The New Parenthood and the Old Ambivalence about Disability: Baby Doe, Prenatal Testing, and Disability Rights

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Introduction

In the past half-century, medical advances in prenatal and neonatal care have recast the moral landscape at the edge of life, death, and disability. Genetic screening technologies make it possible to discern characteristics of the unborn and abort on the basis of prenatal disability. Improvements in neonatal care allow doctors to save newborns previously beyond hope, many of whom possess disabilities that can be treated but cannot be cured. These advances have thrust a pair of intractable questions upon parents, prospective parents, and the law.[1] When is it acceptable to have an abortion on the basis of prenatal disability? When is it acceptable to refuse lifesaving treatment on the basis of neonatal disability? More broadly, when may new parents and prospective parents choose death rather than nascent life with a disability?[2]

These questions strike at the ideals and principles at the core of the disability rights movement. Yet disability advocates have struggled to formulate a consistent response. In the neonatal context, advocates have cast disability as a neutral biological fact. They have argued that non-treatment on the basis of disability constitutes invidious discrimination and that disability should not be a permissible consideration in such decisions. In the prenatal context, the same advocates have cast disability as an undesirable biological impairment. They have expressed moral outrage about abortion on the basis of disability, but they have not argued that disability should be an impermissible consideration in decisions for abortion. Instead, disability advocates contend that the law should seek to ensure that these decisions rest on accurate portrayals of disability.

There are a variety of grounds on which to explain these disparate responses. The most common one is perhaps the most obvious: the two contexts rest on opposite sides of the biological event of birth. An exhaustive explanation, however, must go deeper. Disability advocates have traditionally divided conceptions of disability between a pair of seemingly irreconcilable models.[3] The medical model casts disability as an undesirable biological impairment synonymous with illness. According to this view, disability is an intrinsically undesirable deviation from normal human functioning. The social model, by contrast, casts disability as a social construction comparable to race. Under this view, cultural and institutional practices transform intrinsically neutral differences among individuals into disabilities.

As many scholars have noted, the two models present woefully inadequate descriptions of the world. The social model is right to describe disability as a product of social ordering, yet it ignores that impairments may be inherently undesirable apart from their social meaning. The medical model recognizes this possibility in focusing on

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[1] As will become clear, these questions are not new. However, the acceleration of medical innovation has put them in particularly stark relief.

[2] In this Essay, "selective non-treatment" refers to decisions concerning neonates and "selective abortion" refers to decisions concerning fetuses. Elsewhere in the literature, selective non-treatment may refer to decisions against treatment for adults as well as neonates. I will make clear when I mean to refer to the broad phenomenon rather than this narrow one. Selective abortion is different from elective abortion in that abortion is chosen on the basis of fetal disability.

[3] The disability community is not a monolithic entity, nor do disability advocates reflect the constituencies of that community with perfect proportionality. Descriptions that convey a single viewpoint of the community and disability advocates convey the majority viewpoints conveyed by national advocacy groups and academics that identify as disability advocates.

biological impairment, yet it ignores the disabling effects of prejudice and stigma. Given the symmetry between the strengths and shortcomings of the two models, some disability advocates have advocated for a vision of disability that combines portions of each approach. A number of scholars weighing legal questions have adopted such a view. Still, disability advocates continue to organize discourses in disability around this tired dichotomy.

The disability community's disparate responses to selective non-treatment and selective abortion suggest an alternate conception of disability. It is not merely that both the social and medical models of disability contain elements that might be put to good use in a more unified model of disability. Rather, the polar conceptions of disability reflected in these approaches mirror sentiments simultaneously present within the disability community, individual disability advocates, and society more broadly. We greet disability with profound ambivalence.[4] It is at once an undesirable affliction and a neutral form of human variation. Disability is a source of pride and shame, empowerment and disempowerment, personal identity, and personal destruction. It heightens our desires to both uplift those in need and to devalue them and their neediness.[5]

These sentiments are not easily reconciled. Yet responses that deny ambivalence impart moral certainty and abstraction where ambiguity and uncertainty reign. Defenders of selective non-treatment and selective abortion describe a world less burdened by disabling conditions. Opponents describe a world less burdened by negative valuations of human difference. We can only wish that things could be so clear. It is, moreover, a destructive wish. In denying our ambivalence about disability, we cloak our doubts in aspirations that ignore the difficulty of the decisions before us. We seek to impose a tidy moral principle that cannot bring order to an impossibly untidy situation. The result is hurtful behavior that does not respond to individual circumstances.

The path to addressing this dynamic begins at its acknowledgment. Lawmakers should not seek to impose moral clarity on parental decisions about disability at the edge of life. Rather than deny our conflicting views about disability, the law should allow their expression in structurally ambivalent regimes. Lawmakers should not merely avoid provoking destructive denials of ambivalence about disability, however. They should actively encourage constructive expressions of ambivalence and thereby discourage our persistent tendency to impose abstraction on disability. More broadly, the law should steer clear of both overt devaluations of disability and aggressive representations of

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[4] This line of analysis draws its inspiration from ROBERT A. BURT, DEATH IS THAT MAN TAKING NAMES: INTERSECTIONS OF AMERICAN MEDICINE, LAW, AND CULTURE (2002). Burt describes social responses to death as a product of social ambivalence about death. He then assesses how the law should address that ambivalence. This Essay finds that social responses to disability are also characterized by ambivalence, albeit a different kind of ambivalence. It then assesses how the law should address that ambivalence.

