
Prenatal Diagnosis and Disability: The Ultimate 'Technological Fix'?

Joan Rothschild

This chapter is adapted from 'Discourses of the Imperfect', chapter 7 of *The Dream of the Perfect Child* by Joan Rothschild, published by Indiana University Press, 2005.

© *Joan Rothschild* 2006

Abstract

Prenatal diagnosis entered medical practice in the 1970s, its use becoming routine in the decades to follow. If a birth defect is detected prenatally, the decision most often is to abort the pregnancy. Although made privately in the doctor's office, each decision is replicated thousands of times, the result to mark some fetuses not worthy to be born. While the hope is for a normal, healthy child, the decisions arise out of fear—fear of an imperfect child, mentally and physically impaired. Given a long history of negative attitudes toward disability, which reached a heyday in the negative eugenics of the late 19th and early 20th centuries, this article asks what the effects of prenatal diagnosis practices will be on people with disabilities and on attitudes toward disability. This article explores the meanings of disability in the contexts of changing policies and practices, asking us to rethink research priorities so as to transform reproductive medical practice.

Introduction

National surveys in the US since the 1960s show an increasing percentage of adults approving legal abortion if there is a strong chance of a serious defect in the baby. Discovered in the 60s and developed rapidly in the decades that followed, prenatal diagnosis made it possible to detect birth defects prenatally. Its use has become increasingly routine in medical practice. For a woman with a diagnosed 'defect' there is little 'choice': carry the pregnancy to term or end the pregnancy. For most, the decision is to abort the pregnancy. Although taking place in a privatized and

individualized setting, these decisions are replicated thousands of times in thousands of doctors' offices. The decisions are cumulative, adding up to mark some fetuses as unwanted, not fit to be born, as others gain an illusory stamp of approval.

While the hope is for a healthy, normal, even perfect, child, lurking behind these decisions is fear—fear that the child will be imperfect, that it will have some dreaded impairment. These fears are set within a long and persisting history of negative attitudes toward the physically and mentally impaired. Reaching its heyday in the late 19th and early 20th centuries, the policies and practices of negative eugenics sought to prevent the 'unfit' from procreating, in effect to end their future existence. But the tools were few, limited mainly to involuntary sterilization of populations labeled undesirable. With the advent of prenatal diagnosis in the second half of the 20th century, genetics and reproductive technologies provided a possibly new and far more effective set of tools to eliminate the imperfect.

Is prenatal diagnosis, then, the ultimate 'technological fix'? My concern is not with the motives of medical professionals and parents who engage in prenatal testing, but with the effects such medical practices could have. We need to raise critical questions about what the results of widespread promotion and use of prenatal diagnosis may be. In this article, I explore the views of people with disabilities who may well be further stigmatized, and the effects as negative attitudes may be reinforced. After reviewing the meanings of disability and the purposes such characterizations serve, I place them in the context of prevailing cultural and social standards and the policies and practices that have evolved. I conclude with a call to rethink the relationship of prenatal diagnosis and disability so as to rethink and transform reproductive medical practice. My analysis refers mainly to attitudes and practices in the US.

The shape and character of 'difference'

What makes the handicapped 'special' are the attitudes and reactions of others who are not handicapped; and the greatest harm to the handicapped child or adult stems from this socially engendered impairment of daily life, self-concept and future—not from functional impairments themselves.

So wrote psychologist Kenneth Keniston in the Foreword to *The Unexpected Minority: Handicapped Children in America* (Keniston 1980, iii). For disability rights movement activist Marsha Saxton, born with spina bifida, the 'pitying stares, the smiling condescension mostly from adults' were more oppressive than the leg braces she wore as a child. 'The *oppression* is what's disabling about disability' (Saxton 1984, 299, 307). Sociologist Barbara Altman, reviewing studies of attitudes toward the handicapped, comments, 'It is the subtle but pervasive influence of public attitudes that governs the day-to-day interactions of handicapped individuals and affects (either by support or rejection) the lifestyles they develop' (Altman 1981, 323). For policy analyst Harlan Hahn, the greatest obstacle for the disabled lies in 'attitudes', in the discriminatory and 'destructive process of stigmatizing' (Hahn 1983, 44).

Social critics and activists describe three characteristics of such attitudes, which they find rooted in the culture and its social systems: (1) the disabled are defined by their disability, (2) a functional limitations model, which rests on a biological and medical model, is applied, and (3) the impairment is centered in the individual as that person's 'problem'.

Defined by disability. More than a century ago, in the 1880s, eugenicists began using the word *defective* as a noun (Finger 1984, 284–285). Reflecting then current values, the term conveniently encompassed those who already bore the mark of their socially defined defect, whether they were labeled 'criminal', 'drunkard', or 'cripple'. Although we no longer use the term in this way and have discarded some of the social categories, the labeling remains in an altered form. People with disabilities are defined by their membership in the suspect category (Funk 1987, 22–23). Someone who is blind becomes 'the blind woman', as if blindness were her only characteristic. The 'deaf man' similarly marks someone who cannot hear. The child born with Down syndrome is described as a 'Down's child'. Using stigmatizing terms in discourse 'as a source of metaphor', writes Erving Goffman, 'We tend to impute a wide range of imperfections on the basis of the original one'. Whether the handicap is referred to or avoided, an underlying heightened awareness 'causes the interaction to be articulated too exclusively in terms of it' (Goffman 1963, 5, 19).

A functional limitations model. Categorized and defined in these ways, people with disabilities are labeled inferior. A functional limitations model, and its companion, a medical model, support inferiority labeling. According to ‘biological inferiority theory’, a person’s physical and/or mental impairments cause the problems the individual may face (Oskamp 1988). Biological difference for the disabled is socially and politically constructed to mark them as inferior (Roth 1983, 56–61). Focusing on the impairment and its departure from a norm (also socially constructed) allows any limits to activity such persons have to be socially labeled as ‘handicaps’. Considered functionally limited because they are biologically inferior, people with disabilities are classified as sick, needing treatment, and/or to be segregated and institutionalized. Requiring medical and professional care, they are subjected to a medical model which reinforces discriminatory and dehumanizing attitudes and practices.

This medical model seemingly brought change for the better as new public policies for the mentally and/or physically impaired came into being between 1920 and 1960. Funds were committed, rehabilitation methods and programs were developed, living conditions improved, and professional attention increased greatly. But, according to Robert Funk, director of the national legal arm of the disability rights movement, the status of people with disabilities and attitudes toward them did not change.

(...) the handicapped retained their caste status in the public mind as dependent, unhealthy deviants, who would, in the great majority, always require segregated care and protection. The charity, rehabilitation, and medical professionals ruled the day, providing better care and better services to a people who would, it appeared, retain their childlike dependent status in perpetuity (Funk 1987, 14).

