

2008

## Foreword

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### Recommended Citation

Asch, Adrienne (2008) "Foreword," *Saint Louis University Journal of Health Law & Policy*: Vol. 2 : Iss. 1 , Article 3.

Available at: <https://scholarship.law.slu.edu/jhlp/vol2/iss1/3>

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## FOREWORD

ADRIENNE ASCH\*

In November of 2008, the United States elected Barack Obama, a self-described “mutt”,<sup>1</sup> to be its new president. When Barack Obama was born in 1961, six years before the Supreme Court struck down miscegenation laws,<sup>2</sup> his Caucasian-American mother and Black-African father could not have been legally married in several states in this country. On the same night that Californians overwhelmingly voted for a president who views himself as a person of color—a member of this country’s historically most despised and disadvantaged minority—they denied members of another minority group, gays and lesbians, the right to marry.<sup>3</sup>

The California vote could reflect differences in attitudes toward the particular minority groups, differences in the political power and legitimacy accorded the civil rights and gay rights movements, or differences between acceptance of minority group members in public versus intimate life. First let us consider possible differences in the public attitudes towards, and the political legitimacy of, different minority groups.

Federal and state anti-discrimination law exists because our society has recognized that one’s race, national origin, religion, sex, sexual orientation, age, and disability can negatively influence the opportunities for participation in the public sphere of economic and political life. Stigma,

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1. Barack Obama, President-Elect, Press Conference (Nov. 7, 2008) (explaining that save for his older daughter’s allergy, the family would have preferred to get “a mutt, like me” as a puppy); *see also* Jeff Zeleny & Jackie Calmes, *Obama Seeks Speedy Action on Economy*, N.Y. TIMES, Nov. 7, 2008, at [www.nytimes.com/2008/11/06/us/politics/08transition.html?partner=rssnyt](http://www.nytimes.com/2008/11/06/us/politics/08transition.html?partner=rssnyt) (last visited Feb. 24, 2009).

2. *Loving v. Virginia*, 388 U.S. 1 (1967) (declaring unconstitutional Virginia’s ban on interracial marriage).

3. Proposition 8 was passed by California voters on November 4, 2008. *See* California General Election, Voter Information Guide, Proposition 8 Title and Summary, at [www.voterguide.sos.ca.gov/title-sum/prop8-title-sum.htm](http://www.voterguide.sos.ca.gov/title-sum/prop8-title-sum.htm) (last visited Feb. 24, 2009). For Proposition 8 election results, see California Secretary of State, November 4, 2008 State Ballot Measures, available at [www.sos.ca.gov/elections/sov/2008\\_general/57\\_65\\_ballot\\_measures.pdf](http://www.sos.ca.gov/elections/sov/2008_general/57_65_ballot_measures.pdf) (last visited Feb. 24, 2009).

prejudice, and discrimination affect virtually every facet of the lives of groups protected by state and federal anti-discrimination law, but attitudes toward and experiences of minority groups are hardly identical. The struggles of African-Americans for formal legal equality and equal opportunity that began with the civil rights movement following World War II taught women, gays and lesbians, and people with disabilities how to articulate and fight for their own rights and needs.

The rhetoric and demands of the movements share common characteristics, but the recognition accorded to the different groups in law and in politics still bears notable differences. Although no one would seriously claim that Barack Obama's election to the presidency signals the end of racism, there are strong and powerful laws and norms against racial discrimination, unequal treatment, and adverse outcomes based on race. It is virtually unimaginable that an employer could successfully assert that race was a bona fide occupational qualification for any job, but employers may deny a job to a person who is gay, lesbian, bisexual, or transgendered (GLBT) without violating federal anti-discrimination law. Forty-five years of anti-discrimination law have eroded the notion that male and female biological differences dictate different roles for women and men, and the nation's police, military, professions, and elected bodies all include significant numbers of women. There is no "undue hardship" defense for employers who make hiring decisions based on race or sex, but there is such a defense to employment discrimination claims based on disability.<sup>4</sup> If the Civil Rights Act of 1964 to end discrimination based on race, creed, color, national origin, and sex is the standard for thinking about anti-discrimination law, we can see that law and social acceptance of formal equality for other minorities lags far behind.