[5] This Essay labors to avoid formulations that cast people with disabilities as the "other" to be addressed from the perspective of "normals." This pitfall has prompted criticism from the disability community. *See* JAMES I. CHARLTON, NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT (2000). Accordingly, this sentence might instead read as follows: "It heightens our desires to both uplift those in need and to devalue ourselves and our neediness." Throughout, usage of the terms "we" and "our" seek to capture social views of disability consistent across cultural and societal contexts. At points, this societal "we" may inevitably cast people with disabilities apart as the "other." In these instances, of course, such views may not capture the understanding of individuals with disabilities so set apart, though it may. The latter point is particularly relevant for the discussion *infra* at notes 222-259 and accompanying text.

disability as neutral difference.[6] Much though we may desire clarity and consistency, this prescription will often suggest ambiguity and disjunction.

This Essay proceeds as follows. The first two Parts develop a descriptive understanding of disability as inevitably characterized by ambivalence. Part I chronicles the conflicting approaches disability advocates have taken in response to selective non-treatment and selective abortion. Part II argues that these disparate responses reflect ambivalence about disability that pervades the disability community itself. The final two Parts develop a set of normative prescriptions for how the law should approach our persistent ambivalence about disability. Part III contends that legal regulation of selective non-treatment and selective abortion should encourage constructive expressions of ambivalence about disability. Part IV explores how this normative prescription should inform legal regimes in other areas of the law. I conclude with a discussion of what ambivalence about disability suggests for rights discourse and the disability rights movement.

I. The New Parenthood and Disability Rights

In a sense, selective non-treatment and selective abortion on the basis of disability present the same broad question: when is it acceptable for parents and prospective parents to choose death for their offspring rather than life with a disability? Yet this formulation ignores a vital biological process that separates the two issues: birth. Legally, birth confers personhood and its attendant protections. Socially, birth connotes a moment of empathy and human connection. Politically, birth marks the edge of contentious territory in the abortion wars. In part for these reasons, birth separates a pair of divergent policy prescriptions for disability advocates with respect to selective non-treatment and selective abortion. This Part argues, however, that to understand these policy prescriptions we must look beyond abortion politics.

A. The Baby Doe Controversy and Selective Non-treatment

Modern discourse around selective non-treatment invariably returns to the Baby Doe controversy. Born in 1982 with Down syndrome and a blocked esophagus, the child at issue in that controversy required immediate corrective surgery to save his life.[7] Although the surgery would have been both routine and low risk, the infant's treating physicians at Bloomington Hospital disagreed about the proper course of action. One group suggested immediate surgery. The other suggested that the infant receive no treatment and be allowed to die. After a short deliberation, the child's parents chose the

[6] The distinction between viewing disability as neutral human variation and viewing it as inherently undesirable is a loose one. Both views can suggest a wide array of potential policies, some of which may even overlap. The idea here is that we orient ourselves toward disability as if it were either a marker of diversity or a marker of tragedy. This orientation has implications beyond individual policy prescriptions in a particular context.

[7] For the most thorough history of the Bloomington Baby Doe case, see JEFF LYON, PLAYING GOD IN THE NURSERY 21-58 (1985).

latter course.[8] They reasoned that people with Down syndrome could not achieve a "minimally acceptable quality of life" and that therefore death would be best for the infant, their two other children, and the family as a whole.[9]

A strict reading of the law indicated possible criminal liability for parents, physicians, and hospitals involved in non-treatment.[10] The hospital accordingly sought a declaratory judgment in Indiana state court. The court convened in a hospital storage room hours after the child's birth.[11] In a sparse opinion, it held that the infant's parents had the right to choose a "medically recommended course of treatment" for their child.[12] The judge explained later that the state's role as *parens patriae* became complicated in cases like *Doe*, as "it could not be said that the parents were not acting in the best interests of the child."[13] The Indiana Supreme Court refused to issue a writ of mandamus upon an appeal filed by the county's deputy U.S. Attorney.[14] The infant died while the Attorney flew to Washington D.C. to file an appeal with the Supreme Court.[15]

The case generated a national furor, fueled in large part by abortion politics. The right-to-life movement seized upon the controversy as an opportunity to broaden its appeal and challenge the internal logic of the pro-choice movement.[16] President Ronald Reagan took a personal interest in the case,[17] as did his surgeon general C. Everett Koop.[18] A few weeks after Baby Doe's death, Reagan directed the Department of Health and Human Services to address selective non-treatment as a civil rights issue under Section 504 of the Rehabilitation Act.[19] The Department issued a series of regulations requiring hospitals to post conspicuous notices that non-treatment on the basis of disability violated federal law. If this was inadequate warning, the regulations established

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[8] The discussions are recounted in *id.* at 22-29. The parents reportedly reached their decision in less than half an hour. *Id.* at 27-28.

[9] In re Infant Doe, No. GU8204-004A (Monroe County Cir. Ct., Apr. 12, 1982).

[10] John A. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 217-235 (1975).

[11] LYON, *supra* note 7 at 30.

[12] In re Infant Doe, No. GU8204-004A (Monroe County Cir. Ct., Apr. 12, 1982).

[13] *June 8, 1982, Letter of Judge John Baker to Anonymous Person*, 2 ISSUES L. & MED. 81, 82 (1986). The judge stressed that "[t]o say that parents are neglectful implies that the State or society knows what is best for the child." *Id.*

[14] State ex rel. Infant Doe v. Baker, No. 482, S 140 (May 27, 1982).

[15] *See* LYON, *supra* note 7 at 36-37. The writ was denied. Infant Doe v. Bloomington Hosp., 464 U.S. 961 (1983).

[16] *See* Constance Paige & Elisa B. Karnofsky, *The Antiabortion Movement and Baby Jane Doe*, 11 J. HEALTH POL'Y & L. 255, 258 (1986) ("Right-to-life advocates believed that a newborn infant would be a 'victim' the general public could identify with more readily than the fetus.").

