Chapter 3

Flexible Eugenics

Technologies of the Self in the Age of Genetics

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In other words, our essence is ours to choose, depending on how we direct our selves with all our baggage, DNA included.
DAVID BARASH, *"DNA and Destiny," 1998*

In 1994, John Wasmuth and his laboratory colleagues published an account of the discovery of FGFR3, the gene for achondroplasia—the most common form of heritable dwarfism—in the journal *Cell* (Shiang et al. 1994). Hailed soon after in the *Scientist* as the article most frequently cited during 1995, Wasmuth's publication revealed that 98 percent of those affected with achondroplasia have an identical mutation in the molecule FGFR3, a receptor for what is called a growth factor.[1] Among other things, the discovery opened the possibility for prenatal screening for this condition. During the many years of work that led to the publication of Wasmuth's article, molecules, scientists, and technicians were drawn into engagements not only with one another but also with patients, physicians, and genetic counselors. Genetic knowledge emerged, in this case as in others, as a coproduction of clinical diagnosis and treatment regimes as well as the molecular technologies and other research practices that constitute laboratory life. Patient populations contributed to laboratory and clinical knowledge through their tissue samples in countless experimental and diagnostic contexts, and through what the historian M. Susan Lindee (chapter 2, this volume) describes as the emotional knowledge that families living with genetically different members accumulate.

The long-term work on dwarfism and related skeletal dysplasias depended on the collection of research samples from individuals from all over the world affected by these conditions. The samples were held in a tissue registry established to bank research materials. This story, too, had its fair share of competition and collaboration, not only in the search for a "dwarfism gene" but also in the quest for the gene for Huntington's disease,[2] on which Wasmuth had previously worked, and which, as it turned out, lies on the same chromosome as FGFR3. Indeed, the successful search for the Huntington's

gene figures prominently in the mobilization of scientific and popular support for initiating the Human Genome Project, but that is another story. The multilayered discovery processes we recount here are instances of science-as-usual at the beginning of the twenty-first century.

One year after Wasmuth published his article, Clair Francomano, chief of medical genetics at the National Human Genome Research Institute at the National Institutes of Health, attended the national convention of the Little People of America (LPA), the U.S. national organization for people of short stature. Dr. Francomano is a long-standing researcher and health service provider for people with heritable dwarfism and a member of the LPA Medical Advisory Board. As she tells her story, "The first thing I saw when I came to this convention last year [after the discovery of the gene was publicized] was one of the people wearing that 'Endangered Species' T-shirt.[3] It really made a very big impact on me. And I really worry about it. I worry about what we're doing and about how it's going to be used and what it means to the people here" (Francomano 1997, pers. comm.).

Dr. Francomano's response was to chair several workshops for LPA members on the Human Genome Project. There, she explained genetic technologies and programs, listening attentively to the fears and hopes of short-statured people. She also expressed her own aspirations concerning the possibilities opened up by genetic research, and her dismay that new discoveries might be eugenically deployed. Her aspirations centered on gene therapy for specific ailments—such as ear and breathing problems, back pain, and skeletal problems—associated with dwarfism. In addition, Dr. Francomano collaborated in designing a membership-wide survey for the LPA on attitudes toward prenatal testing. Like Dr. Francomano and the officers of the LPA, we also want to know what Little People—a term widely used among people with dwarfing conditions to refer to themselves—in all their biomedical and political diversity want and do not want from this emergent genetic technology. We consider such desires to be part of science-as-usual in this history of the rapidly transforming present.

In this essay, we examine forms of embodiment and subjectivity emerging from relations between biomedical experts and lay health advocates in an era when genetic explanations, and desires for genetic improvement, appear to be proliferating throughout U.S. public culture. We address both biomedical technologies, like limb-lengthening surgery and prenatal diagnosis, and social technologies, like the organization of self-help groups such as the Little People of America. Our analysis of genetic and eugenic thinking in action underscores what Foucault (1988) calls "technologies of the self," the practices by which subjects constitute themselves, and work to improve themselves, while living within institutional frameworks of power. The expansive salience of genetic narratives and practices across a broad range of social groups in the United States today shapes embodied under-

standings of selfhood in historically specific ways. Those living with heritable dwarfism, and the researchers associated with them, are no less subject to these social and historical processes than the general population is: increasingly, we all live inside a world saturated by genetic discourses. Yet the consequences of dwelling inside these geneticized perspectives and practices are highly differentiated.

Born with bodies that historically have been stigmatized, dwarfs were among the first people in the United States to form an organization of social solidarity based on phenotypical difference.[4] The LPA, founded in 1957, became one of the first U.S. health advocacy groups to cooperate with biomedical and, especially, genetic researchers. This biosocial coalition between those born with a stigmatized difference and researchers and medical service providers was at once a site of productive resistance to widespread social prejudice and a domain of normalization. More recently Paul Rabinow (1996) has used the term *biosociality* to describe the conscription into a new identity politics as people come to align themselves in terms of genetic narratives and practices. This is something that Little People (LPs) began experimenting with as a social form decades before recombinant technology called into play new social forms.