Characteristics such as race and sex have been markers of social identity for many reasons. They have been thought to be readily observable, to be biological givens, immutable and not chosen.<sup>5</sup> There are no negative moral connotations to being male or female, African-American, or Caucasian, but the same cannot be said for being gay or lesbian. The recent popularity of the claim that gays are not responsible for their sexual orientation because it is genetically-based suggests that their orientation would be blameworthy if it was a matter of choice.

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4. 42 U.S.C. § 12112(b)(5)(A) (2000).

5. Of course, the phenomena of light-skinned African-Americans "passing" for white, the development of techniques to change one's sexual characteristics, as well as increased genetic knowledge indicating that there is more diversity within members of one racial group than there is among people of different racial characteristics only compound the difficulties of making sense of racial and sexual categories.

Disability shares characteristics with both groups of minorities, but also has distinctive features. Like race and sex, disability is perceived as an obviously biological category. Unlike minority sexual orientation, it is not or no longer seen as a moral flaw or symptomatic of moral flaws. Like sexual orientation, however, one may not be “born with” it, and one’s classification as having a disability, like one’s classification as gay or straight, could change more than once over a lifetime. Someone who cannot hear, walk, speak, or see may be readily marked as disabled in personal interaction. People who cannot hear, walk, speak, or see may feel commonality with American blacks or women who must manage an employer’s surprise and awkwardness when they show up to interview for executive jobs. Someone with epilepsy, diabetes, dyslexia, or bipolar disorder, however, may be as closeted as members of the GLBT world have been. Media take note of how politicians vote on welfare reform, affirmative action, partial birth abortion, or same-sex marriage, but neither the media nor political candidates expect that the millions of men and women with disabilities of all ages, sexual orientations, religions, and races constitute a disability community, or vote based on someone’s stance on disability issues. And in fact, it is hard to think of an issue of great importance to the disability rights movement that has made headlines since the signing in 1990 of the Americans with Disabilities Act (ADA).<sup>6</sup>

Notwithstanding the public’s and the elite’s relative unfamiliarity with the notion of people with disabilities as a minority, the ADA clearly recognizes that tens of millions of people in the United States experience discrimination in employment, government programs, and public accommodations. The ADA embodied the understanding of disability articulated by disability rights activists, scholars, and legal advocates for decades: that lack of education, unemployment, and societal marginality stemmed not from anything inherent in physiologic, sensory, cognitive, and psychological impairment, but rather from the interaction of impairment with a society uncomfortable with, and not accepting of, people with impairments.<sup>7</sup> Thanks to laws such

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

7. For an early exposition of such a view from a legal scholar, see Jacobus tenBroek, *The Right to Live in the World: The Disabled in the Law of Torts*, 54 CAL. L. REV. 841 (1966). Early academic writing articulating a social analysis of life as a person with a disability 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); Harlan Hahn, *Paternalism and Public Policy*, SOC’Y, Mar. 1983, at 36, 36. An early federal analysis with an explicitly civil rights approach can be found in U.S. COMM’N ON CIVIL RIGHTS, *ACCOMMODATING THE SPECTRUM OF INDIVIDUAL ABILITIES* (1983). An important collection of essays on disability can be found in *AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS* (Leslie Pickering Francis & Anita Silvers eds., 2000).

as the ADA and the Individuals with Disabilities Education Act, more children with disabilities go to school and college with non-disabled students.<sup>8</sup> Non-disabled people now see people with Down syndrome and cerebral palsy going shopping and sitting in restaurants, and they know them as neighbors, classmates, and coworkers. However, despite legal change and some public awareness of a disability rights movement, activists and observers would say that people with disabilities have not won anything like the public legitimacy or the political recognition that racial or sexual orientation minorities have achieved.<sup>9</sup>

