

MOTHER MATTERS: A FRESH LOOK AT PRENATAL GENETIC TESTING

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Synopsis – Prenatal genetic testing represents the most widespread human application of reproductive technology, and its use is necessarily gendered. Moreover, its application both reflects and generates the process of “geneticization” that increasingly orients contemporary Western-world stories of health and disease. Taking a woman-centered approach, this paper examines some of the stories being told about testing; questions their themes of “reassurance” and “choice,” their construction of “risk,” and their assumptions about disability; and explores the “lifestyle” testing creates for (pregnant) women. Testing itself, and its power to control how we live and the children we bear, raises complex and contradicting matters that require continued and fresh examination.

Geneticists now have available to them numerous techniques to assess the physical status of the fetus during a woman’s pregnancy. The variety of these prenatal diagnostic techniques and the range of fetal conditions they make detectable/diagnosable continue to expand. These screening and testing procedures constitute the most widespread application of genetic technology to humans.

Prenatal genetic testing raises a number of fundamental concerns related to women’s health and health care because how, when,

conditioned by prevailing attitudes about women, their bodies, and their social roles. Women experience testing, therefore, not merely as parents, but in ways peculiar to being *mothers* of children. And, because the world in which genetic and other reproductive technologies are developing is gendered, these technologies cannot escape gendered use. Even if the technologies have not been developed and used specifically to maintain gendered distinctions and increase patriarchal power, as some have suggested (e.g., Rowland, 1984), prenatal testing cannot be neutral in societies such as ours where women are disadvantaged, generally powerless, vulnerable to offers of services because of their diminished status, challenged by prejudicial norms surrounding motherhood, and delegated responsibility for family health.

Although some issues of concern about prenatal genetic testing in North America pertain especially to certain groups of women, many cut across color, ability, economic, and sexual orientation lines. They are relevant to all women because procreation is an ever-present issue for us. Mostly we are busy trying

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why, to, and by whom it is applied will be

safely to *avoid* pregnancy, an activity that occupies the major portion of our adult lives. Less often, we are busy wondering if we are too old or too young to have a baby, busy trying to become pregnant, or busy caring for those we birth and adopt. But whichever keeps us busy, pregnancy, childbirth, and motherhood are (still) seen as central to a woman's definition and role in our society today, and so prenatal genetic testing concerns us all.

Much has been written about the technical aspects of prenatal genetic testing, its potential for use and misuse, and how it might be regulated and paid for. Rather than provide a general survey or evoke the usual critique to address these issues, I want to explore some relatively unexamined aspects of the prenatal testing process and restructure what we see as its problems. These problems, embedded in and inherent to prenatal genetic testing, are mother matters – things of consequence to mothers – and they are also matters for all who believe that mothers (and their children) matter.¹

In what follows, therefore, I will begin by summarizing some technical information about prenatal testing. I will next recount a few of the “stories” geneticists are telling about these testing technologies, and then I will focus on those themes that seem especially to be mother matters, and assess how they do or do not make mothers matter. By providing some interpretations of this activity that are sufficiently “fresh” to be new, as well as bold and impertinent, I hope to underscore how prenatal testing really does matter to us and to future generations.

BACKGROUND

Of all applied genetic activities, prenatal genetic testing (prenatal diagnosis) is probably most familiar to the general population, and also the most used. Prenatal diagnosis comprises all the methods and technologies

currently in use or under development to obtain information about a fetus during pregnancy, as well as evolving methods for studying human embryos created in a laboratory. Included are widely used procedures such as amniocentesis, ultrasonography, and the testing of a woman's blood sample for constituents thought to be associated with fetal problems, as well as techniques more recently made available such as chorionic villus sampling (CVS: the removal of cells from the membranes surrounding the developing fetus in order to study them in a laboratory). Also included are techniques currently under development, such as methods to identify and sort out for analysis fetal cells that may be contained in samples of blood taken routinely from pregnant women.

For many North American women 35 years and over, certainly for those who are white and middle-class, amniocentesis to detect fetuses with the extra chromosome associated with Down syndrome has become part of the “ordinary” medical care received during pregnancy. Other selected prenatal diagnostic techniques are all too quickly being incorporated into routine obstetric care for everyone, with ultrasound scanning almost inescapable for all women seen early enough in their pregnancies at a medical facility, albeit without their prior informed consent and contrary to professional recommendations.

It is of historical interest that examination of the fetus in utero probably dates back to the turn of the century, when the first X-ray picture was taken of a dead fetus (Oakley, 1982). However, prenatal testing as currently practised has been generally available only for about 20 years, with the link between an extra chromosome and Down syndrome first reported only about 30 years ago (Lejeune, Gauthier, & Torpin, 1959). Using fetal cells or amniotic fluid obtained by one or another of the procedures, all recognizable chromosome variations, many selected developmental malformations, and over 150 biochemical

disorders can now be detected. The list continues to expand, with recent technical developments accelerating the adoption of additional procedures to identify specific disorders during early and mid pregnancy. Nevertheless, the major application continues to be screening or testing for fetuses with Down syndrome.

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 conditions with little or uncertain impact on postnatal health and functioning; conditions that will appear, if at all, only in adulthood; and conditions for which treatment exists. Concurrent with the increase in the number of detectable conditions is a movement towards earlier detection – from the 16–20-week period when amniocentesis is employed, to the 10–12-week slot allotted to CVS, to diagnoses made on embryos created in the laboratory at what might be thought of as – 1 week of the initiation of a hormonally induced pregnancy in a woman. Extensions in both dimensions are troubling. But even without them, many thousands of women, pregnant or not, are already confronted by the need to consider how much, if anything, 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. Its very availability necessarily forces every woman at least to consider if she wishes genetic testing – or if she even wishes that testing be available for use by other women – and merely facing this choice is itself difficult, when not painful.