Almost three decades since the medical model took hold, the disabled continue to be oppressed by attitudes and images that perpetuate their caste status. Alan Gartner and Tom Joe, in the introduction to their aptly titled collection, *Images of the Disabled, Disabling Images*, in which Funk’s article appears, state ‘While the emergence of new views has tamed some of the extremes of the medical model, it still holds sway, especially in the training of the “helping professions”’ (Gartner & Joe 1987, 5).

Inherent disability. The medical model, with its individualized focus, reinforces the view that the impairment and its disabling consequences are lodged in the individual. In a study of treatment patterns for children with disabilities that probed parents' and pediatricians' attitudes, Darling and Darling describe a 'clinical perspective' and 'curing model'. Stressing individual adjustment of the family to the handicapped child, physicians do not consider the social context, having no 'social system perspective' (Darling & Darling 1982, 43–44, 214–219). By the same token, the person having a disability is expected to 'adjust' to the world as given. A director of special education programs, Douglas Biklen notes that the print media perpetuate an individualized approach, portraying the issue of treating seriously impaired newborns as an individual problem for parents, doctors, and disabled people themselves (Biklen 1987, 79–95).

Us and them: what purposes does stigma labeling serve?

Why do people with disabilities continue to be categorized and labeled? Why are they stigmatized? Why do such persons continue to be seen as biologically inferior, as sick and needing treatment, their whole lives colored, indeed dominated, by a limit to function in a particular way? Why do we see disability as a 'personal misfortune', the fault lying in the individual?

Irving Goffman's classic study describes stigma as 'an attribute that is deeply discrediting'. A person with stigma possesses 'an undesired differentness from what we had anticipated'. 'By definition', he continues, 'we believe the person with a stigma is not quite human'. And, on this assumption, the 'normals' discriminate and restrict the life chances of the stigmatized, constructing an ideology to explain their inferiority and account for the dangers they represent (Goffman 1963, 3, 4, 5).¹

Depth psychology theories find the sources of such attitudes in people's uncertainties about their own humanity. Just as 'defectives' served this role for eugenicists in the late 19th century, so do John Gliedman and William Roth hold that people with disabilities are cast as 'symbolic Other. The disabled person becomes a kind of talisman, a visible incarnation of death,

sexuality, and dependency, all of which arouse our deepest fears'. Among the most fundamental is the fear 'of the nonhuman and of becoming nonhuman ourselves'. If one's humanity is achieved and proved through conflict and power over the Other, then the 'handicapped person—by virtue of his disability—is the incarnation of our fear of failure, of losing out, of being mutilated and conquered by the Other'. The 'ultimate failure is death'. In the mind of the able-bodied, 'every handicapped person has (...) already died a little (...). His lack—his blindness, or deafness, or paralysis—reminds us of the time when we shall all be blind, and deaf, and paralyzed' (Gliedman & Roth 1980, 374–375).

Relating the freak shows of the past to our continuing fascination with 'freaks' and 'abnormals'—as in the enormous success of the stage, film, and TV versions of *The Elephant Man*—literary and social critic Leslie Fiedler finds that 'those wretched caricatures of our idealized body image (...) appear at first to represent the absolutely "Other"'. But they are 'really a revelation of what in our deepest psyches we recognize as the Secret Self. (...) in the depths of our unconscious (...) we seem forever freaks to ourselves' (Fiedler 1996c, 152).²

Taking a societal perspective, Kaoru Yamamoto, a professor of education, suggests that people who are physically and mentally 'different' function to 'preserve stability in society by embodying otherwise formless dangers'. Thus non-deviates may perpetuate deviates' status because 'society may indeed need the deviates as a symbol of evil, intangible dangers' (Yamamoto 1971, 182, 186).

Literature and popular culture are replete with examples of the ways the mentally or physically disabled represent people's fears and dangers, and evil. Among 'the most persistent' images in film and television 'is the association of disability with malevolence' and with criminality or villainy. 'Deformity of body symbolizes deformity of soul' (Longmore 1987, 66).³ Historian Paul Longmore points to the title characters in the films *Doctor No* and *Dr. Strangelove* who have their forearms encased in black leather, 'crippled' as a result of their evil experiments; Doctor Strangelove is 'confined to a wheelchair'. Ronald Merrick, the 'arrogant, deceitful, and viciously racist' British intelligence officer in the British-made TV series 'The Jewel in the Crown', has a disfigured face and a missing

arm. Disability is punishment for evil; the disabled are portrayed as embittered people who resent and would even destroy the nondisabled.

'Closely related to the criminal characterization (...) is (...) the "monster"' of horror films, and of horror classics such as *The Hunchback of Notre Dame* and *The Phantom of the Opera*. For both the criminal and the monster, continues Longmore, the only solution is death. Similarly for media images of the severely disabled projected in the 1970s and 1980s in which death is the 'only logical and humane' choice. For the quadriplegic in the TV drama *Whose Life Is It Anyway?* the loss of humanity is so acute that suicide is chosen by the disabled character himself. The message is clear: 'Better dead than disabled'. In the case of criminal characters, the 'nondisabled audience is allowed to disown its fears and biases by "blaming the victims"', making them responsible for their own ostracism and destruction'. Through sympathetic portrayals, the nondisabled preserve their own humanity, distancing themselves, avoiding having to deal with disability and its 'problems' as social phenomena.

Leslie Fiedler links pity and sympathy to deep-seated terrors. When we would end the life of the crippled child, an archetype in literature, or that of the severely disabled infant to spare each a life of anguish, it may not be from 'enlightened pity'. Rather, it 'may in part be the product of the same primordial fear of difference and monstrosity that once prompted ritual infanticide'. When we choose quasi-miraculous cures as in *The Secret Garden* and *Heidi*, or in the alternate dream ending for Tiny Tim in *A Christmas Carol*, we are expressing 'a wish that there were no handicapped, that they would all finally go away' (Fiedler 1996a, 44, 46).

Robert Bogdan finds that our responses to freak shows, which flourished in the US from the mid-19th to mid-20th centuries, have reflected the way 'our social institutions managed these people's identities'. "Freak" is not a quality that belongs to the person on display. It is something that we created: a perspective, a set of practices—a social construction' (Bogdan 1988, x–xi). Bogdan and Biklen found a pattern of social construction of 'Handicapism' in the popular media in the 1970s. Images associated physical ugliness with violence and crime; in horror films both physical and mental handicaps were linked with acts of violence and hate. Whether in children's stories, movies, or cartoons, the world of Disney

reinforced stereotypes of mental impairment with frequent use of words such as ‘dumb’, ‘moron’, ‘crazy’. News reports of murders often imputed being alcoholic, incompetent psychotic, or mentally retarded as the cause of crime. In the media, the handicapped appeared generally as dependent and helpless (Bogdan & Biklen 1977, 16–17). Although starting in the late 1970s, these portrayals began to change as TV advertising and programs showed people in wheelchairs or with other disabilities in positive and active ways, one can question how deep such depictions may reach (Longmore 1987, 75–78). Longmore’s 1987 analysis of literature and popular media suggests that old images, and the fears, anxieties, and behaviors they express, can exist alongside an emerging discourse of social awareness.