[17] *See* Lawrence D. Brown, *Civil Rights and Regulatory Wrongs: The Reagan Administration and the Medical Treatment of Handicapped Infants*, 11 J. HEALTH POL'Y & L. 231, 233-34 (1986). Reagan cast infanticide as an important frontier in the abortion debate. *See* RONALD REAGAN, ABORTION AND THE CONSCIENCE OF THE NATION 33-34 (1984) ("Whether we are talking about pain suffered by unborn children, or about late-term abortion, or about infanticide, we inevitably focus on the humanity of the unborn child.").

[18] Koop voiced his opposition to the practice of infanticide in the mid-1970s. *See* C. Everett Koop, *The Slide to Auschwitz*, 3 HUMAN LIFE REV. 101 (1977) (comparing selective non-treatment to the Nazi T-4 program).

[19] *See* Brown, *supra* note 17, at 258.

a national hotline to enable anonymous tips to federal investigators of such misfeasance.[20]

Disability groups unambiguously aligned themselves with these efforts.[21] More than right-to-life advocates, the disability community highlighted the role of misinformation about disability in non-treatment decisions.[22] In its position statement on selective non-treatment, for example, the Association for Retarded Citizens argued that physicians, parents, and lawyers be educated about the present outlook for life with an intellectual disability.[23] However, disability advocates reached the same bottom line as right-to-life advocates. The ARC concluded that even in the presence of full information, physicians and parents should have no right to withhold medical treatment "where the only basis for such a decision is the diagnosis or prognosis of mental retardation."[24] Similarly, the Association for People with Severe Handicaps sought to reaffirm "the equal right to medical treatment for all infants in accordance with the dignity and worth of these individuals, as protected by the Constitution and Bill of Rights."[25]

In the spring of 1982, advocates representing both groups began a series of meetings to coordinate their efforts in litigation, legislation, and the media.[26] These efforts produced mixed results. Disability rights groups contributed as *amici curiae* in a series of cases concerning the legality of the Baby Doe regulations promulgated by the Department of Health and Human Services.[27] In defending the application of Section 504 to selective non-treatment, advocates analogized prejudice against people with disabilities to prejudice against racial minorities and women. They argued that Section 504's protections began at birth, and that therefore non-treatable disabilities should not be an appropriate consideration in treatment decisions at the edge of life.[28] However, the courts

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[20] For a summary of the rise and fall of the Baby Doe regulations, see Leading Cases, *"Baby Doe" Regulations*, 100 HARV. L. REV. 285 (1986).

[21] *See* Douglas P. Biklen & Philip M. Ferguson, *In the Matter of Baby Jane Doe: Does Reagan Really Agree with Us?* 15 SOC. POL'Y 5, 5 (1984) ("Many of us in the disability rights movement were stung by the response of some of our progressive friends to our position. The fact that President Reagan, surgeon general C. Everett Koop, and the conservative right-to-life groups advocated treatment for Baby Jane Doe seemed somehow to contaminate that position in the eyes of the people who are normally our allies in pushing for social change.").

[22] *See* Harlan Hahn, *Public Policy and Disabled Infants: A Sociopolitical Perspective*, 3 ISSUES L. & MED. 3, 23 (1987) ("Disabled citizens are subjugated and oppressed by an environment founded on attitudes of sympathy and paternalism that reflects an erroneous view of disability as personal misfortune."); H. Rutherford Turnbull III, *Incidence of Infanticide in America: Public and Professional Attitudes*, 1 ISSUES L. & MED. 363, 375-79 (1986) (detailing negative views of disability among physicians). For many advocates, the media's treatment of the Baby Doe case presented further testament of prejudice and stigma. *See, e.g.*, Douglas Biklen, *Framed: Journalism's Treatment of Disability*, 16 SOC. POL'Y 45 (1986).

[23] *Treatment of Infants Born with Handicapping Conditions: Hearing on H.R. 6492 Before the H. Comm. on Education and Labor*, 97th Cong. 53 (1982) (statement of The Association for Retarded Citizens).

[24] *Id.* at 51-52.

[25] Biklen & Ferguson, *supra* note 21 at 8 (quoting the position statement of the Association for People with Severe Handicaps).

[26] Paige & Karnofsky, *supra* note 16 at 260-61.

[27] *See, e.g.*, Brief for American Coalition of Citizens with Disabilities. et al as Amici Curiae Supporting Respondents, Heckler v. American Hospital Association, 476 U.S. 610 (1986) (No. 84-1529); Brief for the Association for Retarded Citizens of the United States et al as Amici Curiae Supporting Respondents, Heckler v. American Hospital Association, 476 U.S. 610 (1986) (No. 84-1529).

[28] *See* Brief for Association for Disability Rights Education & Defense Fund, Inc. et al as Amici Curiae Supporting Respondents at 34-51, Heckler v. American Hospital Association, 476 U.S. 610 (1986) (No. 84-

struck down the regulations first for inadequate procedure[29] and later for improper construction of Congressional intent.[30]

The disability community and its allies in the right-to-life movement achieved greater success before Congress. National medical organizations mobilized against the Baby Doe regulations and any application of Section 504 to treatment decisions at the edge of life.[31] They responded more favorably to the possibility of governing these decisions under federal child abuse law. In 1984, representatives for the disability community and the medical community agreed to a set of common "Principles of Treatment of Disabled Infants." The Principles stipulated that discrimination on the basis of disability, regardless of severity, "is morally and legally indefensible" from birth.[32] For additional clarity, the Principles added that an "individual's medical condition should be the sole focus of the decision. These are very strict standards."[33]

The resulting legislation reflected a comparable view.[34] The Child Abuse Amendments required that all infants receive medically indicated treatment subject to three exceptions: (1) if the infant is "chronically and irreversibly comatose," (2) if treatment would "(i) merely prolong dying," (ii) "not be effective in ameliorating or correcting all of the infant's life-threatening conditions," or (iii) "otherwise be futile in terms of the survival of the infant," or (3) "provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane."[35] Since the mid-1980s, the issue of selective non-treatment has faded from the public consciousness.[36] Ostensibly, quality of life considerations remain inadmissible in such decisions.