Irrespective of one’s general attitudes to abortion, values we hold dear appear to be violated whether we accept or we reject testing. Prenatal genetic testing is not just another improvement in obstetric care, despite the tendency of some to call it routine, if not “banal” (Dumez, 1989). Rather, it creates a dilemma, a situation in which we are quite

sure that we will be making a big mistake whatever path we choose. With the application of genetic testing earlier and earlier in fetal life, even before a woman herself actually becomes pregnant (e.g., by studying embryos in vitro), and with the growing number of conditions now detectable, some of which only increase susceptibility to the later development of a health problem, it seems urgent to confront this dilemma and examine directly why we are really testing women; 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. This examination starts with a look at some of the stories told about health, disease, and prenatal testing, considering first what I mean by “stories.”

STORIES

Prevailing biomedical and political systems in today’s Western world largely define health and disease, and normality and abnormality. These systems also determine the individuals to whom the terms healthy, diseased, normal, and abnormal will be attached, and what responses will be provided to those so-labeled. Western biomedicine, itself an ethnomedicine, does not just describe a preexisting biological reality, but is grounded in particular social and cultural assumptions (Wright & Treacher, 1982). Thus, a malady that is diagnosed and treated as a disease in one country may be diagnosed and treated completely differently in another-if it is even noticed as unusual (Payer, 1988). There is no strictly objective and value-free view of disease (or of any other component of the biological world) out there some place just waiting to be discovered. Rather, scientific researchers give biological processes particular forms – diagnostic labels – in different human groups and at different periods of time, making disorders and disabilities social products (e.g., Tesh, 1988).

Their shapes and distributions, as well as how people are assigned to the categories created for study or for intervention, are necessarily subjective. These constructions, what I call “stories,” thereby reflect how those with power at any particular historical time construct a particular physiological or physical condition as a problem.

The word *story* is not used to suggest that what is said or written about prenatal testing, health, and disease is not true. This may or may not be the case, and is not really of concern here. Rather, the word is used in a literary, not a legal, sense to capture the idea that scientists choose their subject matter and present their observations, their research, in the same way that 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 to tell a story, and with their constructions reflecting their personal views and the prevailing social/cultural context.

The distribution of health and disease is influenced by many factors, including social and physical environments, economic conditions, gender, race, personal behaviors, and available health services as well as heredity. This varied list of influences provides scientists with a wealth of raw material from which to construct explanatory stories about the causes of the conditions of concern to them. Their subsequent proposals for ways to reduce the suffering associated with disease are, in turn, constrained by these choices. Which elements in the raw material are chosen to create metaphors and stories describing health and disease, and how this choice is expressed in public policies and private practices, will reflect the background beliefs, the vested interests, and the ideologies of those who choose to study these matters and of those who fund their studies.

Stories, in general, rearrange that which is complex into shapes that simplify and tame.

This is apparent in the increasing use of the language of genetics to tell stories about health and disease in today’s professional and popular media. Using the metaphor of blueprints, with genes and DNA fragments presented as a set of instructions, the dominant discourse emphasizes a simplistic genetic determination for our various frailties and differences from one another, with the double helix employed as illustrative icon (Myers, 1990). Only the extreme may enthusiastically describe human diseases as “typographical errors” (Shapiro, 1990), but this narrative is not out of line with the common contemporary “stories” of health and disease reporting 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.² Structuring most disorders, behaviors, and physiological variations (including such things as schizophrenia and high blood pressure, as well as perfect pitch and the ability of children to sit still to watch television) as, at least in part, hereditary, the authors of these stories proclaim every genetic association they find in bold type.

Genetic screening and testing programs have major roles in these stories, delivering the techniques to find those with these genes, only some of which are associated with what we generally think of as diseases. Applying these technologies thus increases the numbers of those with disorders labeled as “genetic” or with conditions called “abnormal,” and establishes hierarchies among individuals based on their sought-after DNA differences. It also reinforces and reflects standards and power relationships that already exist, because no technology can be value free. As a development in and for an already stratified world, prenatal genetic testing cannot escape stratified use. In North America, the unequal distributions of women’s health deriving from class, race, and other social stratifications have

necessarily shaped the development of these technologies and will necessarily orient their employment, without doubt making them mother matters. But do mothers matter in them? And if so, how?

STORIES ABOUT TESTING

As a major component of genetic stories of health and disease, prenatal diagnosis is given its own narrative shape. Contemporary biomedical stories about it generally present testing either as a "public health" activity to reduce the frequency of selected birth defects, or as a means for "reproductive autonomy," a way of giving women information that will expand their reproductive choices (Lippman, 1986). Unfortunately, both of these common presentations are incomplete because they fail to capture the internal tension of prenatal genetic testing. This tension arises because testing simultaneously comprises a set of conflicting activities. As supporters claim, it may be a way to give women some control over their pregnancies, respecting (increasing) their autonomy to choose the kinds of children they will bear (Hill, 1986). It may be a means to reassure women, enhancing their experience of pregnancy (Royal College of Physicians of London, 1989) and 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 almost unanimously reject any suggestion that testing may be eugenic).

When first read or heard, the language of control, choice, and reassurance used by biomedically oriented supporters seems persuasive, and certainly makes prenatal diagnosis appear attractive. This discourse is also far more promising as a marketing

strategy than the contrasting one employing an image of selection. But looking beneath the surface of the biomedical stories reveals some serious flaws in their attractiveness (apart from the absence of good empiric evidence to support the claim that control, autonomy, and reassurance are actually enhanced).

