must not just ask but vigorously search for responses to these questions now.

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NOTES

1. The use of prenatal genetic testing for the purposes of sex selection comes immediately to mind as perhaps the most blatant example.
2. For example, one factor in choosing age 35 in Canada was apparently the need to ensure that some smaller genetic centers would have a sufficient number of candidates to achieve the procedure rate required for a practitioner to meet professional standards. If a higher age were the cutoff, too few women would be tested to fulfill the standard minimum (Wyatt, personal communication, 1992).
3. Actually, only the number of things called genetic is increasing, not the number of genetic diseases themselves. This increase in “perceived” genetic disorders serves to legitimize offers of genetic help.

BIBLIOGRAPHY


