

Florida State University Law Review

Volume 30 | Issue 2

Article 7

2003

Disability Equality and Prenatal Testing: Contradictory or Compatible?

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Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 Fla. St. U. L. Rev. (2014) .
<http://ir.law.fsu.edu/lr/vol30/iss2/7>

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FLORIDA STATE UNIVERSITY LAW REVIEW



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VOLUME 30

WINTER 2003

NUMBER 2

Recommended citation: Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315 (2003).

DISABILITY EQUALITY AND PRENATAL TESTING: CONTRADICTION OR COMPATIBLE?

ADRIENNE ASCH*

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It takes considerable rhetorical agility to urge the public to support screening programs so as to prevent the conception of handicapped individuals while at the same time insisting that full respect be paid to such developmentally disabled adults as are already among us.¹

Is it possible for the same society to espouse the goals of including people with disabilities as fully equal and participating members and simultaneously promoting the use of embryo selection and selective abortion to prevent the births of those who would live with disabilities? As currently practiced and justified, prenatal testing and embryo selection cannot comfortably coexist with society’s professed goals of promoting inclusion and equality for people with disabilities. Nonetheless, revamped clinical practice and social policy could permit informed reproductive choice and respect for current and future people with disabilities. In the first Section of this Article, I argue that the typical justifications offered by practitioners and researchers for prenatal testing are mistaken about the implications of disability.

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1. HANS S. REINDERS, THE FUTURE OF THE DISABLED IN LIBERAL SOCIETY 1 (2000) (quoting Daniel Wikler).

In the second Section, I explain why I discount the claim that people with disabilities have made great progress—notwithstanding the advent of prenatal testing. I conclude by proposing reforms to our current prenatal testing practices that would meet the challenges posed by many critics.

What has become known as the disability rights critique of prenatal testing has been formulated as follows:

(1) Continuing, persistent, and pervasive discrimination constitutes the major problem of having a disability for people themselves and for their families and communities. Rather than improving the medical or social situation of today's or tomorrow's disabled citizens, prenatal diagnosis reinforces the medical model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved.

(2) In rejecting an otherwise desired child because they believe that the child's disability will diminish their parental experience, parents suggest that they are unwilling to accept any significant departure from the parental dreams that a child's characteristics might occasion.

(3) When prospective parents select against a fetus because of predicted disability, they are making an unfortunate, often misinformed decision that a disabled child will not fulfill what most people seek in child rearing, namely, "to give ourselves to a new being who starts out with the best we can give, and who will enrich us, gladden others, contribute to the world, and make us proud."

In these several contentions can be discerned two broad claims: that prenatal genetic testing followed by selective abortion is morally problematic, and that it is driven by misinformation.²

In what follows, I discuss these claims as applied to social institutions beyond the family, arguing that researchers, professionals, and policymakers, who uncritically endorse testing followed by abortion, act from misinformation about disability, and express views that worsen the situation for all people who live with disabilities now and

2. Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 3, 12-13 (Erik Parens & Adrienne Asch eds., 2000) [hereinafter Parens & Asch, *Disability Rights Critique* will refer to this specific article and *PRENATAL TESTING* will refer to the entire work] (section three is quoting Adrienne Asch, *Reproductive Technology and Disability*, in *REPRODUCTIVE LAWS FOR THE 1990S* 69, 86 (Sherrill Cohen & Nadine Taub eds., 1989) [hereinafter Asch, *Reproductive Technology*]). The critique is not always expressed in exactly this way by all those who share the perspective. Others who hold compatible positions are cited in this Article. For extensive references, see Adrienne Asch, *Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy*, 89 *AM. J. PUB. HEALTH* 1649 (1999) [hereinafter Asch, *Prenatal Diagnosis*]; Parens & Asch, *Disability Rights Critique*, *supra*, at 3-43; and REINDERS, *supra* note 1.

in the future.³

Bioethicists who sincerely promote the goals of inclusion and equality for people with disabilities assert that there is no contradiction or tension between reforming such institutions as schools, workplaces, and the environment to include existing people with disabilities, and seeking to prevent disability in the future through the practice of selective embryo implantation and pregnancy termination. Bonnie Steinbock, for example, writes:

Disability activists have a laudable goal: to change society so that it is welcoming and accepting of people with disabilities. However, there is no reason why society cannot both attempt to prevent disability and to provide for the needs of those who are disabled. As a matter of fact, the rise of prenatal screening has coincided with more progressive attitudes toward the inclusion of people with disabilities, as evidenced in the United States by the passage of the Americans with Disabilities Act.⁴

I believe that Steinbock's position is plausible for a different society than the one in which we now live, a society in which it is perceived to be as legitimate and respectable to have a disability as it is not to have one.

Rather than reiterate the basic outline of the critique of prenatal testing, I focus on Wikler's and Steinbock's belief that it is possible to respect and support existing and future people with disabilities and simultaneously to urge selection techniques to screen out children who would have disabling traits.⁵ I seek to examine the social context in which people choose to raise or not to raise children who would live with disabilities. My concern is to facilitate true reproductive choice for women by urging changes in the way prenatal testing occurs and the rhetoric that surrounds it.⁶

3. I do not speak in this Article for other members of the Hastings Center Project on Prenatal Testing for Genetic Disability, or for any advocacy group associated with the disability rights movement.

4. Bonnie Steinbock, *Disability, Prenatal Testing, and Selective Abortion*, in PRENATAL TESTING, *supra* note 2, at 108, 121.

5. *Id.*; REINDERS, *supra* note 1.

6. I, and nearly all others sharing a disability rights critique of prenatal testing, maintain an ardent pro-choice stance and assert that women should be free to make whatever decision they wish about maintaining a pregnancy or having an abortion. For the most recent elaborations of the disability rights critique, see Parens & Asch, *Disability Rights Critique*, *supra* note 2, at 40 nn.21-22 (referring to the work of others who share a pro-choice orientation to reproductive freedom and a disability rights critique of the routinization of prenatal testing for disability); and see references contained in, Asch, *Prenatal Diagnosis*, *supra* note 2, at 1647, 1656 nn.8-17; Adrienne Asch, *Why I Haven't Changed My Mind about Prenatal Diagnosis: Reflections and Refinements*, in PRENATAL TESTING, *supra* note 2, at 255 n.4.

I. WHAT IS DISABILITY “REALLY” LIKE, OR HOW MISINFORMED ARE PEOPLE ANYWAY?

Prenatal testing, and the more recent and less common embryo screening and selection, are justified by mistaken assumptions about the quality of life of people with disabilities, and are demeaning to existing people with disabilities. These assumptions are mistaken for several reasons:

- 1) They fail to recognize the extent to which the disadvantages associated with impairments result from discriminatory attitudes and practices rather than anything intrinsic to the impairment.
- 2) They place unwarranted emphasis on the size of one’s opportunity range rather than the possibility for meaningful choice and rewarding outcomes within that range.
- 3) They confuse the claim that having a capacity, skill, or experience is a good, with the claim that lacking a capacity, skill, or experience is inevitably bad. This confusion is due in part to the failure to distinguish the absence from the loss of a skill, capacity, or type of experience, and in part from the overly-narrow description of what is good or valuable.

A. *Models of Disability*

For the past quarter century of disability scholarship and theory in the United Kingdom and North America, a significant tension has existed between what is seen as a traditional “medical model” of disability and two newer approaches, termed the “minority group model” and the “social model” of disability.⁷ Theorists with a minority group or a social model argue forcefully that clinicians, policymakers, genetic researchers, and bioethicists err in ascribing the major difficulties of people with disabilities to their physical, cognitive, or emotional make-up. Instead, the theorists assert that the difficulties should be ascribed to the mismatch between the range of people actually in the world and the institutional practices, physical structures, modes of communication, and social attitudes that assume a much narrower range of human beings than exist.