First, these are but partial stories. They exclude the words of women who ignore their physicians' urgings for amniocentesis and report how they prefer *not* to be tested because they don't want to lose the assurances provided by their own bodies that they are healthy and normal. As told by one member of this group, these women seek reassurance by *refusing* testing, perceiving their "risk" not in terms of having a child with Down syndrome, but in terms of what might ensue from entering a process of medical surveillance. Without testing, energy can be directed to enjoying pregnancy; with testing, it might have to be diverted towards fighting a system that would produce problems and create experiences likely to undermine this pleasure. For a complete story about prenatal testing, therefore, women's experiences such as these, which indicate how reassurance comes from many sources (not all linked to genetic testing), must be included.

Second, any story of prenatal testing told univocally in the language of reassurance is clearly too simplistic. Notwithstanding that even the most critical would probably acknowledge that genetic testing can be selectively reassuring for the vast majority of women in prenatal diagnosis programs who learn that the fetus does not have Down syndrome, the bold text 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 need to ask why Down syndrome has become so important, or why we want to find fetuses with this particular condition. It hides the need to consider 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 was one that should be diagnosed before a baby with it was born. It hides the need to consider the possibility that reassurance is a biomedical “fix” that disempowers women and increases their dependency on technology to feel at ease as pregnant women.

Prenatal genetic testing in North America today occurs in a context where the concept of risk dominates the process of becoming a mother (Quéniart, 1988). From the time of their first prenatal visit, women are categorized into high- and low-risk groups. (Interestingly, there is no such thing as a no-risk group, and obstetricians only identify a “normal” pregnancy retrospectively.³) Also of interest, obstetricians generally ignore risks associated with a woman’s home or work environment that can seriously affect her health, pregnant or not, and emphasize (on their risk-scoring sheets) the woman – what she does to herself, what she ingests, and now, more than ever, who she is – as the serious source of risk to the fetus.

By attaching a risk label to pregnancy, physicians reconstruct a normal experience, making it one that requires their supervision. This is clear in the major application of prenatal genetic testing, where risk is conceptualized strictly in terms of a woman’s age and those 35 years and over are automatically and homogeneously labeled as a high-risk group warranting prenatal diagnosis. Biomedical specialists consider these women to have a sufficiently high statistical probability of giving birth to a child with Down syndrome that physicians should routinely offer them prenatal diagnosis in order to detect those with an affected fetus, and to reassure the rest that this condition is not present in the fetus. But, though it is presented as a biomedical fact, to make this recommendation is also to make social statements about the status of a woman in her

mid-30s and about the quality of her fetus.

For example, despite the biomedical classification, women 35 and over are not the only ones at risk for having a child with Down syndrome. 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). Every pregnant woman has some numerical chance of having a child with Down syndrome. What makes one probability high and another low?

The establishment of a statistical boundary to label separate high- or low-risk groups is historically and politically contingent (e.g., in France, “risk” apparently begins only at 38 years, since this is when public funds first cover services [Moatti et al., 1989]). Designating age 35 the point of entry to a genetic risk group and the criterion for prenatal testing, replacing the initial threshold that was no less arbitrarily set at age 40, likely gained currency pursuant to cost-benefit analyses and service-needs assessments undertaken as prenatal diagnosis was developed. No new information was produced to indicate that women 35 to 39 were at greater risk than they had been 10–15 years 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 to make Down syndrome and the quest for normality into technical problems to be overcome, with prenatal testing the response. The process 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 the more women are told that their age creates a risk for the fetus (that *they* create a risk), the more they may want reassurance through testing to allay iatrogenic worries.

Moreover, by orienting a prenatal screening test specifically to detect a particular condition – Down syndrome in this case – a social statement is being made about the quality or the value of fetuses based solely on their genetic/chromosome material. This social statement is a strong one (cf. Lippman & Brunger, in press), saying it is okay if children with certain chromosomes are not born, and that having the condition detected, in effect, is worse than being alive (Asch, 1988). Also of importance, the power to make these statements that set boundaries for who may or may not be born rests 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. Here, as elsewhere, individuals may seem to choose, but their only options are those that have been created by others. As is true of other professional resources, women get to choose only from the offerings biomedicine provides.

Thus, for a complete story of how reassurance relates to offers of prenatal testing to women 35 and over and to their acceptance of these procedures, more than a description of the biological changes that occur over time that put them “at risk” must be included. These stories must be situated in the historical and cultural context in which notions of risk and attitudes to normality are constructed. In North America today, where pregnancy has come to be seen as baby production (Martin, 1987), and where the laborer, the pregnant woman who will produce the baby, is held to certain standards (Rothman, 1989), it is not unreasonable to suggest that stories about testing are incomplete if they fail to take into account its use to insure the quality of both. Freshly – and succinctly – stated, prenatal testing provides “reassuring” quality control and consumer protection. Whatever else it may be, prenatal testing necessarily involves

systematic and systemic selection of fetuses, most frequently on genetic grounds. Biomedicine cannot 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 (though in vitro fertilization with donor ova can), but rereading the reassurance text reveals that biomedicine claims to 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.”⁴ So if reassurance is produced following prenatal diagnosis, it is at best an acquired, not an inherent, characteristic of testing that tranquilizes women who have first been made fearful.