London-based photographer David Hevey, who is also disabled, writes that photographic representations are voyeuristic, manipulating the disabled person’s image. He finds that the work of photographers such as Diane Arbus fulfills roles for the photographer, not for the disabled (Hevey 1992). ‘The use of disabled people is the anchor of the weird (...) the symbol of enfreakment or the surrealism of all society.’ As the

site and symbol of all alienation (...) the “contorted” body (...) does not function as the property of those disabled people observed. Its purpose was (...) as the voyeuristic property of the non-disabled gaze (...) the impairment (...) became the mark, the target for a disavowal, a ridding, of the existential fears and fantasies of non-disabled people.

Hevey goes on to say that newer work of the ‘post New Documentaries’ has made disabled people ‘an even more separate category. While the volume of representation is higher, the categorisation, control and manipulation have become deeper’ (Hevey 1997, 345, 346).

Harlan Hahn ascribes an ‘aesthetic anxiety’ to those holding negative images of people with disabilities, the term referring to ‘the fears engendered by persons whose appearance deviates markedly from the usual human form or includes physical traits regarded as unappealing’ (Hahn 1988, 42). In Goffman’s stigma typology such attributes are classed as ‘abominations of the body—the various physical deformities’ (Goffman 1963, 4). Shunning and devaluing the physically unappealing and unattractive,

the nondisabled may feel their own body image threatened. Anxious preoccupation with appearance in turn reflects socio-cultural norms. Writes Hahn, '[I]n a society that places extraordinary stress on beauty and attractiveness, aesthetic anxiety may be an important component of perceptions of disabled people' (Hahn 1988, 44). Aesthetic aversion and anxiety presuppose social ideals not only of the 'normal' but also of the perfect. As disabilities are measured against such norms, a hierarchy of standards for what is acceptable or unacceptable—aesthetically, physically, and mentally—can begin to emerge.

Setting standards: a hierarchy of beauty and brains

It seems hard for society to accept difference without somehow ranking it, thinking of it as inferior, deficient, dysfunctional (Roth 1983, 56).

Still, although people with disabilities are among the 'different' who are labeled 'inferior, deficient', and 'dysfunctional', there are gradations of inferiority. Disabilities themselves are socially ranked. Sociologist Safilios-Rothschild points to seven interrelated factors—socioeconomic, political, and cultural—that influence the degree of prejudice directed toward the sick and disabled. Three are particularly relevant for studies that have measured social attitudes toward disability:

(3) the prevailing notions about the etiology of illness and the degree of individual 'responsibility' involved in falling ill and remaining disabled; (4) the cultural values or stigmata attached to different physical conditions or characteristics; (5) illness- or disability-connected factors, such as (a) the degree of visibility of the illness or disability, (b) whether or not the incapacitating illness is contagious, (c) the part of the body afflicted, (d) the nature of the illness (physical or mental) and the assumed 'pervasiveness' of the disability, and (e) the severity of functional impairment and the degree of predictability of its course; (...) (Safilios-Rothschild 1970, 5).

In part because they are more readily measurable, attitudes toward physical impairments, that is, visible disabilities, have been studied more. One method to get at differences and types of attitudes is picture-ranking. In a classic study from 1961, children aged 10 to 11, who were both normal

and handicapped, were shown six pictures and asked to identify the boy or girl they 'liked best'. As each selected picture was removed, they were asked their 'next best' choice, the process continuing until the last picture. Starting from 'best', the children chose: (1) a child with no handicap; (2) a child with crutches and left leg brace; (3) a child in a wheelchair, a blanket covering both legs; (4) a child with left hand missing; (5) a child facially disfigured on the left side of the mouth; and (6) an obese child (Richardson et al. 1961, 241–77; Altman 1981, 323–24). Subsequent studies of children have revealed a surprising consistency of results, regardless of race, physical handicap, socioeconomic status, urban-rural differences, and interview setting. Results for both sexes were constant as well, as were sex differences. Boys were more negative toward functional impairments, such as a child in a wheelchair or with missing limb, while girls looked less favorably on impairments with social consequences, that is, facial disfigurements and obesity. As they did for other findings, researchers ascribed sex differences to cultural influences. These included 'stereotypes of physical beauty (...) identified with goodness and (...) physical ugliness (...) with evil' (Richardson, et al. 1961, 246–47). A follow-up study showed the same consistencies in preferences among children from grades 1 through 6 (ages 6 to 11), but some changes beginning to emerge among those in junior and senior high school. In teen years, preferences began to approach those of the same sex parent, the choices along sex lines becoming stronger. Girls were more markedly prone to dislike cosmetically disfiguring impairments, boys to reject the functionally disabled. All, however, ranked obesity last (Richardson 1970, 207–14).

That younger children's preferences hold steady across many possible individual and social divides, and that children's preferences come closer to adults' as the children approach adulthood, indicate the extent to which these attitudes are learned, dependent on widely shared socio-cultural values. Although these picture-ranking studies date mainly from the 1960s, reflecting then prevalent thinking, and follow limited and perhaps simplistic methodologies,⁴ the values and the practices they reflect persist. According to Funk, people with visible physical disabilities continue to be highly stigmatized, the intensity of discrimination depending on the severity and degree of disability (Funk 1987, 25). The

premium is on physical wholeness and attractiveness, as health and beauty standards have become increasingly exacting.

The billion-dollar beauty, health, and fitness industries owe their success in promoting and selling their images in no small measure to tapping into the central role that physical attractiveness plays in our culture and in forming self-concepts.⁵ The young, impossibly flawless specimens portrayed in the media are not just examples of perfect fitness and health. They represent unlimited material success, and the good, the true, and the beautiful. As the physically flawed are associated with evil, so the physically attractive are linked with the good. 'What is beautiful is good', and 'what is good is also beautiful'. And the 'good' in our society is at one with success, writes psychologist Rhoda Unger. She points out that physical attractiveness is associated with 'perceptions of greater social influence, ability to succeed, competence, and likability', while 'negative social judgments' are associated with people having 'lower degrees of attractiveness'. The less attractive are selected as more likely to show symptoms of psychopathology, even epilepsy; they are less desirable for high status employment, and are more likely to be associated with social and political deviance (Unger 1985, 143, 148, 143–46). While the point of her article is to show particularly how attractiveness stereotypes operate in the social control of women, her analysis applies equally to the way socially constructed norms of physical attractiveness can perpetuate negative assessments and reinforce social control of the physically disabled. Because of the beauty standards set for females, women with physical disabilities suffer a double burden, as Michelle Fine and Adrienne Asch, among others, have carefully pointed out (Fine & Asch 1988).

Within given cultures such standards are social and class-based. As Safilios-Rothschild writes,

there are indications that the standards for physical integrity and perfection as well as for beauty are very strict in Anglo-Saxon countries (especially among the middle classes), and any deviation from the highly admired state of perfection is punished by social stigmatization. Not only physical deformities or chronic invalidating illnesses, but also obesity (or even overweight), pimples, oily hair, 'bad' breath or sweating odors are considered intolerable and label the 'afflicted' individuals as deviants. This labeling brings about devaluation, social isolation,

and a more or less potent social stigma according to the nature and degree of the deviation (Safilios-Rothschild 1970, 126–27).