7. Representative writing in the minority group and the social models, contrasting them with the medical model, can be found in VICTOR FINKELSTEIN, *ATTITUDES AND DISABLED PEOPLE: ISSUES FOR DISCUSSION* (1980); JOHN GLIEDMAN & WILLIAM ROTH, *THE UNEXPECTED MINORITY: HANDICAPPED CHILDREN IN AMERICA* (1980); and Harlan Hahn, *Paternalism and Public Policy*, *SOC’Y*, Mar.-Apr. 1983, at 36, 36. A very useful book discussing the merits and deficiencies of many approaches to disability policy is JEROME E. BICKENBACH, *PHYSICAL DISABILITY AND SOCIAL POLICY* (1993). For comparisons of the minority group and the social models, see Tom Shakespeare & Nick Watson, *Making the Difference: Disability, Politics, and Recognition*, in *HANDBOOK OF DISABILITY STUDIES* 546 (Gary L. Albrecht et al. eds., 2000) [hereinafter *HANDBOOK*]; and Jerome E. Bickenbach et al., *Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps*, 48 *SOC. SCI. & MED.* 1173 (1999).

The point is not that humans “construct conceptual worlds,” but that humans construct buildings. The opportunities which are lost to a disabled person are to be attributed not only to the species-atypicality of the person’s biology, but also to the architectural design of the buildings in which some of those opportunities reside.⁸

It is estimated that 19.7 percent⁹ of people in the United States have characteristics considered disabilities for purposes of public policy.¹⁰

Proponents of these social, or minority group, views hold that most of the disadvantages of having impairments are attributable not to the physical, cognitive, or emotional characteristics of individuals, but to the failure to account for everyone when designing physical, economic, and social institutions. According to the social and minority group models, people with nearly all prenatally detectable conditions—whether Down syndrome, spina bifida, Fragile X, Duchenne muscular dystrophy, sickle cell anemia, retinitis pigmentosa, or achondroplasia—can lead fulfilling lives notwithstanding the characteristics that distinguish them from the non-disabled.¹¹ Yes,

8. Ron Amundson, *Disability, Handicap and the Environment*, 23 J. SOC. PHIL. 105, 109 (1992); see also BICKENBACH, *supra* note 7, at 135-81; Adrienne Asch, *Critical Race Theory, Feminism and Disability: Reflections on Social Justice and Personal Identity*, 62 OHIO ST. L.J. 391, 397-410 (2001); Richard K. Scotch, *Models of Disability and the Americans with Disabilities Act*, 21 BERKELEY J. EMP. & LAB. L. 213, 213-18 (2000).

9. According to the 1997 Survey of Income and Program Participation taken by the U.S. Census Bureau, 19.7 percent of the population “had some level of disability and . . . 12.3 percent of the population . . . had a severe disability.” JACK MCNEIL, U.S. DEP’T OF COMMERCE, PUB. NO. P70-73, AMERICANS WITH DISABILITIES: HOUSEHOLD ECONOMIC STUDIES 1 (2001), available at <http://www.sipp.census.gov/sipp/p70s/p70-73.pdf> (last visited Dec. 6, 2002) (on file with author).

10. As can be seen from note 9 and accompanying texts, who counts as a person with a disability, which conditions are considered “disabilities,” and whether conditions labeled “chronic illnesses,” “impairments,” “congenital malformations,” “genetic defects,” “deformities,” and “disorders” should be counted as disabilities are all extremely complex and beyond the scope of this Article. For recent discussions, see Barbara M. Altman, *Disability Definitions, Models, Classification Schemes, and Applications*, in HANDBOOK, *supra* note 7, at 97. I will refer to all health-related departures from species-typical functioning as disabilities, and I consider the three-pronged definition of disability contained in the Americans with Disabilities Act of 1990, 42 U.S.C. § 12102 (2000), as accurately describing the class of people with disabilities:

(2) The term “disability” means, with respect to an individual—

(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;

(B) a record of such an impairment; or

(C) being regarded as having such an impairment.

11. Hans Reinders differentiates people with “disabilities” such as Down syndrome from people with “illnesses,” such as cystic fibrosis and Duchenne muscular dystrophy, applying his social analysis to the former group but claiming (without evidence) that people with these chronic illnesses have diminished lives because of their medical problems, and not because of social arrangements. See REINDERS, *supra* note 1. I, and many other adherents of the disability critique of prenatal testing and selection, include people with all characteristics that are not lethal in the first months or years of life. See Adrienne Asch, *Why I Haven’t Changed My Mind about Prenatal Diagnosis: Reflections and Refinements*, PRENATAL TESTING, *supra* note 2, at 234 [hereinafter Asch, *Reflections*] (quoting other phi-

disability might mean shorter-than-average life expectancies; might entail living with weakness, pain, or fatigue; might require more time than is typical for medical visits or hospital stays; might preclude seeing, hearing, or speaking; might require moving with wheelchairs, crutches, or braces; or might prevent some people from reading, writing, or participating in activities using numbers. Notwithstanding these departures from the species-typical, the social and minority group models contend that virtually everyone with a disability can participate in many everyday activities, experience relationships, discover the world beyond themselves, and contribute to familial, social, political, and economic life.

Many in the field of bioethics such as Steinbock, Singer, Baily, Buchanan, and others who reject the disability rights critique of prenatal testing, acknowledge that a share of the problems of people with disabilities stem from life in a society that has still not made all the changes that would permit them to travel, communicate, learn, work, and play easily alongside their non-disabled peers. Yet they argue that it is better not to have a disability than to have one, and that it is preferable to select against the embryo or fetus with a disabling trait. “The fact that a disability can be under unusual circumstances advantageous is consistent with its being ordinarily a disadvantage. . . . [D]isabilities are not generally advantageous, not something to be hoped for; indeed, they are to be avoided, if possible. They are not merely neutral forms of variation.”¹² Peter Singer, another eminent bioethicist, says:

[O]n the one hand we are naturally sympathetic to the claims of a disability rights movement that models itself on movements defending the rights of women and ethnic minorities, and, on the other hand, we all accept that to have a disability is to be worse off than to be without the disability.

. . . .

. . . There are many things that people who are paraly[z]ed below the waist could not do in any society, no matter how constructed. They cannot visit untracked wilderness, go ice skating, or play football. And many other things that they can do, they can do only with difficulty, and with more time than it would take those who have the use of their legs.

. . . .

. . . The decision to abort a fetus that has, say, Down syndrome, is a decision that says: “Since I will only have two children, I

losophers with the sorts of illnesses Reinders excludes from his analysis, but who share much of my view). See also Diane Beeson & Troy Duster, *African American Perspectives on Genetic Testing*, in *THE DOUBLE-EDGED HELIX: SOCIAL IMPLICATIONS OF GENETICS IN A DIVERSE SOCIETY* 151 (Joseph S. Alper et al. eds., 2002) (discussing individuals and family members affected by cystic fibrosis and sickle cell anemia).

12. Steinbock, *supra* note 4, at 113.

want them to have the best possible prospects for a full and rich life. And if, at the outset, those prospects are seriously clouded, I would rather start again.”¹³

In the same vein, Mary Ann Baily writes:

The background to my decision is . . . my belief that, all other things equal, disability (specifically, a disability for which I would consider an abortion) would make life more difficult for my child, my family, and me. This is not the same thing as saying it would be an overwhelming burden or would make a fulfilling life impossible. . . . It means only that *if I have a choice*, I would prefer to avoid them [the difficulties], for all of our sakes.¹⁴

In their recent book on the ethical issues posed by the new developments in genetics, four bioethicists write: “Shouldn’t parents seek the best—even through genetics—for their offspring? Don’t we expect them to?”¹⁵ During the deliberations that resulted in the book of essays collected in *Prenatal Testing and Disability Rights*, we found that the question of just how bad or different it was to have a disability loomed as the most contentious and divisive topic of all those we examined. If people with and without disabilities expect to use medicine to maintain or restore health and functioning after a heart attack, broken leg, or a back problem, it is because people value the capacities to move, to carry objects, and so forth. If the average lifespan in the United States is upwards of seventy years, and people with cystic fibrosis or muscular dystrophy commonly die before reaching age forty, it seems cruel and tragic to bring such a child into the world if testing and abortion could ensure that children would be free of the genes for those conditions. Any prospective parent would prefer for a child to live out the typical lifespan rather than know that a child would die before the age of eighteen. Similarly, prospective parents who take hearing, seeing, and walking for granted, and as integral to all of life’s rewarding pursuits, are likely to fear that a child who cannot do one of these things will have enormous difficulty in constructing any, much less many, alternative plans of life.¹⁶ Intellectual disability is especially disconcerting to many in today’s society,