So before eligibility for testing for Down syndrome is extended to more and more women of all chronological ages, let us reclaim the term and consider some new ways to tell stories about reassurance that respond to the desire of pregnant women for healthy children but that do not rely on prenatal testing and genetic(ists) control. For instance, Down syndrome is actually relatively rare, even among women 35 and over. Low birth weight and prematurity, unfortunately, are not. Should it be deemed urgent to provide genetic screening to reassure women about Down syndrome but not urgent to provide the adequate diet to the unacceptably large number of pregnant women living below the poverty line that will reassure them that their babies could develop as well as the babies of wealthier women and not be at risk for the childhood mortality and morbidity associated with low birth weight and prematurity? Why should extending prenatal genetic testing to all women be more reassuring than allocating public funds for home visitors, respite care, and domestic alterations that would permit women to manage their special needs should their child be born or, as is more likely, later develop a health problem? Who is served by giving priority to *genetic* reassurance? Why

give it priority when alternative approaches would provide reassurance with respect to (and for) fetal disability, as well as diminish a woman's feeling of personal responsibility for a child's health (Farrant, 1985), without requiring women to select fetuses based on their characteristics?

Stories about prenatal testing that relate how it is really *only* a response to the "needs" of pregnant women for reassurance, something women "choose," must always be placed in context with how need has been constructed and what choosing to be tested means in North America today. Certainly, the storylines about need and choice 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. Is it surprising if a woman offered testing 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? Won't the mere labeling of a pregnant woman 35 years or over as a member of a high-risk group encourage her to "need" allegedly risk-reducing experiences? When prenatal testing is presented as giving nature "a helping hand" because most fetuses with malformations (about 80% of fetuses with Down syndrome, for example) are spontaneously aborted, why wouldn't a woman then consider abortion natural or an automatic component of testing? And when the rest of us repeatedly hear or read stories telling us how the frequency of genetic disorders is increasing, placing further strain on fragile health systems, why wouldn't we support the extension of testing programs as an appropriate social response to decrease this collective "burden?"⁵

Given then that needs, including that for reassurance, are created, the second part of the reassurance storyline depicting women's "free choice" with respect to the use of testing becomes questionable. Can continuing a pregnancy when the fetus has been found to

have Down syndrome be a real choice when society does not truly accept children with disabilities or provide assistance for their nurturance (cf. Retsinas, 1991)? Does a woman have a realistic alternative to diagnosing and aborting a fetus likely to be affected when society views a pregnant woman as the means to a successful reproductive outcome, defined today as a healthy baby? A woman does need some help to raise a child with a disability, and if society does not respect and meet her needs appropriately, she will likely seek a way to avoid the problem (cf. Rothman, 1986). If prenatal testing and abortion of fetuses with the disability constitute the *only* solution offered, is there really a choice? For choice, there must be real options. For a woman to have real choice, she must first be respected in and for herself, not for her role as producer.

Legitimate efforts to avoid unnecessary harm to a fetus in a continuing pregnancy and to protect it from avoidable death or disability are essential, but if healthy children really matter to us, as we say they do, their mothers must matter first. The well-being of children and the well-being of mothers are inseparable. Social, political, and economic neglect of women interferes with the physical and mental development of their children. If we value not only the birth of a healthy child but her or his mother too, we must attend to this neglect.

Reliance on prenatal genetic testing to insure our children's health displaces 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 over 35 (Rapp, 1988), may threaten women's well-being because its circumstances and processes make it an addiction (in social/psychological terms, not physical). Not only is its use socially determined, but prenatal testing satisfies a need to feel good with a fix, creates dependency, and provides substitute gratification. At least so it would seem from

the stories describing how testing releases a woman to enjoy her pregnancy, high with the reassurance that the fetus does not have Down syndrome, and how she can depend on it to provide a healthy baby. Is not the photograph or videotape of her ultrasound scan displayed by a pregnant woman a technological substitute for the changes in her body and feelings that once satisfied and confirmed her about her pregnancy? In this perspective, it seems that regulating prenatal testing is no more likely to preclude the dependence that disempowers women than regulating drugs will preclude addiction. For both drugs and testing, the circumstances in which use is seen as a solution must be changed, especially since the technology – as with drug use – in turn creates a “lifestyle” that is itself troublesome.

PRENATAL TESTING AS LIFESTYLE

Prenatal genetic testing creates a lifestyle insofar as the use, if not the mere availability, of the technology inevitably shapes the experiences of being a (pregnant) woman, and in some ways becomes an end in itself. Prenatal testing, as with other technologies, creates a lifestyle because it shapes issues in new ways, translates everyday life, transforms what is “natural,” and determines how we ought to live.

Pregnancy

Most obviously, prenatal testing shapes the experience and progression of pregnancy. It divides a unique – and unitary – experience into two artificial and not always compatible parts – a social pregnancy and a biological pregnancy – and requires a woman to adapt to the testing process and to a physician’s schedule. It gives others (e.g., physicians) more authority than she has to describe her experiences of her body (cf. Wendell, 1989). When she tells others about her pregnancy, when she visits her physician, and what she acknowledges as evidence that things are

going well are dictated by “testing time” rather than by “women’s time” (Beeson, 1984). The notion of “tentative pregnancy” proposed by Barbara Katz Rothman (1986) limns much of this shape.

Protection and prevention

Prenatal testing, in another process of division, separates a single entity, a pregnant woman, into two: herself and her fetus. By shaping the fetus as separate (and separable) from the woman, prenatal testing makes it possible to assign independent interests (and/or rights) to it, interests not just attached through the mother. This reshaping by prenatal testing in turn makes a pregnant woman a potential object of rules, regulations, and duties established by those seeking to protect these fetal interests, at the least redefining a “responsible” mother as one who does everything to insure fetal health (Robertson, 1983; Shaw, 1980).