B. Prenatal Genetic Testing and Selective Termination

No singular event or controversy has dominated social discourse around selective abortion. The advent of amniocentesis and chorionic villus sampling in the 1950s and 1960s prompted a steady growth in prenatal testing and selective termination.[37] Although these procedures carry a risk of miscarriage and fetal injury, they have been common

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1529) (emphasizing the parallels between Section 504 and Title VII as well as the similarities between race, gender, and disability discrimination)

[29] American Academy of Pediatrics v. Heckler, 561 F. Supp. 395 (D. D.C 1983).

[30] Bowen v. American Hospital Association, 476 U.S. 610 (1986).

[31] For a summary of the medical profession's legal challenges, see Phoebe A. Haddon, *Baby Doe Cases: Compromise and Moral Dilemma*, 34 EMORY L. J. 545, 572-79 (1985).

[32] Principles of Treatment of Disabled Infants, 49 Fed. Reg. 1651, 1651 (Dep't of Health and Human Services, Jan. 12, 1984).

[33] *Id.* at 1652.

[34] For a summary of the legislative outcome, see James Bopp, Jr. & Thomas J. Balch, *The Child Abuse Amendments of 1984 and Their Implementing Regulations: A Summary*, 1 ISSUES L. & MED. 91 (1985).

[35] Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 121, 98 Stat. 1749, 1752 (1984) (codified at 42 U.S.C. 5106g (2006)).

[36] For one of the few attempts to re-raise the issue, see Loretta M. Kopelman, *Are the 21-Year-Old Baby Doe Rules Misunderstood or Mistaken?* 115 PEDIATRICS 797 (2005).

[37] *See* Cynthia M. Powell, *The Current State of Prenatal Testing in the United States*, *in* PRENATAL TESTING AND DISABILITY RIGHTS 44, 44-46.

since the 1970s.[38] In 1983, the American College of Obstetricians and Gynecologists issued guidelines recommending that all pregnant women thirty-five and older be offered amniocentesis to test for Down syndrome.[39] In 2007, the organization extended that recommendation to all pregnant women.[40] Both public demand and tort liability have propelled the development of safer, cheaper, and less-invasive tests available early in pregnancy.[41] Studies place the abortion rate for prenatally diagnosed Down syndrome between 80 and 90 percent.[42]

Although a few disability advocates have expressed concerns about selective termination, most national groups have responded with a curious silence.[43] A 1980 taskforce of the Association for Retarded Citizens could not reach a consensus about the issue; the taskforce reported that it was "divided on the basic issue of whether it should be legal to abort a damaged fetus, although among members of the Task Force, as among the public, the majority finds in the affirmative."[44] However, the group expressed concerns that the practice might "impute a 'less valued' status to newborn infants or other living persons with these handicaps."[45] Neither the Arc nor the American Association on Intellectual and Developmental Disabilities,[46] organizations that played a prominent role in the Baby Doe controversy, have issued position statements on prenatal testing and selective abortion.[47]

Some disability advocates have expressed "raw fear of attitudes that would destroy our kind, whether by genocide, selective abortion, euthanasia, assisted suicide or rationing of care."[48] Yet the prevailing approach can best be captured by the "disability

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[38] *See* Sonia M. Suter, *The Routinization of Prenatal Testing*, 28 AM. J. L. & MED. 233, 236 (2002) ("In light of changing social attitudes toward women and reproduction, prenatal testing boomed in the late 1970s and early 1980s.").

[39] *See* Powell, *supra* note 37, at 45.

[40] *ACOG Practice Bulletin No. 88: Invasive Prenatal Testing for Aneuploidy*, 110 OBSTETRICS & GYNECOLOGY 1459 (2007).

[41] *See* Carolyn Jacobs Chachkin, *What Potent Blood: Non-Invasive Prenatal Genetic Diagnosis and the Transformation of Modern Prenatal Care*, 33 AM. J. L. & MED. 9, 9 (2007) ("Someday soon, virtually any pregnant woman will be able to learn—with 98-99% accuracy—whether her fetus has contracted a serious genetic disorder by undergoing nothing more than an inexpensive, non-invasive blood test.").

[42] *See, e.g.* Ralph L. Kramer et al, *Determinants of Parental Decisions after the Prenatal Diagnosis of Down syndrome*, 79 AM. J. MED. GENETICS 172, 172-73 (1998) (finding an elective termination rate of 86.9%). Some scholars have argued that these studies inadequately account for reporting problems and geographic variation, and have placed the abortion rate as low as 50 or 60 percent. For a summary of these views, see Darrin P. Dixon, *Informed Consent or Institutionalized Eugenics? How the Medical Profession Encourages Abortion of Fetuses with Down Syndrome*, 24 ISSUES L. & MED. 3, 5-7 (2008)

[43] *See* Lisa Blumberg, *Eugenics and Reproductive Choice*, *in* THE RAGGED EDGE: THE DISABILITY EXPERIENCE FROM THE PAGES OF THE FIRST FIFTEEN YEARS OF THE DISABILITY RAG 218, 222 (Barrett Shaw ed., 1994) ("People with disabilities are increasingly aware of and alarmed by the anti-disability bias that underlies much prenatal testing and selective abortion. However, the disability rights movement as a whole has yet to comprehensively address the issue.").