13. Peter Singer, *Severe Impairment and the Beginning of Life*, 99 *APA NEWSL. ON PHIL. & MED.* 246, 247-48 (2000).

14. Mary Ann Baily, *Why I had Amniocentesis*, in *PRENATAL TESTING*, *supra* note 2, at 64, 67.

15. ALLEN BUCHANAN ET AL., *FROM CHANCE TO CHOICE: GENETICS AND JUSTICE* 156 (2000).

16. I use this notion of plans of life because one of the reasons suggested for giving health and health care great social legitimacy is that they are seen as foundational to constructing virtually any satisfying life plan. In the book *From Chance to Choice*, the authors argue that advances in genetics should be used to give control over the health of future children to parents, so that their children may take best advantage of all the opportunities available to them in a complex society. *Id.* at 156-202.

based in written communication and relying ever more on people's facility with words, numbers, and complex ideas. One student of genetics comments that "[m]ental retardation is less desirable than normal mental function, in part because retardation drastically contracts the range of worthwhile lives a person might be able to lead."¹⁷

The question keeps emerging: Just how much of the difficulty posed by disability is "socially constructed?" Could there be a social and natural world in which it would be as easy and enjoyable to live with disability as it is to live without a disability? Does the answer depend upon the particular condition under discussion—for example, should cystic fibrosis be distinguished from deafness (the former affecting needs for medical care and life expectancy, the latter affecting neither)? How much of what is negative about impairment or disability is "intrinsic" to the condition and would remain even in a society more inclusive of disability than the United States in the twenty-first century? If people prize health, and assume species-typical seeing, hearing, walking, speaking, and learning as foundational, is it not undesirable to have a condition that reduces one's general health or that limits or denies such functions as speech, hearing, cognition, or sight?¹⁸

B. *Disability and the Normal Opportunity Range*

People without any disabilities naturally assume that the typical complement of human capabilities is desirable, and perhaps critical, for most plans of life. Health care is given high priority when people rank important social goods because health and species-typical functioning are taken to be essential for having a good life.¹⁹ Although

17. Elliott Sober, *The Meaning of Genetic Causation*, in BUCHANAN ET AL., *supra* note 15, app. 1 at 347, 353.

18. It is important to note that prenatally diagnosable conditions include some that will manifest themselves at different ages in life. Cystic fibrosis and Down syndrome can be determined virtually immediately; muscular dystrophy, retinitis pigmentosa, and other conditions may not manifest themselves until childhood or adolescence; polycystic kidney disease or Huntington's disease may not appear until mid-adulthood. Although some commentators on prenatal testing have different views on the merits of testing depending upon the age of onset of the condition, I discuss the social practice of prenatal testing without regard to the life stage at which the condition expresses itself, for reasons discussed in the last section of this Article. It is also important to note that at times there is reason to distinguish between conditions that affect health—how sick one is, how often one must see doctors for acute distress or flare-ups of chronic conditions—from conditions often termed disabilities, such as deafness, blindness, and intellectual disabilities that have no medical component associated with them. Ron Amundson, *Disability, Handicap, and the Environment*, 23 J. SOC. PHIL. 105 (1992) (discussing the difference between the terms "disability" and "health"). Given that a condition can be detected prenatally and that social practices encourage such testing, for the purposes of this Article it does not matter whether the condition is typically thought of as an illness, disorder, chronic condition, or disability.

19. What makes for a "good life" is a question that has lent itself to a rich body of philosophical literature that cannot be adequately summarized or resolved in this Article. I mention it to point out that evaluating the importance of health, or of any human capacity,

there are variations on what “good lives” contain, many people in the United States would probably say that they would like their children’s lives to include several of the following opportunities: to appreciate beauty; learn about the world; master some skills; make contributions to others; participate in satisfying relationships; live without physical or psychological pain; be safe from physical harm; develop their own interests; find satisfying work; take care of themselves; be interested in other people’s welfare; and make decisions about their lives for themselves without pressure from others. This list is not meant to be exhaustive, and it is not intended to suggest that each life must contain all of these characteristics to be satisfactory to the person living it.²⁰

Bonnie Steinbock quotes a 1989 article in which I wrote:

The inability to move without mechanical aid, to see, to hear, or to learn is not inherently neutral. Disability itself limits some options. Listening to the radio for someone who is deaf, looking at paintings for someone who is blind, walking upstairs for someone who is quadriplegic, or reading abstract articles for someone who is intellectually disabled are precluded by impairment alone. . . . It

can be done with reference to the kinds of lives people hope to lead for themselves, hope to offer their children, and seek to promote in the society. Norman Daniels’ work on justice in health care argues that health care is crucial for giving people access to the range of opportunity in a society, because he sees it as impossible for people with less-than-species-typical health and functioning to be able to avail themselves of the normal opportunity range in the society. See NORMAN DANIELS, *JUST HEALTH CARE: STUDIES IN PHILOSOPHY AND HEALTH POLICY* (1985). For applications in the prenatal testing context, see BUCHANAN ET AL., *supra* note 15. There, the authors do not explicitly set out a list of the components of a good life, arguing that a liberal and pluralistic society such as the United States must permit many very divergent life plans. However, they do state that:

The core notion of eugenics, that people’s lives will probably go better if they have genes conducive to health and other advantageous traits, has lost little of its appeal. Eugenics, in this very limited sense, shines a beacon even as it casts a shadow. Granted, when our society last undertook to improve our genes, the result was mayhem. The task for humanity now is to accomplish what eluded the eugenicists entirely, to square the pursuit of genetic health and enhancement with the requirements of justice.

Id. at 56-57.

20. I make no sweeping claims for the list I give; instead I am influenced by such philosophical writing on quality of life as that found in *ETHICS OF CONSUMPTION: THE GOOD LIFE, JUSTICE, AND GLOBAL STEWARDSHIP* (David A. Crocker & Toby Linden eds., 1998). The list I give bears some resemblance to ideas found in Martha Nussbaum’s essay, *The Good As Discipline, the Good As Freedom*, in *ETHICS OF CONSUMPTION*, *supra*, at 312, 318-20, but note that Nussbaum insists that in order to have such a good life, persons must possess all these capabilities. “The ‘capabilities approach,’ as I conceive it, claims that a life that lacks any one of these capabilities, no matter what else it has, will fall short of being a good human life.” *Id.* at 320.

For discussions of “the good life” as applied to philosophical issues of disability, see David Wasserman, *Distributive Justice*, in *DISABILITY, DIFFERENCE, DISCRIMINATION: PERSPECTIVES ON JUSTICE IN BIOETHICS AND PUBLIC POLICY* 147, 195-200 (Anita Silvers et al. eds., 1998); and David Wasserman, *Philosophical Issues in the Definition and Social Response to Disability*, in *HANDBOOK*, *supra* note 7, at 229-34.

is not irrational to hope that children and adults will live as long as possible without health problems or diminished human capacities.²¹

It is possible to acknowledge that disabilities may preclude some activities that many people find worthwhile—appreciating sunsets, relishing bird songs, experiencing the interaction of body and nature in a hike through the woods. But I now would put my convictions somewhat differently from the words Steinbock quotes. Having capacities is good, but I am not sure that any capacity is an “intrinsic” good. If typical capacities and health achieve value because they enable people to participate in facets of life, it is crucial to note how much of life is open, in today’s society, to people with disabilities. Brief acquaintance with people who have disabilities and who work, play, study, love, and enjoy the world should demonstrate that very few conditions preclude participating in the basic activities of life, even if some conditions limit some classes of them, or methods of engaging in them.

As a person who is blind, I cannot see a baby’s smile, the antics of a friend’s dog, or the paintings of Picasso. I am quite confident that I would get pleasure and satisfaction from such experiences. Nevertheless, if people who are blind cannot enjoy one class of aesthetic experiences, many others are available (weaving, sculpture, music, ocean breezes, etc.). When it is noted that people who are deaf create poetry and theater in American Sign Language, that people with mobility impairments become involved in adapted or typical athletics, that persons with autism or Down syndrome increasingly articulate their own views of their needs and experiences, it is evident that realms of activity often thought unimaginable for people with disabilities are components of many of their lives.