By elaborating the diverse strategies through which dwarfs deploy technologies of the self, or an "ethics of self-care," we are able to illustrate the types of agency by which individuals "can resist the normalizing effects of modern power" (Bevir 1999: 78). In the contemporary United States, LPA members act within a society marked by a long-standing attachment to ideologies of individualism and free choice, which are increasingly imbricated with the intensified commodification and market orientation of the recent neoliberal era. LPs, along with the rest of us, are obliged to be free and are presented with an array of technically mediated choices and with varied discourses of perfectibility: we all live within dominant ideologies of power (Althusser 1971)—in this case, the idea of both choosing and perfecting oneself.[5] There is a convergence, or constitutive tension, between genetic normalization and an individualism that increasingly engages biotechnology—*biotechnological individualism*. From this tension, what we call *flexible eugenics* arises: long-standing biases against atypical bodies meet both the perils and the possibilities that spring from genetic technologies.

We have learned about the genetics of dwarfing conditions and the advocacy of the LPA through our collaborative ethnographic project on new knowledge production in the field of genetics.[6] In order to understand how scientists, clinician-physicians, and members of lay health organizations perform their daily work, we constituted ourselves as a mobile research team. In addition to ourselves, we worked with three graduate research assistants—Erin Koch, Barbara Ley, and Michael Montoya. During the project, we lived on two coasts and were attached to five institutions; much of our communication took place over the Internet, a common enough situation among the genetic knowledge producers we were tracking, but an uncommon way for cultural anthropologists to conduct research. Our traveling methodology followed genetic stakeholders in and out of their various milieus, from national meetings of health advocacy groups to basic research laboratories, and from interviews with clinicians to encounters with families living with heritable conditions like achondroplasia. Like Dr. Francomano and the members of the LPA, our team is concerned about the ways in which molecular discoveries may reinforce eugenic thinking and practices. And like many members of the constituencies among whom we conducted fieldwork, we also recognize the complex interplay that makes it difficult to distinguish the gifts from the iatrogenic poisons of contemporary medical genetics.

A discourse of benefits and burdens, perils and possibilities, and danger and opportunity now surrounds contemporary discussions of genetic technologies and their presumed power to rock the foundations of nature (Paul 1995; Strathern 1992). The attribution of social upheaval to scientific advancement is, of course, not new: interwoven fears and hopes have long been attached to biomedical attempts to "play God" with nature, as the history of nineteenth-century surgery or twentieth-century reproductive medicine bears out. Here and throughout our collective work, we hope to tease out imbrications of the old and the new, the innovations and constraints through which public enthusiasm and dis-ease regularly collide. On this unstable terrain, other powerful cultural discourses surrounding notions of the mastery and perfectibility of nature—including human nature, biology, and molecular genetics—intersect one another with complex and often contradictory effects.

While eugenic thinking has a long and tenacious history in Western societies, we want to be attentive to the specificities of the present moment. Under the shadow of the Human Genome Project and the rise of the biotechnology industries, a heterogeneous array of actors has been drawn into a worldview in which human diversity is increasingly ascribed to genetic causality.[7] In many ways, this perspective builds on older versions of biological reductionism in which barely concealed, barely secularized Protestant notions of predestination identified a social elite by its alleged physical, mental, and social superiority. At the same time that contemporary medical geneticists powerfully distance themselves from prior notions of biological superiority and inferiority, they relocate the intervention of authority and explanations of the body to the molecular level. We have all benefited from previous forms of scientific reductionism and medicalization, as well as suffered their social consequences selectively.

Yet in the popular imagination, as Abby Lippman (1991) points out, the connection between the perceived heritability of complex social traits like intelligence or criminality and the assumed explanation at the level of indi-

vidually carried DNA underlies powerful beliefs in both genetic determinism and the importance of new biotechnologies of genetic improvement. Thus we see the persistence of eugenic thinking in the United States today, where many people across a broad spectrum of social groups consider the genome to be the site at which the human future must or can be negotiated. For us, this expanding genetic worldview among all constituencies, including research scientists, clinicians, lay support groups, and more general populations, is constituted dialectically: on the one hand, an ever increasing number of actors and practices are conscripted into a world defined genetically, in which reductive determinism looms large. On the other hand, democratic possibilities open up as genetic discourses and practices come to occupy multiple locations and to conscript a wider range of actors. Some of those actors may use their new and multiple locations to contest a too-easy determinism or to develop interventions—molecular and otherwise—that they consider choice-enhancing. They may well be viewed as a vanguard in the politics of biosociality, a vanguard from which the rest of us have much to learn. Those who have a consequential stake in this story have taught us to appreciate and track this dialectic in practice, as illustrated in the following narratives drawn from our observations at the LPA national conventions in 1997, 1998, and 1999.