The California vote to deny gays and lesbians the right to marry also reflects complex and subtle differences in how people understand the spheres of public and private life. Whereas law can be a powerful means of changing practices and institutions in the public sphere, it has not been considered an appropriate tool for changing patterns of intimacy in marriage or family life.<sup>10</sup> A state may not bar people from choosing to marry on the basis of race, but courts will not uphold a discrimination claim from a person who believes that she was rejected for a date because of her race. The United States Supreme Court has determined that the “right to procreate” is fundamental and cannot be withheld because of a criminal record,<sup>11</sup> but no law can compel someone to become a genetic or adoptive parent against their will, and no law precludes parents from trying to exercise choice and control over some characteristics of children they raise. Employers may no longer classify jobs as “male” or “female,” but adopting parents may reject an available child based on its sex, race, age, or disability. Similarly, individuals are free to select their procreative partners or use various reproductive technologies to increase their chances of having a child who might be deaf, or female, or who might not have cystic fibrosis.<sup>12</sup>

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8. Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12181-12189 (2000); Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400-1487 (2000).

9. For a trenchant account of public, media, and political hostility to viewing disability as a civil rights and political issue, see generally MARY JOHNSON, *MAKE THEM GO AWAY: CLINT EASTWOOD, CHRISTOPHER REEVE, AND THE CASE AGAINST DISABILITY RIGHTS* (2003).

10. Kenneth L. Karst, *Freedom of Intimate Association*, 89 YALE L.J. 624 (1980) (analyzing what differentiates intimate from more public associations). A provocative article by Elizabeth F. Emens suggests that the state could take certain steps to remove barriers to romantic and marital relationships that might actually give people more choice in deciding whom to date and marry. Elizabeth F. Emens, *Intimate Discrimination: The State's Role in the Accidents of Sex and Love*, HARVARD L. REV. (forthcoming 2009) (on file with author).

11. *Skinner v. Oklahoma*, 316 U.S. 535, 541-42 (1942).

12. For discussions of protections of the preferences of adoptive parents, see references cited in Emens, *supra* note 10. See also MADELYN FREUNDLICH, *ADOPTION AND ETHICS VOLUME 1: THE ROLE OF RACE, CULTURE, AND NATIONAL ORIGIN IN ADOPTION* (2000); MADELYN FREUNDLICH, *ADOPTION AND ETHICS VOLUME 2: THE MARKET FORCES IN ADOPTION* (2000).

In this Foreword I cannot develop a much-needed discussion of the reasons for and against distinguishing marriage and parent-child relationships from the more public ones of employer-employee or leader and citizen; nor can I develop points I have made elsewhere that mate selection and parental selection differ from one another in significant ways.<sup>13</sup> Instead I will try to place the articles that follow in the context of people with disabilities as a group different from and similar to the other groups protected by state and federal anti-discrimination law. Like people of color and gays and lesbians, people with disabilities experience disadvantage in both public and private life. The contributions that follow must be understood as examining how attitudes and practices influence public decisions about medical care, as well as more private decisions about whether children or adults with disabilities will be accepted as legitimate members of families.

#### THE ARTICLES

The articles collected in this Symposium on disability, reproduction, and parenting clearly demonstrate the complexity of fitting disability into the typical framework of minority group analysis in either public or private facets of life. When, if ever, is it appropriate to disaggregate the category of “people with disabilities” into sub-groups based on a particular impairment? When does health status, in and of itself, adversely affect one’s life, quite apart from society’s treatment of people with departures from species-typicality? Is it legitimate for health professionals, prospective parents, or social agencies to consider existing or future disability when they determine which patients they will treat, which adults will become parents, or which children they will create and raise?

The article by Elizabeth Pendo fits most neatly into a minority group analysis of disability, with its focus on unequal treatment in a public realm: access to a physician’s office or to its medical equipment.<sup>14</sup> Pendo points out that since the 1973 Rehabilitation Act,<sup>15</sup> people with disabilities have been entitled to access to programs receiving federal financial assistance.<sup>16</sup> Hospitals, clinics, and private physicians accepting Medicaid, Medicare, and any other federal funds have thus been obliged to be accessible to and useable by people with disabilities for more than thirty years. Yet neither the

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13. Adrienne Asch & David Wasserman, *Where Is the Sin in Synecdoche?: Prenatal Testing and the Parent-Child Relationship*, in *QUALITY OF LIFE AND HUMAN DIFFERENCE: GENETIC TESTING, HEALTH CARE, AND DISABILITY* 172 *passim* (David Wasserman et al. eds., 2005).