C. Having and Lacking Capacities

The reader without a disabling condition may be thinking: “My life would lose pleasure if I suddenly lost my sense of hearing or sight or could no longer lift weights because of a back problem!” I respond by acknowledging that losing capacities one has is a sad or disappointing event, just as losing other things can be sad and disappointing. If I lose loved ones through death, or face the fact that a once beloved person is no longer important in my life, I grieve deeply. If I misplace a treasured letter, I can mourn its loss, but no one can say that I am entitled to own treasured letters or to possess the relationships that produced such letters. If you take my VCR out of my house without my permission, you have removed something from me that I

21. Steinbock, *supra* note 4, at 115 (quoting Asch, *Reproductive Technology*, *supra* note 2, at 73).

am happy to own and use. I will probably be angry at the loss, the violation of my home, the disrespect shown by taking something from me without my permission, and the unexpected change in my circumstances. If I become paralyzed in a car accident, I can be angry at reckless driving, regret the changed method of navigating in the world—I can even note its inconveniences or remember the pleasures of strolling or striding—but I am not owed the ability to stroll or stride, any more than I am owed a VCR. Thus, we should distinguish our thinking about the importance of having capacities from the distress of losing parts of life we prize, and distinguish our concerns for particular capacities from our concerns about losses, changes, or human carelessness or cruelty.

Contrary to the common belief that people born without certain capacities cannot understand how losing them is intolerable because such people never knew the joys of full health or full mobility, I contend that disabled individuals are well aware of what they do not have. They are told all their lives what they are missing, sometimes merely as a description, often in tones of pity and condescension. They are surrounded by people enjoying paintings they don't see, music they don't hear, or sports they don't play. It is utterly ludicrous to think that anyone born with a disability who is not full of sorrow and rage at her condition is simply denying the glories of the world she doesn't know.

Not only must we distinguish valuing health and function from fearing loss, we must also distinguish valuing capacity from valuing the idea of choice. Walking, learning, or seeing permit choices among the range of activities that will be somewhat more constrained if someone does not have a capacity, or has less of it than is customary. Those who insist that a good life requires the full complement of species-typical capabilities are driven by a passion for unrestricted choice and oppose any hindrance to that choice. What is prized is not the sensation of walking itself but how walking enables people to take part in certain activities that might be difficult or impossible otherwise.

No person in the world is likely to be interested in all of the physical, intellectual, and aesthetic experiences the world affords. Even the voracious reader will not delve into every book written in every language or even in her native tongue. No devotee of classical music will have the time to study every available work composed since the twelfth century. The serious athlete is unlikely to become proficient at every known sport or game played in her country, much less to discover the pleasures of games enjoyed on other continents. No proponent of the opportunity range or the "open future" expects anyone

to take advantage of all that the world offers.²² The people who prize the idea of the open future argue that people should have no barriers to their own exercise of choice, self-discovery, and self-realization. The paramount value is that people explore each possible opportunity, but that nothing should get in the way of their own freedom to choose which opportunities to pursue.

If having a capacity is good, is not having a particular ability bad, negative, or “dis-valuable?”²³ My answer is that having a capacity can be good, but the absence of capacity is simply an absence; it need not be seen as negative, “dis-valuable” to be blind any more than it is negative or “dis-valuable” to be shorter than some people, or to be mystified by higher mathematics. In these reflections on valuing capacity, I generally concur with Anita Silvers, who writes:

[I]f disadvantage is tightly tied to impairment, its source does not seem to lie in the loss of something of intrinsic value. This is not to deny that seeing well, hearing well, and moving well possess intrinsic value and are crucial components of more complex activities having intrinsic value. Rather, it is to notice that, although the experience of engaging in these activities can be (but is not always) intrinsically good, not engaging in them is not intrinsically bad.²⁴

If disability is a simple human variation, why do we try to promote good prenatal care in women, or to promote health in the population? There is nothing to lament about capacities to hear, speak, move, or think. The difference between selecting out fetuses and protecting them (by promoting prenatal care for women) is just that. We protect the possibility for capacity when we promote fetal health, but we refuse to acknowledge or permit the growth of people who will not have such capacity when we select against fetuses as potential people with disabling traits. Similarly, there is nothing wrong with possessing skills or aptitudes for athletics, physics, or carpentry; but the society has not yet said that only people who possess such aptitudes are welcomed. The absence of a capacity is not necessarily “bad”; the opposite of having a capacity is not having it; having it and not having it can be equally legitimate ways of living a life.

22. Joel Feinberg, *The Child's Right to an Open Future*, in WHOSE CHILD? CHILDREN'S RIGHTS, PARENTAL AUTHORITY AND STATE POWER 124-53 (W. Aiken & H. LaFollette eds., 1980).

23. Parens & Asch, *Disability Rights Critique*, *supra* note 2, at 23-26 (suggesting that disabling traits are “dis-valuable”). As a co-author of this article summarizing deliberations of a large project group, I was committed to reporting these ideas, but speaking for myself, I do not subscribe to this characterization of disability. There may be undesirable features to life with disabilities, but such features are intimately connected to the way in which disability is perceived, as will be discussed in the next Section of this Article.

24. Anita Silvers, *Formal Justice*, in DISABILITY, DIFFERENCE, DISCRIMINATION, *supra* note 20, at 90-91. But note that Silvers and I differ on whether the capacities are intrinsically good. *See id.*

Those who maintain that disability forecloses opportunity, and that any foreclosed opportunity diminishes life, focus too narrowly on the activity and do not see it as a means to an end, e.g., visual instead of aesthetic pleasure; walking instead of mobilizing or exploring; talking instead of communicating. These assumptions are demeaning to people with disabilities because they exaggerate their hardships and deprivation; obscure the injustice and discrimination they face; and dismiss or discount their own testimony of living rich and rewarding lives.²⁵

Thus far, I have argued that even if species-typical health and function appear to be prerequisites for constructing life plans, people with disabilities can participate in a very large range of activities. Many people with disabling traits manage to have rewarding lives in today's United States, making use of advances in medical treatment, assistive technology, and the social changes that ease participation in travel, school, and work.

II. THE LIMITS OF PROGRESS

Defenders of the practices of prenatal testing and embryo selection deny that these practices are incompatible with greater inclusion and participation of those with disabilities. In this Section, I rebut their claims. They claim that while prenatal testing for disability is becoming more widespread and routine, existing people with disabilities are making dramatic strides towards social and economic equality. I argue that the appearance of progress is illusory, or at least grossly exaggerated.

Gaps remain between people with and without disabilities in terms of education, employment, income, social life, and civic participation.²⁶ According to the traditional medical model of disability, those gaps are inextricably tied to the conditions themselves. With the advent of the minority group and social models, it has become possible to disentangle how factors in the built environment, modes of information dissemination, and laws and practices governing political participation, work, and education excluded, segregated, or limited the lives of people with disabilities. The richness of these latter models of disability is the legislation they helped to create, embodying a national commitment to equal opportunity in education,²⁷

25. Gary L. Albrecht & Patrick J. Devlieger, *The Disability Paradox: High Quality of Life Against All Odds*, 48 SOC. SCI. & MED. 977, 977-88 (1999).

26. 2000 N.O.D./HARRIS SURVEY OF COMMUNITY PARTICIPATION (Harris Interactive, Inc. ed., 2000) (providing the results of a survey conducted for the National Organization on Disability) [hereinafter SURVEY].

27. See Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400-1487 (2000).

public services,²⁸ employment, transportation, and places of public accommodation.²⁹

Those who support vigorous efforts to reduce disabling conditions by preventing the births of people who will have them observe these legal gains and the increased presence of people with disabilities in schools and public places to demonstrate that there is no tension between prenatal selection and including those disabled people already in the population.³⁰ Under their view, it is possible to disvalue the disabling trait, and nonetheless to respect as social and moral equals people who exhibit these disliked traits. Prevailing social attitudes toward people with disabilities, and data about the effects of legal changes on employment, lead me to be anything but sanguine.