AGENCY, NORMALIZATION, AND CONTESTED IDENTITIES

The LPA offers not only a site for biomedical research but also a self-affirming social environment. Most members bear a diagnosis of one of the many heritable dwarfing conditions, and the organization brings them together in a well-elaborated example of biosociality. Genetic enrollment includes conscription into a new identity politics as people come to align themselves with categories increasingly refashioned through emergent genetic discourses and practices. In our era, contemporary social life is rapidly being rescripted in terms of genetic narratives and practices (Taussig et al. 1999). But some aspects of biosociality build on forms of medicalization that predate molecular genetics, providing other embodied foundations for individual recruitment to group identity.[8] Indeed, although the LPA initially was founded as a support organization for all people of short stature, and its membership requirement is based on height rather than medical diagnosis, the LPA has long been interpolated into the milieu of medical genetics. At the same time, not all those born with heritable dwarfism accept the body politics that have emerged from the LPA's hard-fought advocacy.

One site at which we witness the tensions embedded in contemporary genetic and eugenic thinking in action is the meetings of the medical advisory boards that virtually all lay health groups organize. These advisory groups help members communicate with researchers and biomedical service

providers who are experts in their particular (and often rare) conditions. For example, the Medical Advisory Board of the LPA comprises both members of the organization and medical professionals who serve at the invitation of its officers. Since its inception in 1957, the LPA has maintained a strong grassroots orientation. While there is a tradition of cooperative medical research conducted within the LPA membership, the organization's leadership has asserted conscious control over researchers' permissions and protocols. Engagements between medical professionals and membership are carefully negotiated, as is the membership's access to the results of that research. When we interviewed one senior LPA member, for example, he stressed that the organization insists that researchers cooperate with each other, sharing blood and tissue samples that are already banked, avoiding oversampling. He told us a joke about LPA members who have become polka-dotted from the numerous skin biopsies they have provided to researchers over the years. Specific medical interventions are sharply debated and contested in ongoing and negotiated relations.

During our most recent visit to the Medical Advisory Board, a longtime physician member of the board reported on his recent trip to Spain. There, he had visited a surgeon who has been doing limb-lengthening surgeries on dwarfs for twenty years, a procedure that many dwarfs find controversial. The physician presented a video of a young American woman who had gained 12 inches in height through multiple surgeries. The ten-minute video documents a testimonial speech she gave at a fund-raiser for a genetics medical center. The opening image—a life-size blowup of the young woman before the surgeries, standing at 3 feet 10 inches—is followed by her dramatic appearance onstage on crutches (a result of her last operation). She gives a polished and thoughtful speech about how limb lengthening was not merely cosmetic. It gave her not only 12 inches in height but also the experience of being wheelchair-bound for two years, providing enforced tolerance for a range of disabilities. The woman tells her audience, "It's a better life and I'm happier. I'm more independent and confident. Many inner changes took place. I learned that the change was everything I ever wanted." She was fifteen when she reached her decision to have the surgery. Hers is a narrative of challenge, perfectibility, and growth. Reactions on the Medical Advisory Board immediately challenged the young woman's narrative.

During the video screening, the room buzzed with sotto voce comments; as the video ended, the room fell silent. The first to speak was a doctor who raised issues about insurance coverage and the competence of certain surgeons to perform such a complicated task. The first LP to speak asked, "Did she have any involvement with the LPA?" to which the presenting doctor answered, "Yes." The LP continued, "I find it surprising, when you can come here and see at least five hundred successful adults; most would say—if asked the question 'Would you change it'—they'd say 'No.' Here in America, acces-

sibility is a minor issue [that is, for LPs in the United States when compared to Spain]. I like to keep an open mind, but I think it's easier to adapt the environment than to adapt the person." Doctors and LPs rapidly entered the fray. One of each deemed the video's life-size blowup offensive. As the physician put it, "The video itself presents a cardboard cutout of an LP as undesirable and unattractive, in contrast to the whole person who is a foot taller than before."

Dissent broke out among the physicians, including practicing orthopedic surgeons who do not perform limb lengthening. One said, "I have devoted my life to treating the medical symptoms [of dwarfism], and I could never bring myself to lengthen limbs, because I find it abhorrent. I cannot stretch them out for social acceptance. It's more abhorrent to me than prenatal diagnosis." His denunciation highlights the perceived continuities between orthopedic and genetic interventions in the presumed foundational and moral rectitude of "nature" and "natural" variation. It also highlights diverse responses among researchers and clinicians, many of whom express complex critiques anchored in worldviews ranging from religion to political economy and civil rights.

The presenting doctor replied that in a society which promotes breast enlargement, rhinoplasty, and liposuction, dwarfs, too, deserve their right to aesthetic free choice in the medical marketplace. Yet even as he defended the practice, he also stressed that the operation should not be done before adolescence, when the patient and not the parents (who are most often of average stature) can consent to the procedure. Furthermore, he thought most people should not have the operation. He pointed out that, over the past decade, he and his colleagues had performed only thirteen surgeries. One of the elders of the LPA responded, "This is good information to have, and . . . it would be good to make it widely available, because it counters the widespread impression that the clinicians carrying out limb lengthening had created a surgical 'production line.'" Another LP, who works in a clinical setting, offered a final word:

> It's an attitude thing. I look at this as an enhancement, not a correction. But I don't need a correction. I'm OK. Most LPs, especially in this organization, look upon this as, you're telling me something's wrong. I'll make that choice. But I worry about calls from [average-statured] parents with new [dwarf] babies. I get phone calls every day from parents who aren't worried by [serious medical conditions associated with dwarfism, e.g.,] decompression, sleep apnea, with two-week-, four-week-, two-month-old kids, but they want to know about limb lengthening.[9] We'll all benefit from bringing this information out in the open.