[44] Paige & Karnofsky, *supra* note 16, at 257 n. 12.

[45] *Id.*

[46] The Association for Retarded Citizens and the American Association on Mental Deficiency were renamed as such.

[47] The Arc and the American Association on Intellectual and Developmental Disabilities, *Position Statement*, *available at* http://www.thearc.org/NetCommunity/Document.Doc?id=1383.

[48] Barrett Shaw, *Introduction*, *in* THE RAGGED EDGE: THE DISABILITY EXPERIENCE FROM THE PAGES OF THE FIRST FIFTEEN YEARS OF THE DISABILITY RAG ix (Barrett Shaw ed., 1994).

rights critique" of selective abortion associated with Adrienne Asch. Asch argues that choices for selective abortion are driven by popular assumptions that people with disabilities destroy marriages and "lead lives of relentless agony."[49] She adds an "expressivist objection" that abortion on the basis of disability conveys "negative or discriminatory attitudes not merely about a disabling trait, but about those who carry it."[50] Ultimately, however, Asch does not argue that disability should be an impermissible consideration in decisions for abortion. She contends instead that the law should ensure that "our decisions [are] thoughtful and informed, not thoughtless and automatic."[51]

In arriving at this conclusion, Asch and other disability advocates have acknowledged that "the experience of disability does not neatly reflect the experiences of [race and gender groups] for whom negative judgments about their personal characteristic have been exposed as resulting solely from oppression."[52] As Asch writes, "the inability to move without mechanical aid, to see, to hear, or to learn is not inherently neutral. Disability itself limits some options."[53] From this viewpoint, the danger in selective abortion lies in the prejudice it reflects and perpetuates.[54] Accordingly, disability advocates have attacked the unexamined assumptions underlying prenatal testing.[55] They have questioned the low expectations physicians continue to communicate alongside prenatal diagnoses.[56] And they have condemned what they perceive to be a pervasive presumption in favor of abortion.[57]

A few national disability groups have echoed this approach. The National Down Syndrome Society has argued that all expectant parents should be "informed as to the purpose of the various screening and diagnostic prenatal tests" and "given information on

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[49] Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, *in* PRENATAL TESTING AND DISABILITY RIGHTS 3, 20.

[50] *Id.* at 13. For an additional overview of this objection, see generally Deborah Kaplan, *Prenatal Screening and Its Impact on Persons with Disabilities*, 36 CLINICAL OBSTETRICS & GYNECOLOGY 605 (1993).

[51] Parens & Asch, supra note 49 at 28-29.

[52] Marsha Saxton, *Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion*, *in* PRENATAL TESTING AND DISABILITY RIGHTS 147, 150.

[53] Adrienne Asch, *Reproductive Technology and Disability*, in REPRODUCTIVE LAWS FOR THE 1990S 69, 73 (Sherrill Cohen & Nadine Taug eds., 1989).

[54] For a discussion of the dynamic quality of this phenomenon, see generally Abby Lippman, *Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*, 17 Am. J. L. & Med. 15 (1991).

[55] *See, e.g.*, Patricia E. Bauer, *What's Lost in Prenatal Testing*, WASH. POST, Jan. 14, 2007, at B7 (noting that news coverage of prenatal testing has failed to address "a general assumption that reasonable people would want to screen for Down syndrome" and arguing that the answer lies in a "fundamental societal misperception that the lives of people with intellectual disabilities have no value—that less able somehow equates to less worthy").

[56] *See e.g.*, Brian Skotko, *Prenatally Diagnosed Down Syndrome: Mothers Who Continued Their Pregnancies Evaluate Their Health Care Providers*, 192 AM. J. OBSTETRICS & GYNECOLOGY 670 (arguing that medical providers give inaccurate and incomplete descriptions of Down syndrome).

[57] *See, e.g.* George F. Will, *Good Golly, What Did Jon Do?* NEWSWEEK, Jan. 29, 2007, at X (describing prenatal testing as a "search-and-destroy mission" and arguing that "[n]othing—*nothing*—in the professional qualifications of obstetricians and gynecologists gives them standing to adopt policies that predictably will have, and seem intended to have, the effect of increasing abortions in the service of an especially repulsive manifestation of today's entitlement mentality—every parent's 'right' to a perfect baby.")

the risks, limitations and expense" of each test.[58] The NDSS has urged collaboration between the disability community and medical professionals to ensure that this occurs.[59] Similarly, the National Down Syndrome Congress has voiced goals to "[i]mprove the regulation of informed consent and disclosure of information regarding prenatal testing," "enhance training about Down syndrome" for medical professionals, and educate expectant parents who receive a positive test.[60] The Trisomy 18 Foundation has been more frank; it counsels that after a prenatal diagnosis "there is no magic choice that will make this experience easier."[61]

To ensure that decisions for abortion are appropriately informed, these three organizations turned to Congress. Their efforts yielded the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2008,[62] which advances a series of measures to improve the quality of information accompanying diagnoses.[63] The Act authorizes federal funding to "collect, synthesize, and disseminate current evidence-based information relating to Down syndrome or other prenatally or postnatally diagnosed conditions," as well as to coordinate support services for parents and prospective parents receiving such a diagnosis.[64] Support services include education programs for health care providers, a telephone hotline, and an expanded National Dissemination Center for Children with Disabilities;[65] these services will be funded by up to $5 million a year for five years.[66] Introduced by ideological foes Ted Kennedy and Sam Brownback, the bill brought right-to-life advocates and disability advocates into another momentary alliance.[67]

While public dialogue around selective non-treatment reached a national furor, dialogue around selective abortion has remained remote from the national consciousness.[68] Few members of Congress took note of the bill, which passed unanimously in the Senate and by a voice vote in the House.[69] Like the text of the statute, Congressional discussion revolved around the need for information and ignored the

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[58] National Down Syndrome Society, *Position Papers—Prenatal Testing*, *available at* http://www.ndss.org/ (under affiliates, public relations, position statements, prenatal testing).