A. The Persistence of Negative Attitudes Toward People With Disabilities

In passing the Americans with Disabilities Act in 1990 (ADA),³¹ Congress recognized that millions of the nation's population continued to be treated differently and pejoratively by the non-disabled majority:

[I]ndividuals with disabilities are a discrete and insular minority who have been . . . subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society . . . resulting from . . . assumptions not truly indicative of the . . . ability of such individuals to participate in, and contribute to, society[.]³²

In enacting the ADA and its predecessors (Title V of the Rehabilitation Act of 1973,³³ and the Architectural Barriers Act of 1968),³⁴ the federal government recognized the need for the law to redress these systemic problems. Nothing in the nation's practices toward its millions of disabled inhabitants demonstrated success in devaluing disabling traits without also relegating the people with those traits to a status as economic and social inferiors.

Writing from a social constructionist perspective, David Wasserman contends that, "the disadvantages associated with impairments have their source in pervasive attitudes of contempt and

28. See Rehabilitation Act of 1973, 29 U.S.C. § 794(a) (2000) (codifying Rehabilitation Act of 1973, Pub. L. No. 93-112, § 504, 87 Stat. 355).

29. See Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12181-12189 (2000).

30. See BUCHANAN ET AL., *supra* note 15; Steinbock, *supra* note 4.

31. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101-12213 (2000)).

32. Americans with Disabilities Act of 1990, 42 U.S.C. § 12101(a)(7) (2000).

33. 29 U.S.C. §§ 791-794 (2000) (codifying Title V of the Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355).

34. 42 U.S.C. §§ 4151-4156 (2000) (codifying the Architectural Barriers Act of 1968, Pub. L. No. 90-480, 82 Stat. 718).

disrespect. Unlike people with obsolete skills, but like people of color, people with disabilities are not regarded as moral equals by the larger society, and the disadvantages they face reflect their devaluation.”³⁵ Ron Amundson explains the devaluation as follows:

Rehabilitation literature is full of examples of how able bodied people think of disabled people not as having *specific* disabilities, but as being *generally* incompetent. This social image reinforces the illusion that global disadvantages and handicaps flow from nature itself. In turn, the prejudice of the blind person’s global incapacitation provides an excuse to reject the demands of blind people for the kinds of environmental modifications which would increase their access to goals. Like the myths which burden women and ethnic minorities, the myth of the globally incapacitated disabled person is self-supporting.³⁶

Outlawing discrimination in public programs, employment, and places of public accommodation has not markedly altered how social science, medicine, and bioethics discuss disability when it comes to making childbearing decisions. Joan Retsinas further describes this devaluation:

Attitudes toward congenital disability per se have not changed markedly. Both premodern as well as contemporary societies have regarded disability as undesirable and to be avoided. Not only have parents recognized the birth of a disabled child as a potentially divisive, destructive force in the family unit, but the larger society has seen disability as unfortunate.

...
 ... Our society still does not countenance the elimination of diseased/disabled people; but it does urge the termination of diseased/disabled fetuses. The urging is not explicit, but implicit.³⁷

Natalie Angier puzzles about the seeming contradictions in contemporary dealings with the nation’s disabled population: “[T]he dominant culture appears to be moving in two contradictory directions: more accommodating of disabilities in adults, but less tolerant of imperfections in children.”³⁸ Surely it is logically possible to appreciate the species-typical without demeaning those who depart from it, but the historic record and contemporary practices have not displayed such logic. Describing children with disabilities as children with “special needs,” using the euphemism of “special needs adoption” when referring to placing children with disabilities in homes,

35. Wasserman, *Distributive Justice*, *supra* note 20, at 175.

36. Amundson, *supra* note 8, at 114.

37. Joan Retsinas, *The Impact of Prenatal Technology Upon Attitudes Toward Disabled Infants*, 9 RES. SOC. HEALTH CARE 75, 89-90 (1991).

38. Natalie Angier, *Joined for Life, and Living Life to the Full, Twins Challenge Old Views*, N.Y. TIMES, Dec. 23, 1997, at F1.

and maintaining a system of “special education” reveal that people with disabling conditions are “others,” not part of the total community. Were youth with disabling traits truly viewed as deserving of consideration when designing schools, daycare centers, and after-school programs, the programs would be created with the expectation that children differed from one another in many ways, and budget, staffing, and institutions would reflect the true diversity of the nation’s youth.

B. *Translating Law Into Practice*

In the late 1980s, disability policy historian Edward Berkowitz noted that: “The nation concentrates too much of its money on granting tickets out of the labor force and gives too little attention to the demands of the handicapped for tickets into the labor force.”³⁹ Writing about the ADA ten years after its passage, economist Richard Burkhauser takes a hard look at the strengths of the law and at what it has and has not accomplished to improve the status of people with disabilities:

The ADA is a testimonial to the ability of the disability rights movement to affect policy and to the political power of the idea that people with disabilities can and should work.

....

... [M]ost people outside the disability rights movement classify people with disabilities as “not expected to work.” This is true of the general population and more disappointingly it is true of the social science and public policy community.

....

... If they [referring to children but arguably applicable to everyone with a disability] are not expected to work, there is no reason to invest either in infrastructure or in broader social programs to turn sows’ ears into silk purses.

....

... I am now convinced that not only are the majority of people able to work following the onset of a disability but that they, in fact, are already doing so. Hence, public policies that focus on encouraging work following the onset of disability are not based on daydreams or good wishes.⁴⁰

Another observer of the impact of the law on social inclusion and economic participation laments how much remains to be accomplished toward the law’s lofty aspirations:

39. Amundson, *supra* note 8, at 115.

40. Richard V. Burkhauser, *An Economic Perspective on ADA Backlash: Comments from the BJELL Symposium on the Americans with Disabilities Act*, 21 BERKELEY J. EMP. & LAB. L. 367, 367-69 (2000).

It is clear that Congress regarded the deprivation and disadvantage of people with disabilities as giving moral urgency to the antidiscrimination mandate of the ADA. The statute is prefaced by the finding that people with disabilities are, as a group, among the least advantaged members of society (Section 2(a)(6)).

. . . [T]he primary beneficiaries of the ADA are the “disability elite”—those individuals with disabilities who possess indisputable competence, which they are prevented from displaying by structural or attitudinal barriers This, however, is the “trickle-down” pattern we have come to expect from the enforcement of laws against race and gender discrimination; it does not offer the same reproach to a statute designed to eliminate discrimination as it would to a statute designed to improve the material condition of the worst-off or least advantaged.⁴¹

Unfortunately, the public consciousness of disability and the inclusion of adults who have disabilities appear more superficial than genuine. A decade after the passage of the ADA, and nearly thirty years after enactment of the Title V employment provisions of the Rehabilitation Act, people with disabilities are not succeeding in gaining access to work, and courts are frequently ruling against them when they bring cases of employment discrimination.⁴² If society truly believed that people with disabilities could contribute to the nation’s economy, the unemployment rate would be calculated to show that millions of the nation’s disabled population of working age were not in the labor force. Considering that people with disabilities are estimated to be about twenty percent of the nation,⁴³ industry’s failure to pursue their labor and business with accessible product design and representative advertising is astonishing, and actually detrimental to the society as a whole.

Despite the symbolic and tangible changes attributable to laws like the Americans with Disabilities Act, the nation’s disabled population is still less educated, less employed, less involved in civic life, less represented in the political process, and less influential on the design of products than their numbers warrant. Thus, we do not have the inclusive society envisioned by Gliedman and Roth in their 1980

41. David Wasserman, *Stigma Without Impairment: Demedicalizing Disability Discrimination*, in AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS 146, 153 (Leslie Pickering Francis & Anita Silvers eds., 2000).

42. See SURVEY, *supra* note 26; Burkhauser, *supra* note 40; Ruth Colker, *Winning and Losing under the Americans with Disabilities Act*, 62 OHIO ST. L.J. 239 (2001); see also *Chevron U.S.A., Inc., v. Echazabal*, 536 U.S. 73, 74 (2002) (affirming EEOC regulation allowing an employer to screen out a potential worker with a disability if the job is a threat to his health or safety); *Bd. of Trs. v. Garrett*, 531 U.S. 356 (2001) (holding state immunity bars Title I ADA claims for money damages by individuals against a nonconsenting state or its agencies in federal court).