Despite their different subject positions, the LPA officers and the physicians all inhabit a world in which the benefits of individual access to information and tropes of free marketplace choice predominate. A controversial surgical orthopedic intervention into body morphology shows how both its supporters and detractors invoke free choice in presenting their views on variations of biotechnological individualism. Indeed, the LPs, the members of the Medical Advisory Board, and ourselves are no less citizens of what the legal historian Lawrence Friedman (1990) has so usefully labeled the "republic of choice." Limb lengthening proposes to change the individual's recognizable phenotype without intervention into the underlying genotype, a kind of aesthetic and highly technical mastery of normalization. Those who choose the surgery, demonstrating the agency of choice in the biomedical marketplace, elude the judgment of prescriptive "natural" dwarfism inherent negatively in the form of social prejudice and positively in the biosociality of the LPA. Notions of mastery and perfectibility extend well beyond the contemporary United States, of course. But they have been given an upgrade and brought into the realm of science and technology within the rubric loosely identified as modernity, in which individual embodied choices reveal an attachment to the pursuit of progress and perfectibility (Berman 1982). What C. B. Macpherson classically labeled "possessive individualism" (1962) is here linked to identities, the realm of the body, and indeed, genetics.

What we are describing here as flexible eugenics thus involves technologies of the self through choosing and improving one's biological assets.[10] The desire to choose one's self in terms of technological interventions into the individual body incorporates both old and new aspects, from the distant promise of gene therapy to low-tech or routinized technologies such as cosmetic surgery.[11] Such instances signal a shift, one that Emily Martin, inspired by Michel Foucault, identifies as a move away from the powerful external interventions that produced the "docile bodies" so essential to the success of an earlier era of capitalism. Now, with postwar neoliberalism and its expanding emphasis on commodification and marketability, we see the emergence of "flexible bodies" (Martin 1994) obliged to be free, constrained by the tyranny of choice. In this marketplace of biomedical free choice, technology and technique become objects of desire invested with diverse meanings that surely vary for producers and consumers, for research scientists, clinicians, and individual patients, all of whom may imagine their relationship to choice and perfectibility quite differently.[12]

With advances in molecular biology, through which genes are becoming alienable and the modification of specific genes and bodies imagined more and more as an individual choice, biotechnological interventions in the service of individual perfectibility become the objects of desire. Deploying both social and biomedical "technologies of the self" enables people to modify, and imagine modifying, what is seen as natural, while our collective and individual stakes in what counts as natural are continuously renegotiated (Franklin 1997; Ragoné 1994; Strathern 1992). That is, in a world increasingly marked by flexible eugenics, self-realization can become attached to

genetic characteristics, increasingly understood as susceptible to improvement and choice. Thus, long-standing discourses on individualism and choice are now filtered through newer interventions that include the molecular or genetic, as well as older and constantly escalating ones provided by pharmacology and surgery, all in the service of sculpting flexible bodies. It is this flexibility of the individual body as an object of biotechnological choice and desire that then intersects innovations in eugenic thought and practice.

LOVE, DEATH, AND BIOTECHNICAL REPRODUCTION

How might the discourses of biotechnological individualism observed in action at the LPA highlight some social values while obscuring others? This question is richly woven through myriad discussions of love, marriage, family formation, and children, objects of desire prominent in many of the LPA workshops and informal conversations in which we participated. These, of course, involve relations across the generations and are therefore not only aesthetic but also eugenic in the classic sense of the term. For example, discussions concerning aspirations for and celebrations of dwarf children were common throughout the LPA. We also noted a particular emphasis on the value of dwarfs having babies. Thus an affirmation of the value of dwarf children struck us as a sign of resistant biosociality: although dwarfs conventionally have been despised and labeled as imperfect, kinship with and by dwarfs across the generations here has been given an elevated significance, an affirmation of diffuse and enduring identity in the face of the widespread discrimination LPs often face in the larger world.

In a workshop for new parents that was packed with family members of both average and short stature, for example, all participants introduced themselves by saying where they were from and what type of dwarfing condition their child had. Many new parents of average stature were seeking support as they dealt with the shock of having a dwarf child. Other average- and short-statured parents were there to lend such support. An achondroplastic dwarf introduced himself and his wife as expecting a child and said, "And we hope it's a dwarf!" The audience responded to this comment with loud applause.

Two of us attended a workshop on women's health chaired by two female high-risk obstetrician-geneticists. In an audience of twenty short-statured women and two average-statured anthropologists, the first comment offered came from Katherine,[13] who shot her hand up, saying, "I'll start. I'm four months pregnant. . . . " She was interrupted instantly with enthusiastic applause and murmurs of delight from everyone, including the two physicians in the room. Then Katherine asked about her childbirth options, and

a long discussion, framed in extremely positive and supportive tones, ensued about the logistics of childbirth for women of short stature. Doctors and audience were united in viewing pregnancy and childbirth as highly desirable, both looking to biomedical technology to offer progress in obtaining safer and less complicated reproductive outcomes.