Testing makes the behavior of a woman who rejects an offer of amniocentesis carried out for the sake of the fetus have an unusual shape, and when faced with unusual behavior, society likes to assign blame. Thus, while a woman may be absolved of control over the chromosomal occurrence of Down syndrome, the availability of testing may make the *birth* of a child with this condition seem to be subject to her control. If a child with Down syndrome is then born to a woman who has refused testing, it may be constructed as preventable, as an avoidable event, with the child’s mother guilty, or at least responsible, for not avoiding it (cf. Hubbard, 1984). Given that prevention increasingly is 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 “selection by prevention” (Kuitert, 1990)?

Disability

Prenatal testing shapes general attitudes to

disability in multiple ways. In particular, testing shapes disability strictly as a medical problem, even though categorizing disability in this way is quite simplistic. We all have or will likely develop some disability, but this will only become of major consequence when prevailing social, economic, and political policies do not account for these, and convert disability to a handicap. Prenatal testing hides these social roots of handicaps, distracts attention from the policies that create them, and reshapes the problem of disability so that it need not be *ours* collectively – hat will we do to accommodate and embrace the disabled among us? – but becomes one for an individual woman to solve – What will *she* do to prevent it from happening? By this reshaping of the prevention of disability, prenatal testing diverts efforts to change the society that handicaps us and makes individuals the agents of the state.

Abortion

Prenatal testing shapes abortion in ways beyond the models we usually rely on to guarantee women's privacy and control. As suggested earlier, prenatal testing may not only reduce a woman's liberty to *refuse* an abortion, but makes it possible for others to impose a "choice" for abortion covertly, if not overtly.⁶

Geneticists and their obstetrician colleagues influence this "choice" by deciding which fetuses are healthy, what healthy means, and who should be born, merely by offering tests for certain conditions and not others, merely by what they tell parents about these conditions. In this way, specialists come to determine whether a condition will be marginalized, whether it will be an object of treatment or grounds for abortion, thereby gaining power over decisions to continue or terminate pregnancies, power that pregnant women themselves may not always have.

Prenatal testing also shapes control over abortion by legitimizing a role for insurance

companies and governments in what should be an intensely personal matter for a woman herself. 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). A recent report that a health maintenance organization in the United States planned to withdraw medical coverage if a child with cystic fibrosis was born to a woman who could have avoided its birth by aborting the pregnancy after the prenatal diagnosis was made (Billings et al., 1992) gives substance to concerns about the power of testing to shape control of abortion.

However dramatic though, these gross abuses ought not distract us from the seemingly straightforward policies established by testing programs that also reshape abortion decisions. For example, parents' 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 also associated with the professional training of the person who tells them that an abnormality has been found, with rates of abortion higher when the information is related by obstetricians than when it is by geneticists (Holmes-Siedle, Ryyanen, & Lindenbaum, 1987). Even replacing amniocentesis by the earlier CVS reshapes control because geneticists generally view first-trimester terminations as "solving" the "abortion problem," thereby greatly reducing a woman's reluctance to be tested.

Even if no policy has yet been formulated explicitly to reshape control over abortion, the reshaping is embedded in the very process of testing: Someone must provide counseling, some method must be used. And it is insufficient merely to consider the change in the locus of control a "side effect" subject to regulation or ethical review. We can draft and enforce "regulations" that establish who shall

do counseling, when and whether or not ultrasound scans will be shown, and so on to avoid "misuse," but every policy will necessarily reshape control over abortion. It is happening already, and the new shape will reflect the values of those with power and position to establish the regulations.

Aging

Prenatal testing reshapes our perspective on a woman's lifecycle. This stems from the subtle entanglement between prenatal diagnosis and another long-standing problematic for women, aging (Martin, 1987), and from the ways in which testing reflects and reinforces existing attitudes towards women and their adequacy. At the least, the availability of prenatal diagnosis and professionally imposed limits on access to testing have created the "social category" (Nelkin & Tancredi, 1989) of "the older woman." More troublesome, however, is how testing is presented as a tool for women who want/need to circumvent features of aging and suggests they are inadequate on their own. With this tool, the increasing probability of chromosomal nondisjunction associated with increases in a woman's age, the source of her biomedically labeled reproductive "inadequacy" after 35, 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 especially trouble us (Sauer, Paulson, & Lobo, 1990).

Definitions of childbearing age vary with social and cultural contexts. They are not

biological givens. If for every thing, including motherhood, there is a season, the timing of this "season" is historically situated (Rindfuss & Bumpass, 1978). Whose interests are served when postmenopausal pregnancies create a new season for motherhood and a whole new category of mothers? Why the desire to conquer this natural stage of life by again representing menopause as a failure to overcome, by presenting women as inadequate when they are not reproducing? Eggs from younger women and hormonal manipulation make it appear that a woman in her late 50s who becomes a mother has obtained equity with the men who have routinely become fathers at this age and older. But a postmenopausal pregnancy is less likely to be liberating (as marketed) than oppressive in a society that regards women in midlife as defective, that promotes the image of youthful perfection as a woman's goal, and that still measures women by their reproductive performance. Prenatal testing for women 35 and over may not be as transparently ageist as the use of donated/purchased ova to create a pregnancy in a postmenopausal woman, but it, too, reshapes the "older woman" by its reliance on chronological age as a principal criterion for fetal diagnosis. It implies that this sole feature is all that counts (matters) about a woman, and conveys the message that after some (arbitrary) age *she* is a failure.