[59] National Down Syndrome Society, *Position Papers—American College of Obstetricians and Gynecologists*, *available at* http://www.ndss.org/ (under affiliates, public relations, position statements, American College of Obstetricians and Gynecologists).

[60] National Down Syndrome Congress, *Prenatal Screening and Diagnosis* (Aug. 2007), *available at* http://www.ndsccenter.org/resourcs/position1.php.

[61] Trisomy 18 Foundation, Making Decisions After a Prenatal Diagnosis, http://trisomy18.org/site/PageServer?pagename=whatis_decisions (last visited June 2, 2009).

[62] Press Release, *The Down Syndrome Community Celebrates an Important Victory* (Sept. 26, 2008), *available at* http://www.ndsccenter.org/gov/archives/092608.php.

[63] Pub. L. No. 110-374, 122 Stat 4051 (codified as amended at 42 U.S.C. § 280g-8 (2008))

[64] *Id.*

[65] *Id*.

[66] For a discussion of the estimated budgetary impact of the bill, see Congressional Budget Office, Congressional Budget Office Cost Estimate: S. 1810 Prenatally and Postnatally Diagnosed Conditions Awareness Act 2 (Apr. 11, 2008), *available at* http://www.govtrack.us/data/us/110/bills.cbo/s1810.pdf.

[67] *See* Lynn Harris, *More "Common Ground" on Abortion?*, Salon, Mar. 12, 2007, http://www.salon.com/mwt/broadsheet/2 008/03/12/kennedy_brownback/.

[68] Most coverage has simply sought to expose the issue. *See, e.g.*, Gautam Naik, *The Toughest Test*, WALL ST. J., Oct. 25, 2008, at A1. Although the ACOG recommendations, blood test advances, and Palin's candidacy have increased public discussion, it has not approached the pitch of the Baby Doe controversy.

[69] *See* Patricia E. Bauer, *Congress OKs Kennedy-Brownback Disability Diagnosis Bill*, Disability News, Sept. 25, 2008, http://www.patriciaebauer.com/2008/09/25/kennedy-brownback-3/.

ethical issue of what prospective parents should be expected to do with such information.[70] Although disability advocates acknowledged strong parallels between selective non-treatment and selective abortion during the Baby Doe controversy,[71] these comparisons were wholly absent in discussions of the Kennedy-Brownback Bill. By focusing on informed consent, advocates successfully sidestepped questions about when it is acceptable to choose non-existence over life with a disability.

C. Reconciling Responses from the Disability Rights Movement

The disability community's divergent approaches to selective non-treatment and selective abortion appear reconcilable in light of the divergent contexts of which they are a part. Although ethicists like Peter Singer have criticized distinctions between newborns and fetuses,[72] the birth process retains powerful significance as a social, political, and doctrinal marker. So much so that Samuel R. Bagenstos has defended the consistency of the disability community's approaches to selective abortion and selective non-treatment while discerning contradiction in their positions on selective abortion and assisted suicide.[73] He argues that the disability community's simultaneous assent to selective termination and opposition to assisted suicide rests on inconsistent views of individual autonomy.[74] With respect to selective non-treatment and selective abortion, Bagenstos writes that "[i]nfants, unlike fetuses, are clearly 'persons,'" and leaves the issue at that.[75]

Doctrinally, this distinction is an important one. Although the law recognizes a state interest in protecting fetuses,[76] the Supreme Court has held that the Constitution does not grant the full rights of personhood until birth.[77] Under comparable analysis, it would be a stretch to apply existing anti-discrimination laws to invidious distinctions among fetuses.[78] This does not render legal protections for fetuses impossible, however. The legislative response to Baby Doe did not rest on traditional anti-discrimination law; the Child Abuse Amendments took a more circuitous route. Under current abortion jurisprudence, procedural barriers and informational requirements would likely withstand judicial scrutiny in light of the restrictions upheld in *Casey*.[79] A more expansive non-

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[70] *See* 154 Cong. Rec. S1267 (daily ed. Feb. 27, 2008); 154 Cong. Rec. S9341-43 (daily ed. Sept. 23, 2008); 154 Cong. Rec. H9918-20 (daily ed. Sept. 25, 2008).
[71] *See* Paige & Karnofsky, *supra* note 16, at 259-60.
[72] HELGA KUHSE & PETER SINGER, SHOULD THE BABY LIVE: THE PROBLEM OF HANDICAPPED INFANTS 194-97 (1985) (proposing a 28-day period after birth when treatment could be legally withheld from infants).
[73] Samuel R. Bagenstos, *Disability, Life, Death, and Choice*, 29 HARV. J. L. & GENDER 425 (2006)
[74] *See id.* at 461 ("There is no basis in the principles of the disability rights critique to take a laissez-faire position for one of those decisions and a prohibitory position for the other.").
[75] *Id.*
[76] Under *Roe*, this period began at the start of the third trimester. Roe v. Wade, 410 U.S. 113, 163-64 (1973). In abandoning the trimester framework, the Court in *Casey* recognized a state interest in potential life throughout pregnancy to be balanced with the pregnant woman's interest. Planned Parenthood of Southeastern Pennsylvania v. Casey, 505 U.S. 833, 869-79 (1992).
[77] Roe v. Wade, 410 U.S. 113, 156-59 (1973).
[78] This has not stopped some scholars from advancing these arguments. *See* Martha A. Field, *Killing "The Handicapped"—Before and After Birth*, 16 HARV. WOMEN'S L.J. 79, 102-04 (1993).
[79] *See* Bagenstos, *supra* note 73, at 458-59.