Katherine, like many pregnant American women, was concerned about how soon she would be able to hold her newborn child. Her physician had told her that because of prior adhesions in her lumbar area (a common problem associated with dwarfism), her only option for childbirth was a cesarean section under general anesthesia. Women with dwarfing conditions virtually always have cesarean sections, because the shape of the pelvis does not allow for passage of a baby's head. In the United States, cesarean sections typically are done with a spinal block rather than general anesthesia. One of the physicians explained that a spinal block was complicated in cases of people with spinal differences: it "is a really controversial issue. . . . Anesthesiologists are really afraid of . . . [spinal] abnormalities, and with good reason. It's really uncharted territory. . . . If your anesthesiologist is most comfortable doing general [anesthesia], . . . then you're going to have a good outcome; and putting a needle in your back is risky after adhesions, so I wouldn't take the risk." Katherine then asked, "What about the short stature makes it dangerous?" The response from one of the doctors highlights the fact that what are often considered routine medical procedures may be linked to conceptions of standardized bodies. She explained:

> When they're doing regional anesthetic, whether it's spinal or epidural, what they need to get is either a catheter or a needle into that little space—and what is the space like, is there a space? Sometimes in LPs there is no space. . . . They [the doctors] have to have landmarks. They're doing this blindly. . . . If they push on your back . . . they're looking for landmarks and they're saying, 'There's a landmark.' . . . If you have an alteration in your landmark, they have nowhere to start.

The conversation continued, with the physicians focusing on childbirth protocols for women of short stature, members of the audience chiming in with their own experiences, and Katherine trying to figure out how she could ensure that she would hold her child as quickly as possible after delivery.

The encounter between physicians and women with dwarfing conditions underscores three salient points. First, at this meeting the issue was not whether LP women should have children, but the physical logistics of pregnancy and delivery. We imagine that this discussion is a new one: it is unlikely that twenty years ago there even existed high-risk obstetrician-geneticists who would universally support LP women having pregnancies,

and dwarfs' aspirations to reproduce were more highly stigmatized. Second, the concern about obstetrics brings to light the challenges of applying standardized medical techniques to people with nonstandard bodies. The familiar waltz between the normal and the pathological reveals the hidden costs of standardization (Canguilhem 1989 [1966]; Starr 1991). Finally, the encounter illustrates that the different subject positions of the participants shape their concerns about reproduction. The physicians are caught up in the practical matters of applying standardized medicine to people with spinal differences: their agency is best expressed through continuous enhancement of the expertise that will make pregnancies safer.[14] But Katherine, whose questions about anesthesia prompted the discussion of obstetric procedures, is caught up in issues of love and kinship. She wants to know about medical feasibility because she is concerned with maternal-infant bonding after surgery.

The complications of pregnancy and delivery, made even more difficult by the physical challenges of certain forms of dwarfism, may prove too daunting for some short-statured women. Such concerns may be part of the reason there is an active adoption network coordinated by the LPA. The national LPA newsletter, *LPA Today,* says, "The purpose of this service is to find a loving home for every dwarf child. . . . By outreaching to adoption agencies, doctors, hospitals and geneticists and others, we are able to locate available dwarf children for adoptions, and perspective *[sic]* parents who are interested in adopting. The LPA adoption service is not limited to the dwarf community. Average size parents are more than welcome."[15] At the three sessions on adoption at the LPA meetings we attended, flexible eugenics was the norm. Two sessions provided information to people seeking to adopt dwarf children, while the third presented an opportunity for people to discuss their experiences with adoption. All the sessions were attended by both short- and average-statured people interested in, or having experience with, adopting dwarf children, and all offered positive models of self-help.

In each of these sessions, questions arose about the scarcity of American dwarf children available for adoption. The coordinator of the adoption program responded to such questions by telling people they should expect to adopt foreign children. She then explained how she handles the rare American dwarf child who becomes available for adoption. Underlining the predominance of foreign children in the adoption network, the adoption page of the LPA newsletter lists children from India, Bulgaria, and Colombia as available for adoption,[16] and a long article describes a short-statured couple's trip to Russia to adopt a dwarf child there (Dagit 1998: 8).

During the several discussions of the scarcity of American children available for adoption that we witnessed, invariably someone expressed hope that parents in the United States were choosing to keep their dwarf children and not opting to terminate pregnancies after a prenatal diagnosis of a dwarfing condition. This discourse about dwarfism, adoption, and abortion after prenatal diagnosis reveals participants' awareness and imagination of the future in light of recent and expected scientific discoveries and their application in medical practice. Here, heightened consciousness of individual choice and biotechnological futurism converge.