MAKING MOTHERS MATTER

In sum, prenatal genetic testing creates a new lifestyle for women through its transformations of pregnancy, of the fetus, of disability, of abortion as a choice, and of age into new shapes to which *women* must adapt. In light of the gendered nature and use of prenatal testing, this lifestyle seems to be making the wrong things and the wrong people matter (be of consequence).

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 context where individual responsibility to prevent health problems takes precedence over social policies to promote the general well-being of all, the development of remedies for otherwise inescapable problems is probably far less likely than the development of ways to prevent the birth of those who may have such problems. And in this context, the overwhelming support in all public-opinion polls for abortion if a fetal abnormality is detected is not irrelevant.

The human gene map currently under construction will identify fetal variations in DNA patterns. Genes alleged to cause specific diseases, as well as those only associated with increased susceptibility to some disorder, will be found. All the variations that will be mapped can become targets of prenatal testing or embryo selection. Which will be named targets in the quest for improved public health? Which physical, mental, and esthetic characteristics of their children will women want to select? Why? Do women want others to do the selection for them, as will necessarily occur when choices and needs are constructed by others?

Prenatal screening and testing are evolving in a climate of geneticization that favors a DNA-based approach to personal and public health, an approach that is fundamentally expensive, individualized, and eugenic (Lippman, 1991). Giving it priority diminishes incentives to challenge the existing system, which 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 testing in utero indicates it may develop some medical problem. A genetic variation said to be associated with increased susceptibility to lead poisoning was recently described in the literature, with the authors implying this might be a useful objective of a screening program (Wetmur, Kaya, Plewinska, & Desnick, 1991). Does screening (for genes) or cleaning (out lead) represent how we want to prevent the avoidable damage known to occur to the millions of (mostly poor) children unnecessarily exposed annually in their homes to this toxic agent?

Defining a place for prenatal testing in our lives and in our health systems is not easy. 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, and social standing (Lippman, in press). It is perhaps naive to believe we can – or even would want to – disinvent the technologies, but it might be an informative exercise at least to ask some fresh questions about how we might live *without* the extensive use of prenatal testing instead of the usual ones about how we might learn to live with it. We have not really grappled with the economic and eugenic forces propelling testing activities. Why not ask about alternatives to geneticization before remediation (fixing it up) or regulation (keeping it ethical and legal) become women's only demands. Will women settle for "understanding" prenatal testing or shall we determine, too, ways to make it conform to a lifestyle that empowers women?

Asking such questions may be simplified if we rethink the language we use to describe health and healthcare and 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 with families.

Unarguably, illness and disability are hard (difficult) issues, and no one wants to add to

the unnecessary suffering of any individual. But being difficult does not mean that illness or disability must be a totally negative experience (Asch, 1988). Nor does it mean that they must be managed genetically. Health problems all have multiple causes, and to prevent ill health we must eliminate *some* cause of it. *Any cause* will do. Why don't we listen to other stories that do not involve preventing the birth of the individual who might develop the health problem?

Medical technology, prenatal genetic testing included, is especially seductive with its stories of human triumph. But triumphs for an individual are, unfortunately, not necessarily triumphs for the collectives to which she and we all belong. We must never lose our compassion for an individual's situation, but we must also never forget that addressing private needs may dislocate provisions required for our collective societal health or solidify existing inequities in women's positions. 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 in which notions of health and normality are becoming more and more constrained; in which reliance on biomedical technology is being promoted, replacing self-reliance and self-confidence; and in which health problems are becoming privatized and individualized. The disjunction is being played out in sterile debates too quickly (and falsely) polarized between pros and cons that trivialize the possible advantages and disadvantages of prenatal testing in response to women's valid health concerns. These debates incorrectly decontextualize testing, sever its essential relatedness to time and place, 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).

Disjunction exists because we have yet to develop ways for individuals and collectives to thrive and flourish simultaneously. Disjunction makes dialogue about the place of prenatal testing in women's health care especially difficult (if not tense). Yet this only underscores the need to avoid premature closure of the discussion. Why not acknowledge the disjunction now and begin to use our energies to situate, understand, and search for reconciliation as we question the place of prenatal genetic testing in and for women's health care.

We need to question this technology not because of nostalgia for some seemingly simpler past, but because we recognize its power over women, its way of controlling how we live, and its ability to empower others perhaps even more than ourselves. We must not confuse the modern with the good, the newer with the better, or science with the objective, and must learn to grapple 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, demystify their language and metaphors, and determine whether, and to what extent, the technologies they present make mothers and women matter.

We need a fresh evaluation of prenatal testing from the perspective of pregnancy as an expression of self (Martin, 1987), so that we emphasize what a woman feels, the self-significance of pregnancy, and the place of motherhood in her life, rather than determine if testing improves her baby-production process. For a fresh look at prenatal testing from the

perspective of a collective responsibility for health, we need to consider if support for fetal testing programs improves our ability to welcome those with all kinds of abilities to our communities, and if the allocation of resources to genetic services corrects gendered inequities and injustices in the health-care system, instead of determining if the reduced number of births of babies with Down syndrome is cost-beneficial. We need a fresh look at reports of how ultrasound lowers infant mortality rates when these decreases occur because those seen in utero to have conditions that might lead to death in infancy are aborted and never born, and therefore do not have to be counted in rate calculation (Saari-Kemppainen, Karjalainen, Ylostalo, & Heinonen, 1990). We need a fresh look at the reasons for using medical technology. If medical technologies should be of medical necessity, are they then the appropriate means to provide reassurance, comfort, or other important factors in our lives? And we need a fresh look at disability from the perspective that it is a "collective responsibility," no less than a "private tragedy" (Levin, 1990).