14. Elizabeth Pendo, *Disability, Equipment Barriers, and Women’s Health: Using the ADA to Provide Meaningful Access*, 2 *ST. LOUIS U. J. HEALTH L. & POL’Y* 15 (2008).

15. Rehabilitation Act of 1973, 29 U.S.C. §§ 701-796 (2000).

16. Pendo, *supra* note 14, at 30.

existence of the Rehabilitation Act nor the ADA—covering places of public accommodation without regard to federal funding—has ended the unequal access to medical care experienced by people with mobility impairments. Pendo notes that “[t]he problem of physical barriers to the delivery of health care for people with disabilities is a surprisingly under-examined subject . . . Although the Rehabilitation Act and the ADA require that health care programs, institutions, and offices be accessible, few actually are”.<sup>17</sup> She meticulously and exhaustively documents the magnitude of the problem as well as the adverse health effects of inadequate or delayed tests and procedures.

The medical profession excuses the persistence of inaccessible physician offices, examining tables, and mammography machines by saying that there is no consensus on the definition of accessible equipment; that accessible equipment is not available; and that accessible equipment is not necessary because patients can be lifted onto existing equipment.<sup>18</sup> Pendo rejects these contentions. She suggests instead that the inattention to the gynecological and reproductive health needs of women with mobility impairments stems from the pervasive belief that these women are unlikely to have sexual partners and that, in any event, they should not be mothers.<sup>19</sup> Pendo concludes her article by proposing ways that federal programs could go some way to removing the physical obstacles to health care.<sup>20</sup> But no matter how welcome and effective her remedies would be for preserving the physical well-being of this group of patients, accessible equipment alone will not repair the profound attack on a woman’s humanity and sense of self if her physician behaves as though the inability to walk precluded the inability to love and be loved.

The article by Susan Stefan takes up what Pendo believes is at the heart of the neglect of the sexual and reproductive health needs of women with disabilities: the belief that a disability—perhaps especially a woman’s disability—renders its bearer an inadequate or unacceptable parent.<sup>21</sup> Stefan deals with women who have psychiatric, rather than mobility impairments; the women whose situation she explores are already parents, often trying to retain or regain relationships with and rights over their children.<sup>22</sup> Along with Pendo, she faults the non-disabled majority, acting through its laws and social service agencies, for compounding the difficulties

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17. *Id.* at 17-18.

18. *Id.* at Section III.

19. *Id.* at 42-47.

20. *Id.* at 47-55.

21. Susan Stefan, *Accommodating Families: Using the Americans with Disabilities Act to Keep Families Together*, 2 ST. LOUIS U. J. HEALTH L. & POL’Y 135, 140 (2008).

22. *Id.* at *passim*.

these women encounter in preserving their place in their children's lives.<sup>23</sup> Much of her article demonstrates why the ADA's framework has not been employed successfully in fighting for systemic reforms that would, in her view, aid mothers with disabilities and their children.

Stefan argues that

[d]espite obvious parallels between family integration and community integration, efforts to use the ADA to keep families intact in the community when one member of the family has a psychiatric disability have failed almost completely. . . . Despite the fact that a substantial number of families who are subject to termination proceedings have at least one member with a psychiatric disability, both federal and state courts have recoiled from suggestions that the ADA requires state agencies to truly modify their practices, services, or training in recognition of this fact, or to provide more than cursory accommodations (or, in some cases, any accommodations at all) to keep families intact when one member has a psychiatric disability. . . . Instead of case-by-case adjudication, disability advocates should bring systemic ADA discrimination cases seeking to expose and confront the exclusion and discrimination inherent in the operation of the interlocking mental health, social service, and legal systems. Those frameworks, presumptions, and structures essentially erase the possibility of keeping the family together, affirmatively undermine family integrity, and create barriers, burdens, and obstacles to people with psychiatric disabilities remaining with their families. . . . Asking for reasonable accommodations, which requires the agency and court to believe that the barriers to successful parenting can be alleviated by rearranging certain aspects of service delivery, flies in the face of the underlying assumption that the disability itself fundamentally precludes parenting at all.<sup>24</sup>

Stefan's extensive documentation of the obstacles these women face demonstrates what rehabilitation psychologist Beatrice Wright said nearly fifty years ago: that an impairment of one capacity is perceived by others to spread to an impairment in all areas.<sup>25</sup> Stefan's words constitute a powerful indictment of how committed our courts and social service agencies are to creating conditions in which women with disabilities can care for their children.