While physical health and attractiveness are important marks of success, in a highly industrialized culture intelligence is even more greatly prized.

The higher the stage of industrialization and socioeconomic development in a country, the greater the tendency to value intelligence and all the qualities that are conducive to high achievement, productivity, competitiveness, and efficiency. Thus, stupidity is strongly stigmatized, since people with a low IQ have little chance of earning any kind of social status in societies in which one's personal ability and achievement determine his social standing practically to the exclusion of all other criteria (*ibid.*, 127).

The increased value placed on intelligence translates into intolerance of mental illness or mental deviations of any kind. There is a growing tendency to discriminate against stupidity.

In the early 1980s Bogdan and Taylor questioned the validity of the term 'mental retardation' itself, especially from the perspective of those so labeled. The term is 'not just less than useful', but 'seriously misleading'. Its 'scientific aura is deceptive in that it conceals subjective moral and cultural value judgments', mental retardation being 'a demeaning concept which implies a deficiency in the humanity of those tagged'. It is 'a reification—a socially created category'. It points to, not the state of mind 'of the people who are alleged to have it, but the state of mind of those who use the concept in thinking about others'. They conclude, 'Mental retardation is a misnomer, a myth'. Reviewing the dramatic rise in numbers of persons identified as retarded in the 20th century, Bogdan and Taylor note how elaborate classification schemes were devised even as mental retardation continued to be thought of as an absolute condition. For those so labeled, the term 'implies moral inferiority as well as intellectual deficiency'. Moral judgment could well be added to intolerance of those who can't measure up in the 'knowledge society' (Bogdan & Taylor 1982, 6–8, 14, and *passim*).

In current society, then, despite the fitness and body-building craze, brains are more important than brawn. Parents may hope for budding geniuses, but anything less than at least normal intelligence would be a

disaster. And physical disabilities can at least be fixed. Even though beauty and health images set exacting standards, medicine and technology are rising to the challenge. Plastic surgery can correct and even reconstruct 'imperfect' body parts; prostheses and sophisticated mechanical and electronic devices are becoming available for the severely physically impaired. Masking the disability and/or making social participation easier, such measures could help to reduce social stigma for the physically impaired. But no comparable 'fixes' (such as surgery to repair a 'defective' brain) are in the immediate offing for the mentally impaired, unless we count mood or behavior altering drugs that may mask or temporarily reduce symptoms. Far less amenable to correction or technological fix, and of increasing importance to culturally dominant groups, mental disability is the least desirable attribute—at the bottom of the health hierarchy.

But, whether disability is mental or physical, past and current policy and practice have focused on making it disappear. Using whatever scientific, technological, social, or legal measures available, the aim is to make disability just go away.

Social policy and practice: then and now

The prospect of eliminating 'defectives' brings its own moral dilemmas. In the 1950s, evolutionary biologists posed the issue of 'genetic load'. Because science and medicine were making it possible for more 'bad genes' to survive and be transmitted to succeeding generations, natural selection no longer operated to prevent threatened deterioration of the human gene pool. Their patron saint, Charles Darwin, had raised this possibility almost a century earlier. For Darwin, the impetus to treat and protect the weak was moral, although also a product of evolution. Natural selection and a struggle for survival, he maintained, had produced not only physically and mentally superior human beings, but also a 'higher morality'. In civilized societies it was this developed moral sense that now worked to thwart natural selection and therefore to impede further race improvement. As he wrote in *The Descent of Man*, while among 'savages, the weak in body and mind are soon eliminated',

We civilised men (...) build asylums for the imbecile, the maimed, and the sick; we institute poor laws; and our medical men exert their utmost to save the life of every one to the last moment (...) Thus the weak members of civilised societies propagate their kind. No one who has attended to the breeding of domestic animals will doubt that this must be highly injurious to the race of man (Darwin 1871, 133–34).⁶

John Greene describes this as posing a dilemma for Darwin. Practicing a socially conscious morality would weaken and even eliminate the competitive struggle. Yet, much as he might have deplored the ethic of struggle in moral terms, Darwin found it necessary for both race survival and race progress. Could one ‘destroy the very basis of social progress’ through practicing higher morality—itself a product of struggle—and still progress? For Greene, Darwin never dealt adequately with this contradiction. Somehow Darwin believed that the ‘higher impulses’ would win out, bringing humankind to moral perfection, where presumably struggle would no longer be necessary.⁷

Evolutionary biologists and geneticists almost a century later expressed the conflict in terms of cultural and biological evolution. Science, as well as technology—with a little education and moral suasion added—would solve the problems of genetic deterioration that a scientific civilization had produced. They proposed artificial selection, the ‘new eugenics’ variety. If voluntary artificial selection were instituted as societal practice, the genetic load would be sufficiently reduced so as to lessen the need to find and apply cures for genetic disorders. The practice of saving defectives would fall off, there being fewer to deal with. Genetic deterioration would stop, and the way opened for the human species to improve, and progress. But what about interim measures to save and care for the genetically unfortunate? Geneticist Theodosius Dobzhansky restated Darwin’s dilemma in terms of 20th century technology. On the one hand he argued that we should accept an increasing dependence on technology to deal with genetic defects as part of modern life, even though using insulin, for example, might well increase the incidence of diabetes. ‘The remedy for our genetic dependence on technology’, he wrote, ‘is more, not less, technology’ (Dobzhansky 1962, 332). But Dobzhansky also favored using voluntary artificial selection to persuade the genetically defective not to procreate.

The question then becomes, Would artificial selection succeed in decreasing the genetic load if technology continued to operate at cross-purposes? Today, the question is one of technology vs. technology. While prenatal screening carries out a type of artificial selection, even if unwittingly, medical technology enables increasing numbers of even the most severely disabled to survive.

As it was for Dobzhansky, for most of those involved in reproductive practice today, the 'old eugenics' is unacceptable. Thus a form of the Darwin dilemma may still be with us. But perhaps the 'dilemma' remains mainly as a rhetorical device to mask a mindset that supports eliminating the 'defective', if socially acceptable means can be found. Harlan Hahn maintains that 'the prevalent values of the nondisabled majority seem to denote a widespread belief that the principle [sic] solution to the problem of disability is to eradicate it' (Hahn 1987, 200). The disabled, he points out, accounted for one million of the nine million human beings exterminated by the Nazis. Historically, the legal criteria for involuntary sterilization and for therapeutic abortion as they unfolded in the US lend support to Hahn's harsh judgment, which could perhaps apply to reproductive practice today.