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 our public and private support. The question is how to provide support for women in a way that does no harm, that truly enhances health, that does not measure its effectiveness by the money saved when the lives of those with present or future disabilities are prevented, and that leads to the desired society, one that is not itself disabled.

We have a responsibility to mothers today and to the generations of mothers and others that present and future genetic testing programs will, or will not, allow to be born. Via the process of geneticization we are, by our social behavior, today practising what I would call "metaeugenics," selectively determining the culture in which our children

will live (cf. Chadwick, 1987). 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 the genes surviving prenatal diagnosis that are transmitted. Just as we inherit more than genes, we pass on more than genes. Right now, we are selecting – passing on – a culture in which procreation has become reproduction, and in which the *kind* of children we have has become the determinant of the children we will bear.

Given that we are responsible for the future effects of our current activities, the well-intentioned and the unintended, let us work to distinguish short-term fixes from the long-term development of women and mothers. Let us work to serve the *basic* needs of mothers without threatening their, and our, future children. Mothers, and all women, matter, and we must keep posing fresh and impertinent questions about prenatal testing and other marketed biotechnologies to be sure they make them matter even more.

ENDNOTES

1. Let me emphasize very clearly that I take it as given that women using the genetic technologies believe – and believe very strongly – that mothers and their children matter. I also take as given that prenatal testing is troublesome for all women, users and nonusers, supporters 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 criticism of them. Women considering childbearing today face agonizing issues that I was fortunate enough not to have to confront, and as I learn from them, I am awed by their tremendous strength and resilience.

2. To attempt to capture how this single conceptual model is increasingly elicited to reveal and explain health and disease and how it is directing the ways in which intellectual and financial resources are applied to resolve health problems, profoundly affecting our values and attitudes, I use the term "geneticization" (Lippman, 1991; Lippman, Messing, & Mayer, 1990).

3. Even though obstetricians responding to feminist pressure will (grudgingly) acknowledge pregnancy as a

normal state, they still insist on the need for medical/technical intervention in it. This not only creates a paradox, but by implying we can't live normally without technology, it may "naturalize" all technologies applied for supposed health reasons.

4. It also adopts the idea of product liability protection for the physician.

5. In fact, it is but the number of things *called* genetic that is increasing, not the number of "genetic diseases" themselves. This increase in "perceived" genetic disorders serves to legitimize offers of genetic help.

6. The development of preimplantation embryo diagnosis may soon seem to make abortion a "non-issue" because only those embryos passing a genetic screen are likely to be transferred from the laboratory to a woman's uterus to develop.

REFERENCES

- Asch, A. (1988). Reproductive technology and disability. In S. Cohen & N. Taub (Eds.), *Reproductive laws for the 1990s* (pp. 59–101). Clifton, NJ: Humana Press.
- Beeson, D. (1984). Technological rhythms in pregnancy. In T. Duster & K. Garrett (Eds.), *Cultural perspectives on biological knowledge* (pp. 145–181). Norwood, NJ: Ablex.
- Billings, P. (1990). Genetic discrimination: An ongoing survey. *GeneWATCH*, 6(4/5), pp. 7, 15.
- Billings, P., Kohn, M. A., de Cuevas, M., Beckwith, J., Alper, J. S., & Natowicz, M. R. (1992). Genetic discrimination as a consequence of genetic screening. *American Journal of Human Genetics*, 50, 476–482.
- Chadwick, R. F. (1987). Having children. In R. F. Chadwick (Ed.), *Ethics, reproduction and genetic control* (pp. 3–43). London: CroomHelm.
- Drugan, A., Greb, A., Johnson, M. P., & Krivchenia, E. L. (1990). Determinants of parental decisions to abort for chromosome abnormalities. *Prenatal Diagnosis*, 10, 483–490.
- Dumez, Y. (1989). L'amniocentèse: Un examen courant. *Science & Vie*, 169, 56–57.
- Ewing, C. (1990). Australian perspectives on embryo experimentation: An update. *Issues in Reproductive and Genetic Engineering*, 3, 119–123.
- Farrant, W. (1985). Who's for amniocentesis? The politics of prenatal screening. In H. Homans (Ed.), *The Sexual Politics of Reproduction* (pp. 96–122). Aldershot, England: Gower.
- Hill, E. C. (1986). Your morality or mine? An inquiry into the ethics of human reproduction. *American Journal of Obstetrics and Gynecology*, 154, 1173–1180.
- Holmes-Siedle, M., Ryyanen, M., & Lindenbaum, R. H. (1987). Parental decisions regarding termination of pregnancy affecting prenatal detection of sex chromosome abnormality. *Prenatal Diagnosis*, 7, 239–244.
- Hubbard, R. (1984). Personal courage is not enough: Some hazards of childbearing in the 1980s. In R. Ardit, R. D. Klein, & S. Minden (Eds.), *Test-tube women* (pp. 331–355). London: Pandora.
- Hubbard, R., & Henifin, M. S. (1985). Genetic screening of prospective parents and of workers: Some scientific and social issues. *International Journal of Health Services*, 15, 231–251.
- Kuitert, H. M. (1990). Using genetic data: A moral assessment of the direct social consequences. In H. Rigger, J. C. F. Bletz, A. Krijnen, B. Wijnberg, & H. D. Banta (Eds.), *The social consequences of genetic testing* (Proceedings of a Conference, Leidschendam, 16–17 June 1988, p. 31). The Hague: Netherlands Scientific Council for Government Policy.
- Lejeune, J., Gauthier, M., & Torpin, R. (1959). Etude des chromosomes somatique de neuf enfants mongoliens. *Comptes Rendus de l'Academie des Sciences. Serie III, Sciences de la Vie*, 248, 1721.
- Levin, B. W. (1990). International perspectives on treatment choice in NICUs. *Social Science and Medicine*, 30, 901–912.
- Lippman, A. (1986). Access to prenatal screening services: Who decides?. *Canadian Journal of Women and the Law*, 1, 434–445.
- Lippman, A. (1989). Prenatal diagnosis: Reproductive choice? Reproductive control?. In C. Overall (Ed.), *The future of human reproduction* (pp. 182–194). Toronto: The Women's Press.
- Lippman, A. (1991). Prenatal genetic testing and screening: Constructing needs and reinforcing inequities. *American Journal of Law and Medicine*, 17, 15–50.
- Lippman, A. (in press). Prenatal diagnosis: Can what counts be counted?. *Women and Health*.
- Lippman, A., & Brunger, F. (in press). Constructing Down syndrome: Texts as informants. *Santé Culture Health*.
- Lippman, A., Messing, K., & Mayer, F. (1990). Commentary: Is genome mapping the way to improve Canadians' health?. *Canadian Journal of Public Health*, 81, 397–398.
- Martin, E. (1987). *The woman in the body: A cultural analysis of reproduction*. Boston, MA: Beacon Press.
- Moatti, J. P., Lanoë, J.-L., LeGalès, C., Gardent, H., Julian, C., & Aymé, S. (1989, September). *Economic assessment of prenatal diagnosis in*