[F]amily integration . . . is a fundamental component of community integration. . . . [P]ursuing community integration without maintaining family integrity is, in some ways, a meaningless concept that perpetuates discriminatory images of people with psychiatric disabilities as disconnected

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23. *Id.*

24. *Id.* at 138–40.

25. BEATRICE A. WRIGHT, *PHYSICAL DISABILITY: A PSYCHOLOGICAL APPROACH* (1960).



from intimate relationships and incapable of successful parenting, who can never be seen as truly a part of the community.<sup>26</sup>

Stefan's analysis calls to mind psychological and sociological research on how low teacher expectations of minority students correlated with their decreased academic success. Surely she demonstrates that current institutional arrangements work against a woman with psychiatric disabilities ever managing to be a successful mother. The existing arrangements both grow out of a prevailing negative view about the parenting capacities of these women and then perpetuate the view by failing to consider their parenting needs.

In faulting physical, legal, and social barriers to reproduction and parenting faced by women with very different types of impairments, the articles by Pendo and Stefan rest on but do not explicitly address two theoretical questions for disability law, disability studies, and bioethics on which I will make all-too-brief comment here: are there capacities necessary for successful parenting in modern society that could be affected by a parent's disability?; and, is the legal framework available under statutes like the ADA the best one for achieving the goals of integration into community and family life espoused by the movement for disability rights and equality?

Turning first to the topic of parenting, we should acknowledge that there is probably no truly settled philosophy or law on the essential personal qualities or actions of acceptable parents. What children need at different stages in their lives and what their biological, psychological, and social relationship should be to their caretakers are still controversial questions.<sup>27</sup> Despite Pendo's observations about the skeptical attitudes toward parenting by women with mobility disabilities, Stefan points to scholarship, law, and policy that accepts the childrearing potential of people with a range of physical disabilities.<sup>28</sup> She seeks to extend the same social and legal recognition to those with psychiatric impairments.<sup>29</sup> Her views might gain their deserved endorsement and implementation were we to achieve consensus about the duties and skills we expect of parents, as differentiated from the demands of childrearing now carried out by a host of individuals

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26. Stefan, *supra* note 21, at 140, 141.

27. For a useful discussion of the duties of parents, see JEFFREY BLUSTEIN, *A Moral Theory of Parenthood*, in PARENTS AND CHILDREN: THE ETHICS OF THE FAMILY 101, 101-36 (1982).

28. In addition to the references cited in Stefan's article, see a forward-looking and humane California Supreme Court decision, *In re Marriage of Carney*, 598 P.2d 36, 44 (Cal. 1979) (holding that "a physical handicap that affects a parent's ability to participate with his children in purely physical activities is not a changed circumstance of sufficient relevance and materiality to render it either 'essential or expedient' for their welfare that they be taken from his custody.").

29. Stefan, *supra* note 21, at section V B.

and institutions in the modern “village”<sup>30</sup> of childcare. Perhaps there are some essentials that only a child’s primary caretakers—as opposed to grandparents, step-parents, aunts and uncles, teachers, baby-sitters, coaches, or counselors—can provide, but Stefan’s work suggests that society demands that the parent with a psychiatric disability operate without the supports that parents without disability labels take for granted. In effect, more, not less, is demanded in order for someone with an impairment to overcome the prejudice against her carrying out her childrearing responsibilities.