As we have described, many short- and average-statured people we encountered at the LPA celebrate dwarf children but are well aware of the potential for eugenic practices to emerge from the discovery of the genes causing different forms of dwarfism. Although the gene for achondroplasia is known, and prenatal testing is therefore available, it is not routinely tested for today. The condition is simply too rare for widespread prenatal screening to be conducted expressly to detect it. Rather, prenatal diagnosis usually is made as a by-product of routine ultrasound testing sometime during the third trimester, making pregnancy termination illegal and, therefore, unlikely.

As both clinicians and many people affected by genetic abnormalities are aware, however, scientists have developed high throughput biochips with the potential to dramatically change prenatal diagnosis as we know it. Already on the market, these microarrays use silicon chips etched to receive multiple, minute samples of DNA, which may then be rapidly screened using automated computer technology.[17] Instead of testing for a few of the more common genetic conditions, such as Down's syndrome, or a condition specific to the family of a particular couple, as is now usual, the biochip technology will soon provide the means to offer rapid and relatively cheap diagnosis of a wide range of genetic conditions. Achondroplasia is regularly mentioned as one condition for which prenatal DNA chip screenings should and would become generally available. Once again, both the power of biotechnological individualism and the quite understandable fears of a marketplace-driven flexible eugenics are evident in LPA discussions of the chip.

The prospect of a highly efficient diagnostic chip also underscores the significance of speed in contemporary imaginings of the future (Rifkin 1987; Virilio 1986). The cage of late capitalism is a silicon cage and the tempo with which it is associated increases the velocity of industrial machinery (Weber 1958 [1904–05]) to that of the nanosecond tempo of computer technology. The changes suggested by such near-futuristic technologies are deeply unsettling. Yet we stress that, at the present moment, virtually all of us already live "inside" scientific and rapid technological innovation, culturally speaking. Many social groups, from the Catholic Church to some highly creative and respected feminist scholars (e.g., Hubbard 1990; Hubbard and Wald 1993; Rothman 1990, 1998) call for resistance to our inscription into new reproductive technologies like prenatal diagnosis, labeling these technologies per-

versions of nature and repressive aspects of capitalism. We contend that the issues involved are more complicated. There are enabling as well as constraining aspects to genetic knowledge and its associated technologies (Giddens 1984: 177).

This is a position we have come to appreciate ethnographically, through our work with the LPA. The point is nowhere more clear than in the fraught politics of prenatal diagnosis. Historically, and even now, LP couples may have opted for adoption because of the double dominant effect when two people with genetically caused dwarfing conditions reproduce together. Achondroplasia is dominantly inherited in a simple Mendelian fashion. Thus two people with achondroplasia have a 25 percent chance of producing a child with that condition, a 25 percent chance that the two nonachondroplastic genes will combine to produce an average-statured child, and a 25 percent chance (considered very high by genetic counseling standards) of producing a child with what is known as double dominance, an inevitably fatal condition. Prenatal testing allows LP couples to learn whether their fetus has this double dominant condition and to make a choice about whether or not to terminate the pregnancy rather than deliver a dying baby.

The issue of double dominance was raised during the LPA session on reproductive health. One woman asked whether the physicians knew the consequences of double dominance in cases of partners who are both short statured but have different dwarfing conditions. Another woman explained that her husband had achondroplasia and she had spondyloepiphyseal dysplasia (SED, another type of dwarfism); they had had five children with the double dominant condition, all of whom had died. In response to the question about the effects of hybrid double dominance, one of the physicians offered the observation that almost nothing was known. She then gestured toward the speaker saying, "We have the best evidence [of the consequences] right here." The doctor's evocation of "evidence" tempts us to imagine the complex imbrications between *Laboratory Life*,[18] where animal models are developed for rare conditions that cannot be investigated through human breeding experiments, and the data real people unexpectedly produce for scientists in the course of living their lives as bearers of both rare conditions and children. Here, too, we see flexible eugenics at work.

Physicians at the LPA session stressed the importance of having a definitive diagnosis for one's own dwarfing condition in advance of becoming pregnant. One told a story about a pregnant couple who thought they were both achondroplastic dwarfs, but

> lo and behold they weren't. One was and one wasn't, and we didn't know what the other had and no way of finding out, . . . so the pregnancy was on the line. . . . If you were in a situation . . . where you had SED and you were pregnant and your partner had achondroplasia, and your concern was that you would have a double dominant, then you might want to have amniocentesis for a prenatal test. Some people would choose to end the pregnancy and other people would not do that, [but] they would have to know the prenatal diagnosis early in the pregnancy. . . . But if you become pregnant [without knowing your own diagnoses], that all becomes either not possible or extremely difficult.