The eugenicists were the first to clearly link defectives to reproduction, justifying the connection 'scientifically' and seeking to implement it legally and socially in the name of race survival and 'betterment'. Their technical solution was involuntary sterilization for the 'unfit'. The decision by the US Supreme Court in *Buck v. Bell* in 1927 that upheld the sterilization of a 'feeble-minded' young woman in Virginia opened the way for the heyday of eugenic sterilizations in the US. Reaching a peak in the 1930s with over 2,000 a year, reported sterilizations were performed on more than 60,000 persons between 1907 and 1963 (Robitscher 1980, 270; Reilly 1991).⁸ Carefully crafted to meet court challenges, laws passed in the 1920s and 30s clearly rested on a eugenic rationale. For both criminals and the feeble-minded—the main objects of legislation—the purpose was to prevent transmitting their defective genes to their offspring. In the beginning, both institutionalized males and females were sterilized. By the 1930s, 'mentally defective' young women and girls became the main targets.

Although there was a sharp decline in involuntary sterilizations in the 1940s, in 1975 twenty-four states still had eugenic sterilization laws, and as late as 1981 such laws remained in 13 states (Dunn 1975, 280; Sherlock & Sherlock 1982, 946). And although sterilizations dropped off to below 500 after 1960, it was not until the 1970s that reforms finally repudiated the eugenic theories on which the laws had rested. With reform came change in the rationale and arguments, and change in the laws' focus. As eugenic justification for sterilization was discredited and the courts acted on the growing challenges to due process and rights to privacy, the focus shifted to the individual herself. The 'state's compelling interest' in preventing procreation by the mentally retarded now became based on weighing such issues as the individual's competency to care for a child as well as on social costs, and on 'informed consent', not on the nature of the prospective child itself. But those labeled mentally retarded remained a suspect category, the wisdom of allowing persons so categorized to procreate still open to question by the law and mental health professionals alike.

In a curious pattern of events, however, just as the onus shifted from defective offspring to defective adult and the eugenic rationale no longer served to support legal sterilization, the 'defective fetus' was emerging as legal justification for therapeutic abortion. Coincidentally perhaps, abortion policy took over where sterilization left off to prevent the reproduction of so-called defectives. Abortions performed for fetal deformity actually predated mid-20th century attempts to legalize it as a criterion. By the late 19th century, mainly in response to the efforts of physicians, stringent state laws were in place to make abortion a crime except to save the life of the mother. Accepted practice had been to allow abortion until the point of 'quickening', that is, until the woman felt life. Acting less than out of moral concern, physicians sought to shut out competition and gain full control over reproductive medicine, including abortion (Luker 1984, chap. 3).⁹ Medical practice, therefore, was not closely bound by the letter of the law. Between 1890 and 1950, physicians who performed abortions tacitly agreed to include among their criteria: protection of the life and health of the mother, cases of rape or incest, and the possibility of 'fetal deformity'. Eugenic sympathies apparently played a role in the early period in supporting physicians' willingness to abort for possible

fetal defects. But medical criteria, especially dangers to the fetus from a woman's contracting rubella (German measles) or from being exposed to high levels of radiation from X-rays early in pregnancy, were more generally acknowledged and the case. As records became more readily obtainable in the post-World War II period when most obstetrical care had moved into the hospitals, hospital surveys showed approximately one in four abortions performed for 'fetal indications', with the highest proportion of these for rubella.

In 1959, therefore, when the American Law Institute proposed a model statute to reform state abortion laws, its provisions reflected what had been actual medical practice for more than half a century. Included among the cases specified for approval of abortion were those to protect the life and health of the mother, cases of rape or incest, and 'cases where there was a probability of congenital defects appearing in the embryo' (Luker 1984, 69, 278n7). Greater public attention was building on the issue of possible fetal deformities, perhaps due in part to a number of rubella outbreaks. But it was the publicity surrounding the so-called Finkbine case in the early 1960s that served to heighten public awareness, and provide a catalyst for legal reform. As Kristin Luker recounts, Sherri Finkbine's physician, learning that she had taken the sleeping pill Thalidomide, had recommended abortion. Reports had just begun to surface linking the drug to teratogenic effects on the embryo, including severe deformities of the limbs and hands. Just before the abortion was to take place, press stories (the original local story initiated by Finkbine herself to warn other women) made both the abortion and Finkbine a center of intense public controversy, and she was denied the abortion. Although Finkbine was able eventually to obtain one in Sweden (afterwards the physician told her the fetus was so severely deformed it would not have survived), the debate on what had once been routine practice, though under growing question in professional circles, was now out in the open. Physicians who supported a 'broad' interpretation of abortion indications—including psychiatric reasons—wanted legal protection for their practice. As the Finkbine case became a catalyst for professionally led abortion law reform efforts, a fetal deformities provision was written into reform statutes enacted in the late 1960s and early 70s.

The provision became highly controversial because, according to Luker, 'strict' constructionists found this the most offensive criterion of all. It brought into the open the moral issue of the fetus as a person. In cases such as the life and health of the mother, or rape or incest, it could be argued that the fetus was being sacrificed for 'some "greater good"'. But the fetal indications criterion meant that the fetus's existence could 'be ended for its own good' (Luker 1984, 89, 122).¹⁰ To those who held that the fetus was a 'real' person, not merely a potential one, aborting a 'damaged' embryo was totally unacceptable.

Although some medical professionals and later the 'right-to-life' movement opposed making fetal indications a legal basis for abortion, they were in the minority among the public in the 1960s. A Gallup poll at the time showed over half of those surveyed agreed with Finkbine's position (Luker 1984, 82, 280n20), and support for being able to terminate a pregnancy for fetal abnormalities was to grow in the years that followed. The public's views cited at the beginning of this article referred to a review of surveys on abortion attitudes sponsored by the National Opinion Research Center (NORC) of the University of Chicago over a 15-year period from 1965–1980. Granberg and Granberg found that the percentage of adults approving of legal abortion 'if there is a strong chance of serious defect in the baby' rose from 57% in 1965 to 79% by 1972, and to 84% by 1973. Although taking a slight dip in the late 1970s, the figure was up to 83% in 1980 (Granberg & Granberg 1980, 252). Throughout most of the 1970s decade, better than four out of five adults surveyed nationally approved of terminating a pregnancy for a defective fetus, a view that has held constant into the 80s and 90s.

In 1973, in *Roe v. Wade*, the US Supreme Court ruled abortion to be a private right through the second trimester. Invalidating restrictive laws in the states, the legalization of abortion made controversy over a fetal indications provision moot. When prenatal diagnosis developed in the 1970s and subsequently became accepted practice, it did so in this climate, in which abortion was legal up through the second trimester for any reason, and in which public thinking agreed that it was permissible, even desirable, to 'prevent' the birth of a child *known* to be defective. Over the years since, abortion opponents' attempts to chip away at a

woman's right to choose have succeeded in making it more difficult for some women—especially those younger and/or poorer—to obtain an abortion. But, in pursuing their ultimate goal to outlaw all abortions, vocal opponents of abortion for the most part have not included attempts to restrict aborting for a fetal anomaly among their tactics.