Stefan’s proposals point to questions that disability scholars have raised about whether any one “model” (medical, social, or minority group) adequately addresses the situation of people with disabilities.<sup>31</sup> If, as Stefan suggests, genuine accommodation of the strengths and limitations of mothers with psychiatric disabilities requires that courts and social agencies modify expectations, practices, and services, perhaps the ADA’s framework of remedying discrimination will not suffice to induce policy-makers and bureaucracies to change.<sup>32</sup> Stefan’s work is an excellent illustration of the insights contained in Scotch and Schriener’s “human variation”<sup>33</sup> model of disability. Her argument, like theirs, is that not only physical structures and communication barriers, but social and institutional procedures and environments need to accommodate the full range of individuals who actually inhabit the world; otherwise, no society can be said to be truly inclusive of all its members. Stefan shows how a society that genuinely espoused a human variation approach could reform itself so that mothers with psychiatric disabilities could provide their children with what love, commitment, and skills they possessed, being assured that their children—like the children of parents without diagnosed impairments— would receive support from other individuals and institutions committed to the flourishing of families.

The last three articles in this collection focus on a question quite different from how society should deal with its members who have disabilities. They

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30. See HILLARY RODHAM CLINTON, *IT TAKES A VILLAGE AND OTHER LESSONS CHILDREN TEACH US* (1996).

31. For discussions of the value of using several approaches to disability policy, see JEROME E. BICKENBACH, *PHYSICAL DISABILITY AND SOCIAL POLICY* (1993); Richard K. Scotch & Kay Schriener, *Disability as Human Variation: Implications for Policy*, 549 *ANNALS AM. ACAD. POL. & SOC. SCI.* 148 (1997); TOM SHAKESPEARE, *DISABILITY RIGHTS AND WRONGS* (2006).

32. In my view, the ADA’s requirements for making government programs and places of public accommodation accessible to people with disabilities could be read broadly enough to require the changes Stefan proposes. My comments about the need to supplement the ADA’s civil rights framework with a “human variation” approach arises from my recognition that the public and many courts and commentators have construed the law more narrowly.

33. Scotch & Schriener, *supra* note 31, at 154-57.

consider the emotionally charged, sensitive, and uncomfortable question of whether and how reproductive decisions and policies should be influenced by the potential for disability. I use such words as “sensitive,” “emotionally charged,” and “uncomfortable” because the topic implicates the politically divisive issues of abortion and the moral status of embryos, and the historically freighted matter of eugenics.

Paul Lombardo sets the stage for the perspectives advanced by Janet Malek and Judith Daar when he demonstrates how ideas about eugenics and evolution have become part of twenty-first century culture wars.<sup>34</sup> Lombardo’s contribution builds on his monumental work aimed at showing how bigotry was aided by flawed science in the nineteenth and early twentieth-century United States.<sup>35</sup> American science during that time lent itself to the goal of eliminating social problems by predicting which people were likely to be unfit parents or to produce children with undesirable characteristics. In his article, Lombardo does more than point out that the science was wrong and aided hostility to people who were poor, whose native language was not English, or who were not Caucasian; he goes on to argue that some current opposition to past eugenics or to contemporary prenatal diagnosis and selective abortion is being espoused by people who are wary of such well-established science as evolution.<sup>36</sup> Some of those who think of themselves as anti-eugenics are also opposed to many other scientific and cultural developments of the past century, and he therefore cautions readers to reject any specific practice simply because it is labeled “eugenic.”<sup>37</sup>

Lombardo’s message nicely frames the articles by Judith Daar and Janet Malek. Their pieces advance a debate about the societal and familial implications of the class of reproductive and genetic technologies designed to avoid the births of children with disabling traits. With different emphases and argumentative strategies, they each contend that everyone benefits if people use embryo screening, prenatal testing, and selective abortion to reduce the numbers of people with impairments who are born. Daar examines the place of preimplantation genetic diagnosis not only in debates about the meaning of health and disability, but also in the context of assisted reproduction more generally. Malek responds to disability rights

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34. Paul A. Lombardo, *Disability, Eugenics, and the Culture Wars*, 2 ST. LOUIS U. J. HEALTH L. & POL’Y 57, 72-7 (2008).