The idea of choice is powerfully present in this discussion. Here, physicians encourage genetic tests so their dwarf patients can make individual choices about their own reproduction.[19]

The story of double dominance illustrates how a controversial technology involving reproductive choice and eugenic abortion holds different meanings when used inside and outside a particular community. Within the LPA there are widespread fears that the general public will use testing to eliminate dwarf fetuses, not to prevent the birth of dying infants, as dwarfs themselves may choose to do. Indeed, in discussing her aspirations for gene therapy with us, Dr. Clair Francomano was very clear that she believed the only appropriate use of prenatal diagnosis was to avoid the birth of a child with the double dominant condition. The value of choice also underlies the apocryphal stories we have heard repeatedly about dwarf couples using prenatal testing to prevent the birth of children of average stature.[20]

We use the term *flexible eugenics* to underscore the sort of productive and problematic contradictions outlined above. These examples illustrate the complexities of living in a market-driven society that places a premium on individual choice and, at the same time, largely embraces the emergent standards posed by genetic normalization. But as our analysis demonstrates, the idea of a specifically eugenic relation to one's individual genes does not play out in a simple fashion. The people we have met through the LPA are highly attuned to the perils of eugenic thinking; many of them alternately resist and counterappropriate the push to perfectibility as specifically biological or biomedical. Yet like the rest of us, they may desire individual improvement or perfectibility in other ways that are deeply consonant with shared aspects of our cultural milieu.

PESSIMISM OF THE INTELLECT, OPTIMISM OF THE WILL

Genetic counseling and the kind of advice we see circulating at the LPA provide arenas in which both flexible eugenics and resistance to it may become operationalized. At the LPA meetings, one of our team who has conducted long-term fieldwork among genetic counselors met an unusual genetic

counselor. As a person with osteogenesis imperfecta (brittle bone syndrome), the genetic counselor told the story of both her struggles and the support she had received in becoming a genetic counselor with great reflexivity. Some doctors did not want an obviously disabled person confined to a wheelchair to counsel pregnant women about conditions that might include her own. Others immediately defended her right as a professional to work with *all* clients, not merely the ones who could handle what they presumed to be the visual impact of her condition. Volatile mixes of paternalism, affirmative action, and eugenic and feminist thinking swirl through the personal life and professional experiences of this young woman. In response, she has resolved to specialize as a genetic counselor in reproductive issues affecting people with disabilities. She is surely well positioned to hear the aspirations, fears, and consequences that molecular genetic technologies invoke as they are played out in the lives of those whose stake in their outcome is most direct. Yet in less obvious ways, we all have a stake in this unfinished story.

Flying home from the LPA meetings in Los Angeles, we chatted with a flight attendant whose family, as it turned out, lives in the suburb where the LPA meetings had just been held. When she heard the reason for our journey, she immediately commented that her town was buzzing: her mother and her mother's friends had all noted the presence of Little People at the many malls and restaurants where tourists and locals might mingle. They found the LPs "cute" or "interesting." She, however, had gotten into a fight over the dwarfs with her best friend from high school. The friend had exclaimed, "I just saw the most disgusting thing: two dwarfs, a couple, with a baby carriage and a baby dwarf. Why would people like that want to reproduce?" The flight attendant said to us, "I told her they probably want to have babies just like you and me; everyone wants to have babies, why not them? I bet their lives aren't so bad. You've got [facial] neuralgia, I bet your life is tougher than theirs is." Our airborne informant continued for some minutes to express her shock and indignation at her friend's bad attitude.

Reframing the problem, if we engage an understanding of the impact of contemporary American genetic thinking and practices empirically, both flexible eugenic thinking and resistance to it are everywhere, permeating outward from the researchers, clinicians, and affected people to the suburban residents, service personnel, and sympathetic anthropologists who encounter them in daily life. We are all rapidly being interpolated into the world of genetic discourse, where resonances, clashes, and negotiations among interested parties occur at increasing velocity. While all historical moments are, by definition, transitional, we live in particularly fraught times insofar as an understanding of a shift in scientific and social thought surrounding genetics is concerned. At the risk of abusing a Gramscian truism, we note that a working knowledge of the political history of eugenics gives us reason for pessimism of the intellect, but an ethnographic perspective on

the openness of these encounters and practices may give some cause for optimism of the will.

NOTES

1. The FGFR3 mutation is a genetic rarity in which all cases of achondroplasia are caused by the same mutation. The general rule is that different mutations within a given gene lead to the same disorder. For instance, virtually every family affected with Marfan syndrome (Heath 1998a,b), also a focus of our ongoing research, has a distinctive mutation in the gene for the connective tissue molecule fibrillin.

2. A dominantly inherited, fatal neurological disorder that has played an important role in the development of the Human Genome Project and in recent discoveries in molecular biology.

3. At the annual LPA meetings, a number of T-shirts are available for purchase at the expo. One such T-shirt in 1998 was a takeoff on the Tommy Hilfiger logo with the words "Tommy Dwarfiger." Another looked like a university T-shirt, with the text "Dwarf U." One of the more popular T-shirts in the last few years has been one with the text "Dwarf, Endangered Species" on the front.

4. Representations of dwarfs wishing ill to people of average stature resonate with a discriminatory apparatus that dwarfs face which is deeply rooted in popular culture and folklore and evident in stories like "Rumplestiltskin" and in movies like *Freaks* and, more recently, the Austin Powers movies (for the masses) and the *Red Dwarf* (for cognoscenti). Literature abounds with dwarf protagonists: *Mendel's Dwarf* (Mawer 1999), *The Tin Drum* (Grass 1959), *Stones from the River* (Heigi 1994), and *The Dwarf* (1967), by the Nobel prize-winning author Pär Lagerkvist.