discrimination requirement would raise unaddressed questions about the content of the woman's right and would not necessarily be struck down.[80]

Although abortion restrictions may be doctrinally feasible, the disability rights movement has traditionally aligned itself with the political left,[81] including on the issue of abortion.[82] For many disability advocates, abortion rights represent an independently important cause.[83] From this perspective, efforts to restrict abortion rights therefore could present more costs in jeopardized political alliances and the erosion of abortion rights than they would garner in benefits for disability rights.[84] However, this type of calculus did not prevent the disability community from cautiously "hop[ping] into bed with the Right-to-Lifers" during the Baby Doe controversy.[85] Admittedly, that controversy concerned infants rather than fetuses; however, anti-abortion activists hoped to blur the lines between the two categories and roll back abortion rights.

It is difficult to compare these threats. Anti-abortion activists in the Baby Doe controversy sought to extend into the fetal context a social consensus that newborns are entitled to legal protection.[86] In defending that social consensus, disability advocates did not proactively seek abortion restrictions. Yet the political heat generated by the controversy provides a testament to its perceived importance on both sides of the abortion wars,[87] a point openly recognized by disability advocates.[88] Restrictions on selective abortion or prenatal testing, moreover, could come in a variety of forms, some of which would present less of an obvious affront to abortion rights more broadly.[89] Informational or procedural requirements, for example, might provide an unfortunate precedent for

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[80] *See, e.g.*, Gonzales v. Carhart, 550 U.S. 124 (2007) (upholding the federal Partial-Birth Abortion Act). *But see* Reva B. Siegel, *Dignity and the Politics of Protection: Abortion Restrictions under* Casey/Carhart, 117 YALE L.J. 1694 (arguing that the Court's focus on the woman's dignity interests does not presage the assault on abortion rights feared by many pro-choice activists).

[81] *See* RICHARD K. SCOTCH, FROM GOOD WILL TO CIVIL RIGHTS: TRANSFORMING FEDERAL DISABILITY POLICY 41-59 (1984) (describing the relation between the disability rights movement and the civil rights movement).

[82] *See* Paige & Karnofsky, *supra* note 16, at 259 ("the right-to-life movement had historically been at loggerheads with disability rights groups because the latter were mostly pro-choice"). However, that position has long been an uneasy one. *See* JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT 278 (1993) ("Legalized abortion is one of the most divisive issues for the disability rights movement, one that the movement has dealt with largely by keeping its distance.").

[83] *See* Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible*, 30 FLA. ST. U. L. REV. 315, 317 n.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.").

[84] For such a calculus, see generally Blumberg, *supra* note 43.

[85] Mary Johnson, *Killing Babies: Left and Right*, 6 THE DISABILITY RAG 22, 22 (1985).

[86] For an acknowledgment of this consensus, see Judith Jarvis Thomson, *A Defense of Abortion*, 1 PHIL. & PUB. AFF. 47, 47 ("I am inclined to agree, however, that the prospects for 'drawing a line' in the development of the fetus look dim. I am inclined to think also that we shall probably have to agree that the fetus has already become a human person well before birth.").

[87] *See generally* Paige & Karnofsky, *supra* note 16.

[88] *See* Biklen & Ferguson, *supra* note 21, at 5 ("We cannot allow this issue to become some kind of loyalty test for liberalism.").

[89] For a set of possible restrictions, see generally Dorothy C. Wertz, *Drawing Lines: Notes for Policymakers*, *in* PRENATAL TESTING AND DISABILITY RIGHTS 261. The least threatening restriction would probably be information requirements.

other areas of abortion jurisprudence, but not a particularly novel one after *Casey*. It is not clear that even a ban on selective abortion on the basis of disability would erode other abortion protections beyond comparable issues like sex selection.[90]

The feminist response to sex-selective abortion, moreover, indicates that pro-choice views and political affiliations do not a priori rule out positions favoring abortion restrictions. Ethical issues raised by sex-selective abortion parallel many of the issues raised by selective abortion on the basis of disability.[91] Like disability rights advocates, feminists have condemned sex-selective abortion practices as a product and proponent of social oppression.[92] However, the two contexts are distinct in many ways. Many feminists agree that some uses of sex-selective abortion—like efforts to achieve balanced family gender ratios—do not necessarily reflect a devaluation of a particular gender.[93] Neither gender faces abortion rates comparable to those reported for some disability diagnoses. Evidence of a rising disparity between reported male and female births in countries like China and India has nevertheless generated alarm among women's rights advocates.[94]

Feminist scholars have advocated restrictions or bans on these practices, particularly for countries experiencing disparate birth rates.[95] In the United States, where sex-selective abortion has been less prevalent and used primarily for family balancing and gender order, these efforts have been muted.[96] Many scholars contend that the threat represented by sex-selection in the United States does not rise to such a level to warrant seeking restrictions and risk weakening abortion rights more broadly.[97] Some, however, argue for restrictions or even a categorical ban on the use of sex-selective technology despite these risks.[98] Such efforts demonstrate a willingness on the part of some pro-

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[90] Given that abortion advocates have long cited cases of fetal disability as among the most important reasons for abortion rights, this point should not be over-emphasized. *See infra* notes 176-179 and accompanying text. Such a measure might therefore garner a strong backlash from other pro-choice groups.

[91] For a concise overview of issues surrounding sex-selective abortion, see Daniel Goodking, *Should Prenatal Sex Selection be Restricted? Ethical Questions and their Implications for Research and Policy*, 53 POPULATION STUDS. 49 (1999).