At the socio-cultural level, then, prenatal diagnosis seemingly takes over where sterilization leaves off. The nondisabled, write Gliedman and Roth, 'deny the feelings evoked by disability by denying that the handicapped really are a problem'. To soothe their consciences and handle their fears, the nondisabled readily turn to science and technology, invoking a technological fix (Gliedman & Roth 1980, 376). Prenatal diagnosis, it could be argued, offers the supreme 'technological fix'. Enabling medicine to select out the defective and the disabled before they are born, reproductive science and technology offer the prospect of a future in which we will no longer have to deal with the effects of a gene or chromosome gone awry.

But with prenatal diagnosis came a shift in language and stated medical objective. Sterilization policies and then therapeutic abortion policies singled out persons and their supposedly defective genes. Although an underlying rationale, especially for sterilizations, was to eliminate the defects and diseases that such persons carried and could perpetuate, policies focused on the defective individuals. With prenatal diagnosis the stated objective of medical policy became the prevention of *disease*. In 1973, Michael Begab, president of the Association on Mental Deficiency, saw in prenatal diagnosis a particularly effective means to 'win the battle against mental retardation', once the procedure was 'perfected'. 'In the right hands, diagnosis and abortion, coupled with an effective public education program to reach vulnerable women, is [sic] a powerful tool for the prevention of mental retardation' (Begab 1974, 519, 524). The disorder itself was the scourge—whether cystic fibrosis, Down syndrome, spina bifida, or 'mental retardation'. Prevention became the key to make the problem of disability just go away.

Yet the means to do it has remained through focus on the individual—in this case the potential individual: the fetus, or embryo. An interesting reversal has taken place. Just as the old medical model of disability, resting

on biological inferiority, has begun to be seriously challenged, reproductive medicine, using the language of prevention, is serving to remedicalize and rebiologize disability. Prenatal diagnosis provides the means for reproductive medical professionals to renew medicine's claim to define disability and control its treatment. Professionals in reproductive medicine become the new arbiters of who and what is labeled and ranked as defective.

With the 'geneticization' of disease (see Lippman 1991, 15–50)¹¹ the fault is re-lodged in the individual, the bearer of flawed genes. But, unlike the old eugenic model, there is reputable science to back it up. Genes take on renewed power to define and label the defective, to separate the imperfect from the perfect, and to justify eliminating the former. Under the new medical model, more tellingly than under the shaky rationale of the early eugenicists, the 'defective' can once again be labeled biologically inferior. The model could make it easier to justify abstracting, dehumanizing, even eliminating people with disabilities.

The new discourse of the imperfect in practice

When parents respond negatively to a diagnosed defect in their fetus, having opted for prenatal diagnosis in the first place, they reflect and reinforce the prevailing medicalized and biologized model of disability. This model of disability is the framework in which reproductive science and technology, medical professionals, and parents intersect within reproductive medical practice to produce a discourse of the imperfect, and perfect, child. Public acceptance of the disabled individual as a genetically defined, inferior deviant is strengthened as social-psychological, medical, and socio-cultural approaches to disability converge. Argue Gliedman and Roth, deviance analysis by the social pathologist of other disadvantaged groups, such as poor blacks, alcoholics, or homosexuals, is only one approach of many and therefore open to question. But for disability, the 'expert' view of the pathologist is accepted as natural and thus prevails.

No professional needs to convince us that disability is a kind of deviance. Just as we see that handicaps are disease like conditions, it seems only natural that the handicapped role defines the legitimate needs of handicapped people.

This is a 'triumph of (...) therapeutic morality (...) without parallel in any other area of civil society' (Gliedman & Roth 1980, 302).

Reassigning a genetic basis to disability takes the deviance perspective one step further. Lost in the renewed obsession with genes and the precipitous rush to geneticize disability and disease is the critical fact that almost all impairments do not have a genetic cause. Indeed, most disabling impairments are not due to *inherited* birth defects, nor are they congenital.¹² Nor are all prenatally diagnosable conditions genetic in origin. Of the approximately 3 percent of babies born in the US with birth defects, the causes for 70 percent of them are unknown (National Center on Birth Defects 2002). High on the list of causes are low birthweight babies who are born disproportionately to very young mothers and others lacking proper prenatal care. Even as the Birth Defects Prevention Act of 1998 seeks to implement prevention through data collection, research, and education (Birth Defects Prevention Act 1998), a genetic mindset persists. As the defect is re-lodged in the individual, who harbors the malevolent gene, the distinction between an inborn, that is, 'inherent' condition and one that is *inheritable*, that is, genetically transmittable, is lost. The type of prevention that captures the public relies on the miracle of medicine and technology to eradicate birth defects, rather than on less newsworthy preventive programs that try to improve prenatal care and efforts to extend adequate health care for all.

The rebirth of the medical and biological model of disability, with its genetic base, has coincided with the coming into its own of a disability rights movement. Advocates have sought to define their own needs and treatment, and have organized to change public policies as well as public images and attitudes. The re-emergent disability model stands in direct opposition to these advocates' efforts. As Deborah Kaplan, a lawyer with the World Institute on Disability, writes,

Prenatal screening as a widespread social practice appears to be at odds with some of the goals of the disability rights movement (...) many prominent disability leaders question its value and ethical basis (Kaplan 1993, 610).

We now have a wheelchair-using Barbie doll and more integrating of children with disabilities into regular school classrooms and programs (Canedy

1997, A1, D4; Lewin 1997, 1, 20). But are these signs of new attitudes, or do the old ones persist as before? Four years after the 1990 Americans with Disabilities Act sought to outlaw employment discrimination, a *New York Times* article reported that the numbers of disabled people entering the workforce had not significantly increased, noting 'A well-intentioned law fails to erase prejudice and a lingering culture of dependency' (Holmes 1994, 22). At a session on social attitudes and self-perceptions about disability at the 1996 meeting of the American Sociological Association, panelists and audience alike attested to the many ways people with disabilities still encountered stigma in almost every venue, and faced professionals whose attitudes still reflected the medical model ('Acceptance of Disability (...) 1996). In 1993, the National Center on Child Abuse and Neglect reported that children with a physical, mental, or emotional disability were twice as likely to be maltreated or abused as other children ('A Disabled Child (...) 1993, A21).

In the 1970s ethicists raised questions about the effects of prenatal screening on the treatment of people with disabilities, only to see such concerns fade from mainstream discussion by the next decade. In view of the persistence of negative attitudes and the availability of the technological fix to eliminate defects and the 'defective', we need to ask more pointedly what happens to those children with a condition whose birth could have been prevented? What happens to others living with the condition? Will it increasingly be asked: Why should society be burdened by the presence and care of impaired individuals, since their condition and very existence were preventable?