35. See, e.g., PAUL A. LOMBARDO, *THREE GENERATIONS, NO IMBECILES: EUGENICS, THE SUPREME COURT AND BUCK v. BELL* (2008); Paul A. Lombardo, *Taking Eugenics Seriously: Three Generations of ??? are Enough?*, 30 FLA. ST. U. L. REV. 191 (2003); Paul A. Lombardo, *Facing Carrie Buck*, HASTINGS CTR. REP., Mar.-Apr. 2003, at 1.

36. Lombardo, *supra* note 34.

37. *Id.* at 58.

critiques of routine testing. My comments in this Foreword certainly cannot do justice to their contributions. Let me only highlight how each article contributes to the two topics with which I introduced the articles: the similarities and differences between the minority category of disability and other minority categories, and the differences in accepting people with disabilities in public versus family life.

When we say that someone has an “impairment” or “disability,” we indicate that there is a negative departure from a norm expected of human beings.<sup>38</sup> A woman with cystic fibrosis has more frequent health problems and may die sooner than her sister who does not have the condition; a man with fragile X syndrome may not develop the intellectual skills for driving a car or for pursuing many jobs. Even in a future society wholly committed to inclusion and equal opportunity for people with disabilities, these people might be prevented simply by the characteristics of cystic fibrosis or fragile X syndrome from undertaking certain activities or playing certain social or occupational roles. And because, even in an imaginable non-discriminatory and inclusive society someone with muscular dystrophy may experience limitations in the range of life choices that someone who is African-American will not, it seems sensible, prudent, and perhaps morally required to prevent bringing into the world people who are likely to experience these limitations. Supporters of embryonic and fetal testing can agree that many problems of people with disabilities stem from unjust social arrangements and simultaneously believe that it would be better not to bring people with disabilities into the world if their births can be avoided.<sup>39</sup>

Judith Daar reviews a range of ethical issues posed by those apprehensive about the social implications of using preimplantation genetic diagnosis. She discusses the “spectrum problem” (how serious or mild the disability to be prevented, or how early in life it manifests itself), the responsibility for health conundrum (does the individual or her parent bear responsibility for her health after birth?), and the “expectation problem” (the possibility that parents, children, and society will expect that only “perfect” children will be born).<sup>40</sup> These ethical concerns notwithstanding, Daar maintains that “at the end of the day, . . . PGD will make sustainable and

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38. Christopher Boorse, *Concepts of Health*, in HEALTH CARE ETHICS: AN INTRODUCTION 359, 359-93 (Donald VanDeVeer & Tom Regan eds., 1987).

39. For only a few examples of this view, see the discussions in ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS AND JUSTICE (2000); Bonnie Steinbock, *Disability, Prenatal Testing, and Selective Abortion*, in PRENATAL TESTING AND DISABILITY RIGHTS 108 (Erik Parens & Adrienne Asch eds., 2000); Mary Ann Baily, *Why I Had Amniocentesis*, in PRENATAL TESTING AND DISABILITY RIGHTS 64 (Erik Parens & Adrienne Asch eds., 2000).

40. Judith F. Daar, *Embryonic Genetics*, 2 ST. LOUIS U. J. HEALTH L. & POL'Y 81, 92-117 (2005).

essential progress in advancing human health.”<sup>41</sup> In the concluding section of her article, she states that “[w]hile worries abound that PGD will promote recklessness toward health in children spared of familial diseases, and disdain for those who do manifest genetic anomalies, nothing in our past treatment of sickness and health suggests such a future.”<sup>42</sup> As one illustration of her contention that advances in human health can be attained without disrespecting people who do not avail themselves of all potential health-promoting technologies, she says that there is no discrimination against parents who refuse to vaccinate their children, or against the unvaccinated children.<sup>43</sup> Daar is not alone in her belief that it is possible to use PGD and other selection technologies while maintaining a commitment to promote societal inclusion of existing people with disabilities,<sup>44</sup> but Pendo’s and Stefan’s contributions suggest that the society is not as non-discriminatory as Daar believes it to be.