5. In part, Americans operationalize the push to perfectibility by relying on an ideology of exercising individual choice. Discussions of individualism have a long history in American studies, one that can be traced back to de Tocqueville, who identified individualism as a distinctively American characteristic (1835). C. B. Macpherson (1962) examined a more broadly Western notion of individualism in political theory. Linking individualism and capitalist accumulation, Macpherson describes a concept of "possessive individualism."

6. The field research on which this essay draws was supported by NIH/NHGRI/ELSI grant # 1RO1HG01582, for which we are deeply grateful.

7. McGill epidemiologist Abby Lippman labeled the process *geneticization* (Lippman 1991). In our fieldwork we have found that both this terrain and Lippman's concept itself are contested.

8. Veterans associations (Young 1995) and Alcoholics Anonymous (Powell 1987) provide examples of such sociality forged earlier in the twentieth century.

9. One encounter at an LPA session for parents also illustrates parental interest in limb lengthening. At a session billed as a "Teen Panel," at which short-statured teens answered questions from an audience of average-statured parents, one parent asked if any of the teens had considered, or would consider, limb lengthening. All four of the young women on the panel vigorously shook their heads no. One of them spoke quite emphatically, saying, "No, no way. I have too many things I want to do with my life. I don't have time."

10. We are indebted here to the sociologist Troy Duster (1990), who suggests that eugenics is already embedded in contemporary genetic practices through an ideology of choice: with the new genetics, eugenics will come not through state policy but through "the back door," through individual choice.

11. Biotechnological individualism and the reign of free marketplace "choice" seems apparent in, for example, Eugenia Kaw's 1993 description of Asian-American women, who may deeply identify with their cultural roots yet seek to transcend racial identity and exercise choice by choosing cosmetic surgery that anglicizes their eyes. In her work on changing attitudes toward the body, the historian Joan Brumberg (1988, 1997) describes a shift away from moral self-control to control of the unruly body. Especially for women, control over diet, exercise, and, for those who can afford it, plastic surgery enables individuals to choose the bodies they will accept as their own.

12. Biomedical and biotechnical interventions may well have other meanings in different national and local contexts. For example, Taussig's work concerning Dutch genetic medicine shows that normalcy, rather than perfectibility, is strongly marked and desired (1997). Lynn Morgan's 1997 analysis of sonography in Ecuador also points toward the context-specific interpretations attached to biotechnological interventions.

13. In this essay, we use only first names when we use pseudonyms.

14. On the hidden costs of standardization, see Starr 1991.

15. *LPA Today* 35, no. 3 (May-June 1998): 7.

16 *LPA Today* 35, no. 3 (May-June 1998): 7.

17. The molecular biotechnology lab where Deborah Heath carried out fieldwork in 1992 and 1994 was working on a prototype for the biochip at that time. Among rival groups working on the same technology was the biotechnology company Affymetrix, which is now in the forefront of microarray technology (http://www.affymetrix.com/technology/synthesis.html; accessed in June 1999).

18. Our debt to Latour and Woolgar (1979) should be evident here.

19. The ideology underlying contemporary genetic counseling, offered in a mode known as nondirective counseling, is one based on the idea that knowledge enables individuals to make informed choices. Taussig (1997) has argued that this knowledge is not always perceived as enabling choice and in some cases is experienced as constraining choice.

20. We and our informants have no evidence that there is any truth to such stories. In fact, the research position held by Clair Francomano, the physician whose story opens this essay, makes it very likely that she would know if any such cases had occurred.

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Chapter 4

The Commodification of Virtual Reality

The Icelandic Health Sector Database

Hilary Rose

When newspapers around the world reported, "Iceland sells its people's genome," it read to many, not least Icelanders themselves, as if Brave New World had finally arrived. It is now clear that the remarkable events on this small Nordic island must be understood as part of a much wider shift. As the big pharmaceutical companies, venture capital, and the state gravitate toward predictive medicine and pharmacogenomics, Iceland may be the first example of pharmacogenomics in action, but unquestionably it is not going to be the last.

There is a distinct irony to recent developments in pharmacogenomics: This potentially immense innovation, actively pursued by global pharmaceutical companies and venture capital, requires as its precondition a universal health care system.[1] Only the old welfare states have universal health care records. Not for the first time does the relationship between the organizational structures of health care provision and the development of genetics come into visibility and importance.[2] For pharmacogenomics, only the old welfare states offer what they speak of in their depoliticized language as a "good" population.[3]

Although the conflict over the Icelandic database broke in 1998, its origins go back to the summer of 1994. Then two Harvard-based clinical neurologists, the Icelander Kari Stefansson and his U.S. colleague Jeff Gulcher, were visiting Iceland to collaborate in a study of multiple sclerosis (MS) with an Icelandic neurologist, John Benedikz. The research project was to look for a possible genetic predisposition to the disease. In "helicopter science" mode, the researchers flew in during the summer, secured as many samples as possible from patients and their families, and then returned to the Medical School at Harvard to do the lab work.[4]

Stefansson's ambitions and vision, however, were much wider than search-