43. MCNEIL, *supra* note 9, at 1.

groundbreaking work on disability that laid out a minority group analysis and showed that children and adults with disabilities were expected to play no valued social role whatsoever.⁴⁴ It is in this discriminatory society in which researchers develop tests to discover disabling traits in embryos and fetuses; clinicians urge prospective parents to use these tests; government bodies endorse population screening for certain conditions, such as cystic fibrosis,⁴⁵ and support the use of funds from public and private health insurance to pay for such tests.

III. THE "MESSAGE" OF SELECTING FUTURE CITIZENS

In the preceding sections of this Article, I have discussed the contention that embryo selection and prenatal testing stem from society's misinformation about life with disability. Life with nearly all disability potentially contains rewarding personal relationships, stimulation and discovery, self-development, and contributions to others. Although not every difficulty of living with a disabling condition or health problem stems from society's failure to include its disabled citizens, a very large number can be traced to discriminatory attitudes and the social distance and segregated or restricted opportunities created by the non-disabled majority. I now take up the claim that the societal promotion of the selection techniques is morally problematic. I would argue that at least some of the rhetoric that endorses selecting children's characteristics conveys bias and disrespect for people with disabilities, and not merely information about the effects of a disabling trait.

Detractors of the disability critique have labeled one of its major components the "expressivist argument."⁴⁶ Although I am not comfortable with the term and think that the concerns about parental attitudes toward all children are as important as the concerns about disability, I continue to support a version of this argument. Before discussing the social practices that give rise to my belief that the genetics and medical professionals are giving an offensive message, let me state that I am concerned with what professionals do by way of promoting testing; I am not making any claims that prospective parents' familial goals and reproductive decisions should be evaluated by outsiders, or can be understood as communications to outsiders.

Elsewhere I used the following words to characterize possible re-

44. GLIEDMAN & ROTH, *supra* note 7, at 31-42.

45. "CF genetic testing should be offered to adults with a positive family history of CF, to partners of people with CF, to couples currently planning a pregnancy, and to couples seeking prenatal testing." NAT'L INST. OF HEALTH, U.S. DEP'T OF HEALTH AND HUMAN SERVS., GENETIC TESTING FOR CYSTIC FIBROSIS, (Apr. 14-16, 1997), at http://consensus.nih.gov/cons/160/160_intro.htm (last visited Feb. 3, 2003) (on file with author).

46. See BUCHANAN ET AL., *supra* note 15.

actions of the disability rights movement to the current practices of prenatal selection:

People with just the disabilities that can now be diagnosed have struggled against an inhospitable, often unwelcoming, discriminatory, and cruel society to fashion lives of richness, of social relationships, [and] of economic productivity. For people with disabilities to work each day against the societally imposed hardships can be exhausting; learning that the world one lives in considers it better to “solve” problems of disability by prenatal detection and abortion, rather than by expending those resources in improving society so that everyone—including those people who have disabilities—could participate more easily, is demoralizing. It invalidates the effort to lead a life in an inhospitable world.⁴⁷

In evaluating whether certain actions or practices send messages, James Lindemann Nelson contrasts flying the Confederate flag over the South Carolina Statehouse (which he argues sends a possibly negative and offensive message to African-Americans) with the uses of prenatal testing made by prospective parents, which he believes contain no clear communication and need not offend anyone.⁴⁸ Like Nelson, I agree that the parental actions are not intended and should not be viewed as communicative. Nelson, however, goes on, “[b]ut rather than individual choices, consider the general social practice of developing and disseminating more and more tests for more and more conditions: Does that practice not express a clearer and plainly objectionable meaning . . . ?”⁴⁹

Nelson concedes that prenatal testing “take[s] place against a very disturbing historical backdrop concerning the place to which people with disabilities have been assigned in American society.”⁵⁰ He concludes that the social endorsement of testing and abortion is much less settled and clear in what it intends or conveys than displays of the Confederate flag at the state capital.⁵¹ Perhaps he feels that if the societal motive for screening to prevent the births of children with disabilities was analogous to historical and contemporary American racism, there would be reason for disability advocates to limit women’s reproductive freedom and to ban the use of the technology. In this he forgets that the critique of testing and selective abortion is intended to change professional practice and rhetoric and to give more comprehensive information about disability to prospective par-

47. Asch, *Reflections*, *supra* note 11, at 240.

48. James Lindemann Nelson, *The Meaning of the Act: Reflections on the Expressive Force of Reproductive Decision Making and Policies*, in *PRENATAL TESTING*, *supra* note 2, at 196, 208-10.

49. *Id.* at 207-08.

50. *Id.* at 209.

51. *Id.* at 210.

ents. Critics have never intended to curtail women's decision-making about their reproductive lives.

A. *Clinical Practice*

Clinicians providing medical services and prenatal counseling to pregnant women (whether obstetricians, nurse practitioners, midwives, or genetic counselors) obviously play crucial roles in communicating whether prenatal testing should be undertaken, what the tests reveal, and what they can mean for the health of the potential child and the life of the family. Despite the professional commitment to non-directiveness in genetic counseling, it is clear that many professionals do not practice in a way that legitimates the choice to maintain a pregnancy of a fetus affected by a disabling trait.⁵² Counselor education contains little opportunity for contact with disabled children or adults in non-medical settings where clinicians could observe how people with disabilities manage day-to-day life.⁵³ An especially troubling example is the finding by Lippman and Wilfond that pediatric and prenatal genetic counseling gave radically different information about the same conditions to families.⁵⁴ In situations where parents were raising infants and young children with Down syndrome and cystic fibrosis, counselors stressed ways in which lives of the affected children would resemble those of non-disabled peers, focusing on capacities for education, stimulation, play, and relationships. By contrast, the stories given to prospective parents if the diagnosis was made prenatally concentrated on medical complications and differences from the lives of non-disabled children.⁵⁵ Such differences in information run afoul of non-directiveness.

It is hard to read the very different descriptions contained in Lippman and Wilfond's report of the prenatal and post-birth accounts of Down syndrome and cystic fibrosis as anything other than:

If you can avoid this bad thing, you should; if you weren't lucky enough to avoid it, we don't want to tell you how really awful it is going to be. We fear you won't be able to stand it, so we will let you find out for yourself. We don't have to give you news we think won't help you feel good about your child.

If prospective parents are ever to have the opportunity to make thoughtful decisions about whether they are prepared to raise a child

52. Parens & Asch, *Disability Rights Critique*, *supra* note 2, at 5-8.

53. For a discussion of genetic counseling, see Barbara Bowles Biesecker & Lori Hamby, *What Difference the Disability Community Arguments Should Make for the Delivery of Prenatal Genetic Information*, in *PRENATAL TESTING*, *supra* note 2, at 340-57; and Parens & Asch, *Disability Rights Critique*, *supra* note 2.

54. Abby Lippman & Benjamin S. Wilfond, *Twice-Told Tales: Stories about Genetic Disorders*, 51 *AM. J. HUM. GENETICS* 936, 936-37 (1992).

55. *Id.*

with a prenatally detectable disability, they need to know as much as counselors can tell them about the overall experience of children and families living with the diagnosed condition. Omitting the ways in which a child with cystic fibrosis or Down syndrome can participate in the life of family, school, and community underscores disability as a negative factor, especially if the information parents are given about what children with either condition cannot do focuses on the needs for medical follow-up or on shortened life expectancy. Similarly, the parent learning that her or his newborn daughter or son can expect to go to school, get a job, and enjoy loving relationships with others should not be kept in ignorance regarding the need for medication, therapy, or hospitalization that may be part of her or his child's life. The premise of counseling, or of educating people about their own and their children's possible futures, is that anyone contemplating raising a child or actually involved in parenting will profit from learning about what could be in store. If professionals in one instance accentuate the negative, and in another instance accentuate the positive, they show disrespect for the intelligence and sincerity of the people who rely upon them for information and assistance. Counselees in each situation deserve to learn as much as they can from knowledgeable professionals; and professionals betray the people they serve by slanting the information in the direction of a particular result. If counselors, midwives, and obstetricians are truly committed to patient decision-making and to informed reproductive choice, they should be providing enough information about life with a disabling condition so that prospective parents can imagine the ways in which life can be worthwhile as well as those in which it can be difficult. Similarly, the parent of a toddler whose health is going to be affected by the need for medications, home-based therapy, early educational services, or hospital stays should be able to take account of those factors when deciding where to live and what job to seek. The stated neutrality and non-directiveness of genetic counselors is very much open to question if further research determines that these differences in prenatal and pediatric counseling are the norm.