Janet Malek also endorses using these technologies and takes on some of the arguments that have been leveled against what she calls the “Strong Claim,” that “potential parents are morally required to use reproductive genetic technologies to reduce the likelihood that their future children will have a serious disability when the burdens of doing so are reasonable.”<sup>45</sup> Malek does not deal directly with the ways that existing social practices contribute to the difficulties faced by people with disabilities such as fragile X syndrome or cystic fibrosis; she simply asserts that they “diminish a future child’s ‘capacities for human flourishing’”.<sup>46</sup>

The strength of Malek’s article is in her discussion of other disability equality-based challenges to the routine use of reproductive genetic technologies for preventing disability in future children. Not surprisingly, as a longtime participant in this conversation, I’m not convinced that she fully represents or responds to these arguments.<sup>47</sup> One can have reservations about these technologies and accept many of her points about the ambiguity of claiming that any “message” about existing people with

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41. *Id.* at 87.

42. *Id.* at 117.

43. *Id.* at 115.

44. I have made a version of a compatibility argument in Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315 (2003) [hereinafter Asch, *Disability Equality*].

45. Janet Malek, *Disability and the Duties of Potential Parents*, 2 ST. LOUIS U. J. HEALTH L. & POL’Y 119 (2008).

46. *Id.* at 122.

47. In addition to my article *supra* note 44, see Adrienne Asch, *Why I Haven’t Changed My Mind About Prenatal Diagnosis: Reflections and Refinements*, in PRENATAL TESTING AND DISABILITY RIGHTS 234 (Erik Parens & Adrienne Asch eds., 2000) [hereinafter Asch, *Why I Haven’t Changed My Mind*].

disabilities is sent by users of these technologies.<sup>48</sup> One can also agree that we do not yet have sufficient empirical evidence to claim that there is, or is not, a “loss of support” for people with disabilities based on expanded interest in these technologies. As has already been said in this very Symposium, one should question how strong the support is for people with disabilities in today’s society despite the existence of civil rights protections.

Malek discusses of the merits and drawbacks of the “parental attitudes” argument, that these technologies foster parental reluctance to welcome and appreciate a child notwithstanding a trait that leads to foreseeable challenges, and her article advances this relatively under-developed strand of critiques of reproductive genetic technologies.<sup>49</sup> It harkens back to my comments earlier about a needed theory of parenting. What qualities should parents have to carry out their responsibilities? What are their responsibilities? Does moral parenting begin before a child’s birth, even if legal parenting does not? Should prospective parents be required, rather than permitted or encouraged, to decide which diagnosable characteristics in unimplanted embryos or gestating fetuses preclude their bearers from joining a family? What will be the consequences for privacy and intimacy if society, rather than prospective parents, decides which traits are unacceptable or too problematic for the community and the family?

And with these last questions, we see how this Symposium should provoke serious reflections about the minority category of disability, the differences between disability and other minority categories, and the difficulty and dangers of extending laws appropriate to public life to the intimacy of family life. I would like to conclude this commentary by reiterating a point that I and others have made in previous writing: family intimacy and privacy will be best preserved when the larger society welcomes and supports all its members, defining institutions and environments that comfortably incorporate the enormous variation in human beings. Archaic, quaint, socialistic, and anachronistic as it may appear, I continue to believe that the founding documents and the laws of this nation lead us to envision a world in which society will support the parenting capacities of women and men and the potential for growth, development, and contribution of children. Disease, disorder, impairment, and disability will be understood to be some among many of a person’s characteristics, and people will be integrated into society, our communities, and families, as unique wholes, not as sets of characteristics. When people know that the

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48. See Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 3 (Erik Parens & Adrienne Asch eds., 2000); Asch, *Why I Haven’t Changed My Mind*, *supra* note 47; and Asch, *Disability Equality*, *supra* note 44.

49. Asch & Wasserman, *supra* note 13.

world is welcoming, individuals with and without disabilities will be free to take on parenting or to decide that role is not one they want to play. Similarly, parents with and without disabilities will be able to decide whether their potential for rewarding family life will be unduly compromised by a diagnosable characteristic in an embryo or fetus that could become their potential child. Law probably should not make such intimate decisions, but it can shape the social world in which intimate decisions are made.