A British psychologist, Theresa Marteau, extrapolating from a number of studies about attitudes toward genetic diseases, writes that 'it is possible that attitudes towards those with genetic conditions for which screening is available will become more negative', given first, that attribution for the causes will affect attitudes and second, that 'attributions are influenced by the use of existing screening services' (Marteau 1992, 189). Intolerance could be hardest on those with mental impairments, which have the highest incidence of all birth defects and are the most feared. Asked for an image of 'serious genetic defects', respondents in a national sampling of adults in the US in 1990 indicated 'primarily that of Down's syndrome and other mental defects'; physical defects were mentioned much less frequently, though

more often by the men than the women, bearing out earlier findings (Singer 1990, 251).¹³ A study in Tel Aviv, Israel, found that the most frequently mentioned associations about genetic disorders included the symptoms of mental retardation, pain, and visible malformations; self-directed emotions of fear, relief, and shame; and causes such as bad genes, heredity, and pregnancy complications (Shiloh & Berkenstadt 1992, 191–200).

The major users of prenatal diagnosis continue to test and abort for mental impairments at a high rate. Given negative attitudes toward physical disabilities as well as toward mental ones, minor physical malformations such as a clubfoot, hip dislocation, or cleft lip, revealed through ultrasound, could also come to be less tolerated, even if they could be surgically corrected after birth. If the more privileged among users continue to select out the undesirable, and give birth to fewer children with mental and physical impairments, 'unacceptable' children could become clustered increasingly in poorer and marginalized communities. A class- and culture-based hierarchy of birth criteria would then be built into the health care system. Among the consequences would be fewer social services for people with disabilities, greater gaps in opportunities between rich and poor, and diminished resources for research on causes, treatment, and cure of birth defects. Most disturbing, eugenicists' claims linking mental and physical defects to the poor and selected racial and ethnic groups, once without empirical validity, could come closer to reality.¹⁴

Negative eugenics need not be the inevitable outcome of the practice of prenatal diagnosis; its use need not lead to a technologically and medically defined health-based hierarchy of birth. Nor need we be Luddites and reject the remarkable advances in genetics and reproductive technologies. Rather, by exploring the dimensions of disability, we can critique research priorities and raise critical issues about the direction and uses of prenatal diagnosis, and how changes to reproductive medical practice could occur. People with disabilities and their advocates, some medical professionals, pregnant women who are affected, and feminist ethicists are among the counter-voices that are being heard to challenge and educate for practices that do not deny difference. A transformed reproductive medical practice would use our technologies and our science to produce healthy babies that are wanted and cared for in all their diversity.

Notes

- 1 For a useful summary of the literature on stigma see Coleman (1997), 216–231.
- 2 See also Fiedler (1977) *Freaks*.
- 3 The following discussion paraphrases and quotes Longmore (1987), 66–70.
- 4 Barbara Altman's careful review of studies of attitudes toward the handicapped cautions about certain limitations of these studies, such as their survey of limited populations (mainly students), their use of stereotyped conditions as attitude objects, and their concentration on the more severe disabilities (Altman 1981).
- 5 The craze for fitness and perfect health has a considerable history in American society. Harvey Green, pointing out how notions about gender, race, sex, and beauty evolved in the course of the 19th and 20th centuries, explores why we remain obsessed by pursuing the perfect body today. See Green (1986).
- 6 Quoted in Greene (1959), 332; see also Greene (1961).
- 7 See discussion in Greene (1959), 332–34.
- 8 Much of the material in this review comes from Philip Reilly's *The Surgical Solution* published in 1991, as well as from Robitscher's (1973) *Eugenic Sterilization* and from legal sources cited in the text. See especially Reilly (1991), 94–95, for summary of statistics.
- 9 Much of the discussion in this section is drawn from chapters 3 and 4 of Luker's book (1984), *Abortion and the Politics of Motherhood*.
- 10 From extensive interviews conducted for her book, Luker concluded that the fetal indications provisions continued to be 'the least ideologically tolerable', a virtual anathema, to activists opposing abortion. The issue cut to the deepest level of the personhood of the fetus, suggesting the 'idea that humans can be ranked along some scale of perfection', excluding those that fall below a certain standard.
- 11 Lippman coined the concept.
- 12 Infirmities of age, rather, increase the likelihood of having a disability, the person joining the one in five Americans with a disability, or the more than one in ten with a disability classed as severe.
- 13 Singer's first conclusion was that 'attitudes toward prenatal testing for genetic defects are overwhelmingly favorable at this time', 250.
- 14 Sociologist Troy Duster is especially concerned that eugenics might enter via the 'back door', through government-mandated mass screenings aimed at various racially and ethnically designated target populations. See Duster (1990).

References

- 'A disabled child is seen more likely to be abused' (1993), *New York Times*, October 7, A21.
- 'Acceptance of disability and its correlates' (1996), session 130, American Sociological Association Annual Meeting, New York City, August 17.
- Altman, Barbara M. (1981), 'Studies of attitudes toward the handicapped: the need for a new direction', *Social Problems* 28 (3): 321–37.
- Begab, Michael J. (1974), 'The major dilemma of mental retardation: shall we prevent it?', *American Journal of Mental Deficiency* 78 (5): 519–29.
- Biklen, Douglas (1987), 'Framed: print journalism's treatment of disability issues', in Alan Gartner and Tom Joe (Eds.), *Images of the Disabled, Disabling Images*, New York: Praeger, 79–95.
- Birth Defects Prevention Act of 1998, Public Law, 105–168.
- Bogdan, Robert (1988), *Freak Show: Presenting Human Oddities for Amusement and Profit*, Chicago: University of Chicago Press.
- Bogdan, Robert and Douglas Biklen (1977), 'Handicapism', *Social Policy* 7 (5): 14–19.
- Bogdan, Robert and Steven J. Taylor (1982), *Inside Out: The Social Meaning of Mental Retardation*, Toronto: University of Toronto Press.
- Buck v. Bell*, 274 U.S. 100 (1927).
- Canedy, Dana (1997), 'More toys are reflecting disabled children's needs', *New York Times*, December 25, A1, D4.
- Coleman, Lerita M. (1997), 'Stigma: an enigma demystified', in Lennard J. Davis (Ed.), *The Disability Studies Reader*, New York: Routledge, 216–231.
- Darling, Rosalyn Benjamin and Jon Darling (1982), *Children Who Are Different: Meeting the Challenge of Birth Defects in Society*, St. Louis: The C.V. Mosby Co.
- Darwin, Charles (1871), *The Descent of Man*, London: John Murray.
- Davis, Lennard J. (Ed.) (1997), *The Disability Studies Reader*, New York: Routledge.
- Dobzhansky, Theodosius (1962), *Mankind Evolving*, New Haven: Yale University Press.
- Dunn, Rex (1975), 'Eugenic sterilization statutes: a constitutional re-evaluation', *Journal of Family Law* 14 (2): 280–308.
- Duster, Troy (1990), *Backdoor to Eugenics*, New York: Routledge.
- Fiedler, Leslie (1977), *Freaks: Myths and Images of the Secret Self*, reprint (1993), New York: Anchor.