- France. Unpublished manuscript presented at joint meeting of European Health Economic Societies, Barcelona, Spain.
- Myers, G. (1990). The double helix as icon. *Science as Culture*, 9, 49–72.
- Nelkin, D., & Tancredi, L. (1989). *Dangerous diagnostics: The social power of biological information*. New York: Basic Books.
- Oakley, A. (1982). The origins and development of antenatal care. In M. Enkin & I. Chalmers (Eds.), *Effectiveness and Satisfaction in Antenatal Care*. London: Heinemann.
- Payer, L. (1988). *Medicine and culture*. New York: Viking.
- Quénart, A. (1988). *Le corps paradoxal: Regards de femmes sur le maternité*. Montréal: Editions St. Martin.
- Rapp, R. (1988). The power of “positive” diagnosis: Medical and maternal discourses on amniocentesis. In K. L. Michaelson (Ed.), *Childbirth in America: Anthropological perspectives*. (pp 103–116). Hadley, MA: Bergin & Garvey.
- Retsinas, J. (1991). The impact of prenatal technology upon attitudes toward disabled infants. *Research on the Sociology of Health Care*, 9, 75–102.
- Rindfuss, R. R., & Bumpass, L. L. (1978). Age and the sociology of fertility: How old is too old?. In K. E. Taueber, L. L. Bumpass, & J. A. Severt, (Eds.), *Social demography* (pp. 43–56). New York: Academic Press.
- Robertson, J. A. (1983). Procreative liberty and the control of conception, pregnancy and childbirth. *Virginia Law Review*, 69, 405–464.
- Rothman, B. K. (1986). *The tentative pregnancy: Prenatal diagnosis and the future of motherhood*. New York: Viking.
- Rothman, B. K. (1989). *Recreating motherhood: Ideology and technology in a patriarchal society*. New York: Norton.
- Rowland, R. (1984). Reproductive technologies: The final solution to the woman question. In R. Arditti, R. D. Klein, & S. Minden (Eds.), *Test-tube women* (pp. 356–369). London: Pandora.
- Royal College of Physicians of London. (1989). *Prenatal diagnosis and genetic screening: Community and service implications*. London: Royal College of Physicians.
- Saari-Kemppainen, A., Karjalainen, O., Ylostalo, P., & Heinonen, O. P. (1990). Ultrasound screening and perinatal mortality: Controlled trial of systematic one-stage screening in pregnancy. The Helsinki Ultrasound Trial. *Lancet*, 336, 387–391.
- Sauer, M. V., Paulson, R. J., & Lobo, R. A. (1990). A preliminary report on oocyte donation extending reproductive potential to women over 40. *New England Journal of Medicine*, 323, 1157–1160.
- Shapiro, R. (1990, November). *The human blueprint*. Lecture, Science College Public Lecture Series, Concordia University, Montreal.
- Shaw, M. (1980). The potential plaintiff: Preconceptional and prenatal torts. In A. Milunsky & G. J. Annas (Eds.), *Genetics and the law II*. New York: Plenum.
- Tesh, S. N. (1988). *Hidden arguments: Political ideology and disease prevention policy*. New Brunswick, NJ: Rutgers University Press.
- Vekemans, M., & Lippman, A. (1984). Eligibility criteria for amniocentesis. *American Journal of Medical Genetics*, 17, 531–533, 539.
- Wendell, S. (1989). Toward a feminist theory of disability. *Hypatia*, 4, 103.
- Wetmur, J. G., Kaya, A. H., Plewinska, M., & Desnick, R. J. (1991). Molecular characterization of the human δ -aminolevulinic acid dehydratase 2 (ALAD²) allele: Implications for molecular screening of individuals for genetic susceptibility to lead poisoning. *American Journal of Human Genetics*, 49, 757–763.
- Wright, P. W. G., & Treacher, A. (Eds.). (1982). *The problem of medical knowledge*. Edinburgh: University of Edinburgh Press.