B. Rationales for Test Development

Remember that scientists persuaded Congress to budget three billion dollars over fifteen years to map and sequence the human genome, promising that the new knowledge would lead to treatments and cures for disease and disability. "In 1988, Congress appropriated funds . . . to begin planning the Human Genome Project. Planners set a 15-year time frame, estimated that the price tag would be \$3 bil-

lion, and laid out formal goals to get the job done.”⁵⁶ Francis Collins explains the project’s purposes this way:

Scientists wanted to map the human genetic terrain, knowing it would lead them to previously unimaginable insights, and from there to the common good. That good would include a new understanding of genetic contributions to human disease and the development of rational strategies for minimizing or preventing disease phenotypes altogether.⁵⁷

Although the goal is said to be cure or treatment, to date researchers have developed very few therapies that would help anyone now living with a genetic condition.⁵⁸ Instead of developing therapies or treatments for most of the genetic conditions for which the specific gene is known, researchers developed prenatal tests and embryo selection techniques that inform prospective parents about future children, but do nothing for anyone now living with a genetic condition. Some prospective parents will seek out information yielded by the tests even if they intend to continue a pregnancy regardless of the finding, but generally, the purpose of screening embryos or testing fetuses is for women (and their partners) to decide whether to carry a particular fetus to term. Several scholars who have reflected on the phenomenon of prenatal testing acknowledge that the resources are allocated to testing and counseling on the assumption that most people who learn that an embryo or fetus carries a disabling trait will not proceed with implantation or pregnancy. Promoting informed reproductive choice may be the stated goal of test developers, but the generally expected and desired result of a disability diagnosis is the termination of that particular pregnancy in hopes that the next one will yield an embryo or fetus free of a detectable disabling trait.⁵⁹

Consider that as yet there are tests for only some of the many single-gene traits. Geneticists have not sought funding to develop the prenatal test for hair or eye color, for example, because these traits have relatively little social consequence. There is nothing negative ascribed to having blue eyes or brown, blond hair or black. Developers of tests for embryos and fetuses believe that prospective parents will (or should) wish to avoid the births of children who will have disabling conditions because the perceived difficulties of their lives

56. Francis S. Collins, *Shattuck Lecture—Medical and Societal Consequences of the Human Genome Project*, 341 NEW ENG. J. MED. 28, 28 (1999).

57. *Id.*

58. A notable exception was reported by Gina Kolata as follows: “The achievement, announced yesterday in France, comes after a decade of widely heralded promise followed by dashed hopes for the revolutionary treatment.” Gina Kolata, *Scientists Report the First Success of Gene Therapy*, N.Y. TIMES, Apr. 28, 2000, at A1.

59. See, e.g., Arthur L. Beaudet, *Carrier Screening for Cystic Fibrosis*, 47 AM. J. HUM. GENETICS 603 (1990) (discussing the benefits and harms associated with the implementation of cystic fibrosis carrier testing to reduce the burden of cystic fibrosis on society).

are likely to outweigh benefits to the child, the family, and the society. The tests do nothing to promote the health of the developing fetus or the health of the pregnant woman. Rather, they are offered so that people may decide against becoming a parent of a child with a particular characteristic that clinicians and policy makers understand to be detrimental to a satisfying life for the child or the family, or that may require outlays of societal resources. Andrews and Hibbert describe the attitude toward disability found in law, science, and medicine as follows:

The very notion of wrongful birth and wrongful life—conveying the idea that having a child with a disability that could have been “prevented” through abortion is a legal wrong—seems vastly at odds with the ideas about disability that serve as the foundation for the Americans with Disabilities Act.

. . . .

In large measure, the history of eugenics is a history of brutality against the disabled. . . . Even today, much of the writing about genetic discoveries includes economic analyses about the cost of care for people with a particular genetic mutation, implying that society would be better off had they not been born.⁶⁰

The authors go on to speculate that: “Once genetic disease is no longer seen as a random characteristic, this may reduce our communal commitment to people with genetic disabilities.”⁶¹ When commentators talk about the social costs of providing medical care, education, or supportive services for children and adults with disabilities, they neglect to point out that non-disabled children and adults require societal investment; that the costs of creating an accessible society must be borne simply to assist the vast majority of people with non-diagnosable, non-genetic conditions that arise during a life; and that people with disabilities can contribute to the economy and to their families by virtue of the characteristics they have in addition to their impairments.⁶²

C. Line-Drawing

If prenatal testing and embryo selection are not intended to give messages about which types of children the society will accept and welcome, proposals for “drawing lines” about the types of tests to be offered or withheld must be carefully examined and, in my view, rejected. Many clinicians and bioethicists fear that the consumerism of

60. Lori B. Andrews & Michelle Hibbert, *Courts and Wrongful Birth: Can Disability Itself Be Viewed as a Legal Wrong?*, in AMERICANS WITH DISABILITIES, *supra* note 41, at 318, 318-19.

61. *Id.* at 321.

62. NORMAN J. WAITZMAN ET AL., THE COST OF BIRTH DEFECTS: ESTIMATES OF THE VALUE OF PREVENTION 115-41 (1996).

assisted reproduction, the anxieties of people who delay parenting and expect to have only one or two children, and the pressures parents feel to give their children “the best” start in life all contribute to a desire for “‘designer’ children.”⁶³ To counter these tendencies, some are urging that researchers decline to develop, and clinicians decline to provide, tests that inform people about what professionals perceive to be traits that do not pose serious harms to the child or the family.

Jeffrey Botkin and Thomas Murray argue that some information and choice is inimical to what good parents should consider and to what a caring society should accept.⁶⁴ Botkin distinguishes traits for which tests should and should not be offered by appealing to a notion of parental harm caused by raising children with some diagnosable conditions, saying that they should be able to get information “designed to prevent harms to parents that are approximately the same magnitude as the harms of an unwanted pregnancy.”⁶⁵ On his parental harm criterion, prenatal diagnosis should not be offered for late-onset conditions, such as Huntington’s disease or breast or colon cancers; nor would they be made available for traits he would describe as not seriously threatening the interests parents should have in raising children.

Murray, too, opposes what he describes as the desire for perfectabilism, that would lead parents to seek diagnoses of “trivial” conditions.⁶⁶ I read Murray as believing that the conditions for which tests have been available are of sufficient gravity that prospective parents should get to decide whether or not they can imagine living with and adequately nurturing a child with the disability.⁶⁷ Although he does not wish to ignore the concerns of people with a disability critique of prenatal selection practices, he appears to be able to imagine that professionals should draw the line as to which conditions parents should consider when making decisions about their families, and which they should not. When professionals develop tests and offer them to parents, then, Murray and Botkin would both argue for creating a list of the serious conditions that parents should think about, and of refusing to give prospective parents the chance to decide for themselves which characteristics of future children might be of significance to them. Murray and Botkin share some of the disability critique of current practice; they recognize that at least some disabling traits in some families do not preclude rewarding lives for individuals and families; and they disagree that prospective parents

63. THOMAS H. MURRAY, *THE WORTH OF A CHILD* (1996); Jeffrey R. Botkin, *Fetal Privacy and Confidentiality*, HASTINGS CENTER REP., Sept.-Oct. 1995, at 32.

64. MURRAY, *supra* note 63; Botkin, *supra* note 63.

65. Botkin, *supra* note 63, at 36.

66. MURRAY, *supra* note 63, at 137-40.

67. *Id.*

should retain an openness to the many characteristics that every child will display.