- Fiedler, Leslie (1996a), 'Pity and fear: images of the disabled in literature and the popular arts', in Leslie Fiedler, *Tyranny of the Normal: Essays on Bioethics, Theology & Myth*, Boston: David R. Godine, 33–47, (originally published 1982).
- Fiedler, Leslie (1996b), *Tyranny of the Normal: Essays on Bioethics, Theology & Myth*, Boston: David R. Godine.
- Fiedler, Leslie (1996c), 'The tyranny of the normal', in Leslie Fiedler, *Tyranny of the Normal: Essays on Bioethics, Theology & Myth*, Boston: David R. Godine.
- Fine, Michelle and Adrienne Asch (1988), *Women with Disabilities: Essays in Psychology, Culture, and Politics*, Philadelphia: Temple University Press.
- Finger, Anne (1984), 'Claiming all of our bodies: reproductive rights and disability', in Rita Arditti, Renate Duelli Klein, and Shelley Minden (Eds.), *Test-Tube Women: What Future for Motherhood?*, London: Pandora, 281–297.
- Funk, Robert (1987), 'Disability rights: from caste to class in the context of civil rights', in Alan Gartner and Tom Joe (Eds.), *Images of the Disabled, Disabling Images*, New York: Praeger, 7–30.
- Gartner, Alan and Tom Joe (1987), 'Introduction', in Alan Gartner and Tom Joe (Eds.), *Images of the Disabled, Disabling Images*, New York: Praeger, 5.
- Gartner, Alan and Tom Joe (Eds.) (1987), *Images of the Disabled, Disabling Images*, New York: Praeger.
- Gliedman, John and William Roth (1980), *The Unexpected Minority: Handicapped Children in America*, New York: Harcourt Brace Jovanovich.
- Goffman, Erving (1963), *Stigma: Notes on the Management of Spoiled Identity*, Englewood Cliffs, NJ: Prentice Hall.
- Granberg, Donald and Beth Wellman Granberg (1980), 'Abortion attitudes, 1965–1980: trends and determinants', *Family Planning Perspectives* 12 (5): 25–61.
- Green, Harvey (1986), *Fit for America: Health, Fitness, Sport, and American Society*, New York: Pantheon Books.
- Greene, John C. (1959), *The Death of Adam: Evolution and Its Impact on Western Thought*, Ames, Ia: Iowa State University Press.
- Greene, John C. (1961), *Darwin and the Modern World View*, Baton Rouge: Louisiana State University Press.
- Hahn, Harlan (1983), 'Paternalism and public policy', *Society* 20 (3): 36–46.
- Hahn, Harlan (1987), 'Civil rights for disabled Americans: the foundation of a political agenda', in Alan Gartner and Tom Joe (Eds.), *Images of the Disabled, Disabling Images*, New York: Praeger, 181–203.

- Hevey, David (1992), *The Creatures Time Forgot: Photography and Disability*, New York: Routledge.
- Hevey, David (1997), 'The enfreakment of photography', in Lennard J. Davis (Ed.), *The Disability Studies Reader*, New York: Routledge.
- Holmes, Steven A. (1994), 'In 4 years, disabilities act hasn't improved jobs rate', *New York Times*, October 23, 22.
- Kaplan, Deborah (1993), 'Prenatal screening and its impact on persons with disabilities', *Clinical Obstetrics and Gynecology* 36 (3): 605–12.
- Keniston, Kenneth (1980), 'Foreword', in John Gliedman and William Roth (1980), *The Unexpected Minority: Handicapped Children in America*, New York: Harcourt Brace Jovanovich.
- Lewin, Tamar (1997), 'Where all doors are open for disabled students', *New York Times*, December 28: 1, 20.
- Lippman, Abby (1991), 'Prenatal genetic testing and screening: constructing needs and reinforcing inequities', *American Journal of Law and Medicine* XVII (1 and 2): 15–50.
- Longmore, Paul K. (1987), 'Screening stereotypes: images of disabled people in television and motion pictures', in Alan Gartner and Tom Joe (Eds.), *Images of the Disabled, Disabling Images*, New York: Praeger, 65–78.
- Luker, Kristin (1984), *Abortion and the Politics of Motherhood*, Berkeley, CAL: University of California Press.
- Marteau, Theresa M. (1992), 'Psychological implications of genetic screening', in Gerry Evers-Kiebooms, Jean-Pierre Fryns, and Jean-Jacques Cassiman (Eds.), *Psychosocial Aspects of Genetic Counseling*, Birth Defects Original Article Series 28 (1), New York: John Wiley-Liss.
- National Center on Birth Defects and Developmental Disabilities (2002), *Birth Defects: Frequently Asked Questions*, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control.
- Oskamp, Stuart (1988), 'The editor's page', in Adrienne Asch and Michele Fine (Eds.), 'Moving Disability beyond "Stigma"', Special Issue, *Journal of Social Issues* 44 (1).
- Reilly, Philip (1991), *The Surgical Solution: A History of Involuntary Sterilization in the U.S.*, Baltimore: Johns Hopkins University Press.
- Richardson, Stephen A. (1970), 'Age and sex differences in values toward physical handicaps', *Journal of Health and Social Behavior* 11 (3): 207–14.
- Richardson, Stephen A., Norman Goodman, Albert H. Hastorf, and Sanford M. Dornbush (1961), 'Cultural uniformity in reaction to physical disabilities', *American Sociological Review* 26: 241–277.

- Robitscher, Jonas (Comp. and Ed.) (1973), *Eugenic Sterilization*, Springfield, Ill: Charles C. Thomas.
- Roth, William (1983), 'Handicap as a social construct', *Society* 20 (3): 56–61.
- Safilios-Rothschild, Constantina (1970), *The Sociology and Social Psychology of Disability and Rehabilitation*, New York: Random House.
- Saxton, Marsha (1984), 'Born and unborn: the implications of reproductive technologies for people with disabilities', in Rita Arditti, Renate Duelli Klein, and Shelley Minden (Eds.), *Test-Tube Women: What Future for Motherhood?*, London: Pandora, 298–312.
- Sherlock, Richard K. and Robert D. Sherlock (1982), 'Sterilizing the retarded: constitutional, statutory and policy alternatives', *North Carolina Law Review* 60 (5): 946.
- Shiloh, Shoshana and Michael Berkenstadt (1992), 'Lay conceptions of genetic disorders', in Gerry Evers-Kiebooms, Jean-Pierre Fryns, and Jean-Jacques Cassiman (Eds.), *Psychosocial Aspects of Genetic Counseling*, Birth Defects Original Article Series 28 (1), New York: Wiley-Liss, 191–200.
- Singer, Eleanor (1991), 'Public attitudes toward genetic testing', *Population Research and Policy Review* 10: 235–255.
- Unger, Rhoda Kesler (1985), 'Personal appearance and social control', in Marilyn Safir, Martha T. Mednick, Dafna Israeli, and Jesse Bernard (Eds.), *Women's Worlds: From the New Scholarship*, New York: Praeger, 142–151.
- Yamamoto, Kaoru (1971), 'To be different', *Rehabilitation Counseling Bulletin* 14 (3).