Sadly, I believe that the very desires that would have Murray and Botkin limit diagnoses to only some, but not all, characteristics that might be determined prenatally, turns the professional assistance to reproductive autonomy into the very “message” about the badness of disability that alarms critics of the current practices. Why should parents be told by test designers: “We think that cystic fibrosis, or muscular dystrophy, or deafness, or Down syndrome should make parents think at least twice before contemplating childraising; but other conditions are too trivial for parents to object.” If prenatal selection is not intended to harm existing people with the conditions that can now be diagnosed and instead is designed to give value-free information to prospective parents, creating an official list of conditions that parents should worry about will have an undesirable effect on the societal acceptance and self-esteem of those with the listed conditions. Why should it be acceptable to avoid some characteristics and not others? How can the society make lists of acceptable and unacceptable tests and still maintain that only disabling traits, and not people who live with those traits, are to be avoided? If it is legitimate to be a person with a disability, or to parent a child with such a disabling condition, should the society make a list of “serious” and “trivial” characteristics?

Endorsing testing and selecting against some traits, and refusing to let people select against other traits, will surely exacerbate the discrimination and stigmatization of future children with the listed conditions. I, and many others with a disability critique of the existing practices, find this suggestion of line-drawing clear evidence that the current arrangement and any future line-drawing reforms are much too close for comfort to running the Confederate flag up the flagpole. The flying Confederate flag tells people historically victimized by racist discrimination that racism and the history of racism is and was acceptable; enumerating a set of testable genetic diseases tells people who currently have those conditions that it would be better if prospective parents went to considerable lengths to prevent the births of children with those conditions. Consequently, I can only urge people who support reproductive choice and also support disability inclusion and equality to oppose line-drawing efforts. It must become as acceptable to test for tone deafness or color blindness (if tests are ever developed) as it now is to test for certain forms of deafness and blindness. Undoubtedly, more prospective parents will terminate for the latter conditions than the former, but at least the decisions will be those of the people ultimately raising children, and not society, in the form of its insurance carriers and clinicians as gatekeepers.

A word should be said about line-drawing in the context of the nation's continuing struggle over women's rights to abortion. So long as the courts uphold women's freedom to end pregnancies for any reason during the first twenty-four weeks of gestation, most people who seek to use diagnostic techniques to make termination decisions will get the information about the fetus within the time limit for legal abortion. But suppose the courts were to ban abortions after the first trimester, or after twenty weeks of pregnancy, leaving an exception for abortions sought after receipt of prenatal diagnostic test results? Martha Field argues that any abortion exceptions based on disability would send just the sort of devaluing message proponents of testing claim is absent from the current enterprise.

An argument based upon discrimination against the handicapped does not dictate whether there will be any abortion right or how long any such right will last. It only maintains that the same rules must be adopted without regard to whether the child-to-be is projected to have a disability. Under this view, states could not prohibit third-trimester abortion while making an exception for disability. Nor could they make any exception for disability if they were able to and did prohibit abortion generally.⁶⁸

At the outset of this Article, I indicated that I would focus on the question of whether society could simultaneously promote social and moral equality for people with disabilities in the world and nonetheless work to urge people not to reproduce children who would have disabling conditions. I believe that it will be very difficult for most families to consider bringing children with diagnosable disabilities into the world if they know that the society believes that their births should have been prevented. When I wrote about prenatal diagnosis in 1989, I described prospective mothers (and I would say all prospective parents) as hoping "to give ourselves to a new being who starts out with the best we can give, and who will enrich us, gladden others, contribute to the world, and make us proud."⁶⁹ Writing about "maternal practice," (but it can apply to fathers as well), Sara Ruddick suggests that the third basic component of maternal (or parental) work is to nurture the growing child so that she or he will be an acceptable member of the larger society.⁷⁰ Raising children is work, whether or not the child has a characteristic termed a disabling trait. Virtually every parent worries about whether his son's moodiness or her daughter's adventurousness will cause problems down the line. Will children find friends, love, work, community? Will others appreciate them—warts and all? Will children grow to find a place for

68. Martha A. Field, *Killing "The Handicapped"—Before and After Birth*, 16 HARV. WOMEN'S L.J. 79, 110 (1993).

69. Asch, *Reproductive Technology*, *supra* note 2, at 86.

70. SARA RUDDICK, *MATERNAL THINKING: TOWARD A POLITICS OF PEACE* 17-23 (1989).

themselves that they will take pride in, will comfortably rest in?

If these are the anxieties of all parents raising all children, those anxieties can only be heightened if parents know and love a child whose disabling characteristics meet with aversion, social embarrassment, discrimination, and exclusion. Only when policies, laws, medical professionals, schools, and media communicate that it is respectable and legitimate to live with a disability, and only when day-to-day reality approximates the aspirations that gave rise to the Americans with Disabilities Act, will it be possible to imagine that the social problems of disability will not compound any biological limitations. Ever-increasing prenatal testing and vigorous enforcement of existing anti-discrimination laws might continue to develop along their separate tracks, because geneticists and doctors work in arenas quite different from the advocates for greater social services, increased access to education, and employment for the nation's disabled population. Yet I persist in believing that as part of the goal of creating such a welcoming society, we must persuade professionals to change what they tell prospective parents about life with disability; convince those parents to learn about how children and adults in today's world survive and thrive; and then endorse the choices people make about their reproductive and family lives.

Daniel Wikler's words opened this Article with what readers may have interpreted as irony or skepticism. I believe Wikler is committed to the project of supporting full inclusion of disabled people, but believes that prospective parents should refrain from producing children whose genetic endowments compromise their life choices.⁷¹ I fear that the current climate in which prenatal testing takes place displays neither the rhetorical agility nor the social commitment to equality that I desire. If we are ever to make it as least as acceptable to bear and raise a disabled child as a non-disabled one, we must simultaneously commit ourselves to both social reforms that include all people, whatever their characteristics, and to accepting consumerism in the reproductive marketplace. Creating such a climate will take at least as much rhetorical agility as Wikler thinks he has displayed.⁷²

71. REINDERS, *supra* note 1; E-mail from Daniel Wikler, Professor of Ethics and Population Health, Harvard School of Public Health, to author (Sept. 10, 2002, 23:03 CST) (on file with author). See *infra* note 72 for the content of this e-mail.

72. In an e-mail, Daniel Wikler confirmed that he believes it is possible to support screening programs to prevent the conception of handicapped individuals, while insisting that full respect be paid to developmentally disabled adults:

You're right. I do think it's possible but also that it's difficult, i.e., that there is a tension. The ingredients of my view are:

1. In at least some cases the individual would have had greater opportunity for well-being, all things considered, without the disability.

2. Thus if we have a choice between a population in which many have this disability and one in which few do, then all things considered more people will have a better chance of having greater well-being. This consideration belongs on the balance scale, though it is not determinative.

3. There is a bit of tension in holding these two thoughts in one's head simultaneously: [that] this person's disability is likely (though not certain) to decrease this person's likelihood of attaining high levels of well-being; AND that this worth of this person is the same as everyone else's, the disability notwithstanding.

4. One source of tension comes from the fact that so many people with the disability do just fine.

5. Another source is that in some cases (for some "disabilities," it may be most or even all), the reason that the trait detracts from expected likelihood of well-being is that society is unjust (stigmatizing or unjustly unaccommodating).

6. A third source is that in the case of disabilities stemming from a person's genes, or acquired early in life, the person's identity and sense of community may be powerfully affected by having the disability, so that targeting the disability may be understood as denigrating that personal or social identity.

7. A fourth source is the historical record, in which supposedly humanitarian efforts to improve the well-being of future generations have in fact been unjust, violent, and indefensible efforts to rid societies of stigmatized people and groups who in most cases were highly vulnerable. We have to be on guard against this, even when we think our motives are above reproach.

Given 4, 5, 6, and 7, I don't think there is a cost-free way out of the dilemma, and I'm certainly prepared to consider an argument that in some cases the dilemma should be resolved in favor of calling off the effort to prevent the disability from affecting future generations. However, in many cases my view is that the balance scale tilts in the opposite direction, because of 1 and 2. The important thing, in my view, is to grant that both sides of the balance scale have weight; and then to try to do a conscientious job of weighing.

Wikler, *supra* note 71.