[92] *See, e.g.*, Dorothy C. Wertz & John C. Fletcher, *Sex Selection Through Prenatal Diagnosis: A Feminist Critique*, *in* FEMINIST PERSPECTIVES IN MEDICAL ETHICS 240, 249 (Helen Bequaert Holmes & Laura M. Purdy eds., 1992) ("[W]omen should take a stance now against sex selection. Sex selection would increase sexism and sex role stereotyping, and could undo the hard-won advances of the woman's movement.").

[93] *See* MARY ANNE WARREN, GENDERCIDE: THE IMPLICATIONS OF SEX SELECTION 83-88 (1985).

[94] For an account of the international instance of these practices, see Amartya Sen, *More Than 100 Million Women Are Missing*, N.Y. Rev. Books, Dec. 20, 1990, at X.

[95] *See, e.g.*, Ashley Bumgarner, Note, *A Right to Choose?: Sex Selection in the International Context*, 14 DUKE J. GENDER L. & POL'Y 1289 (2007) (summarizing the global practice of sex selection and advocating restrictions on the practice); Monica Sharma, Note, *Twenty-First Century Pink or Blue: How Sex Selection Technology Facilitates Gendercide and What We Can Do About It?*, 46 FAM. CT. REV. 198 (2008) (same).

[96] For a summary of the use of sex selection in the United States, see Jason Roberts, *Customizing Conception: A Survey of Preimlantation Genetic Diagnosis and the Resulting Social, Ethical, and Legal Dilemmas*, 2002 DUKE L. & TECH. REV. 12.

[97] *See, e.g.*, Tabitha Powledge, *Toward A Moral Policy for Sex Choice*, *in* SEX SELECTION OF CHILDREN 201, 206 (Neil G. Bennet ed., 1983) ("[T]o preserve what improvements in their lot women have achieved, society should seek no legal restrictions on reproductive freedom, even on a technology that will be used selectively against females. I recognize its irony, but this position is part of the price of furthering the goal of equal treatment."). For a summary of reasons for this position, see WARREN, *supra* 179-91

[98] *See, e.g.*, April L. Cherry, *A Feminist Understanding of Sex-Selective Abortion: Solely A Matter of Choice?* 10 WIS. WOMEN'S L.J. 161, 223 (1995) ("Because the current use of sex-selective abortion is

choice feminists to weaken reproductive rights in order to safeguard the protections those rights traditionally sought to ensure for women. It is not immediately apparent why disability advocates would be less willing, particularly given the elevated abortion rates for diagnosable disabilities.[99]

Perhaps disability advocates have simply been dissuaded by the political difficulties of an effort to secure restrictions on abortion. Social acceptance of prenatal testing would make such an effort a potentially unpopular one, and practical enforcement would be fraught with considerable difficulty.[100] However, enforcement problems are separate from the expressive content of the law and stated social values.[101] Moreover, the disability community has not wavered in its advocacy for other unpopular positions at odds with its traditionally progressive allies, most notably in its categorical opposition to physician-assisted suicide.[102] It is difficult to imagine that long odds would prompt such unanimous resignation and silence on the part of the disability community, particularly in the absence of any significant discussion amongst disability advocacy groups.

Alternatively, the immediate circumstances surrounding the two controversies may provide some explanation for the different approaches. The Baby Doe controversy galvanized disability rights activists around a shocking single episode. The issue of selective termination, by contrast, has generated a steady stream of discourse but no singular moment of controversy.[103] Moreover, the Baby Doe case energized a previously uninvolved right-to-life constituency that may have helped nudge the disability rights

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based on patterns of male preference and female subordination, and because of the deleterious social consequences of sex-selective abortion for women, a restriction on the availability of fetal sex information is warranted."); Jodi Danis, Recent Development, *Sexism and "The Superfluous Female": Arguments for Regulating Preimplanation Sex Selection*, 18 HARV. WOMEN'S L.J. 219 (1995) (arguing for federal legislation banning the use of preimplanation sex technology); Rachel E. Remaley, Note, *"The Original Sexist Sin": Regulating Preconception Sex Selection Technology*, 10 HEALTH MATRIX 249, 297 (2000) *(*arguing that "an overall ban of preconception sex selection will be the most useful and provide the broadest protection for women and society," but cautioning advocates to take "moderate steps" to reach that ban).

[99] Consider also the hypothetical of abortion on the basis of sexual orientation. Although technology locating a "gay gene" has not yet arrived, scholars have begun to consider the possibility of "anti-gay eugenics." *See* Janet E. Halley, *Sexual Orientation and the Politics of Biology: A Critique of the Argument from Immutability*, 46 STAN. L. REV. 503, 524-26 (1994). If such practices materialized, particularly at the rates experienced by some disability diagnoses, it is difficult to imagine that gay rights activists would not advocate legal restrictions of some kind.

[100] In many ways, these difficulties present analogs in the Baby Doe context. Restrictions on these practices would require close oversight of the medical profession and a nimble response to advances in medical technology.

[101] For a discussion of the importance of the expressive quality of law in political debates, see, for example, Dan M. Kahan, *The Secret Ambition of Deterrence*, 113 HARV. L. REV. 413, 442-45 (1999) (addressing the expressive quality of capital punishment).

[102] For a historical account of the disability rights movement's stance on these issues, see DORIS ZAMES FLLEISCHER & FRIEDA ZAMES, THE DISABILITY RIGHTS MOVEMENT: FROM CHARITY TO CONFRONTATION 132-45 (2001).

[103] This dynamic presents questions of its own. Some have attributed the public emergence of the Baby Doe controversy to mere chance, though this probably oversimplifies. *See* LYON, *supra* note 7, at 36 (describing reporters learning about the case while they waited to hear a different one). Moreover, reports have surfaced concerning abortions for reparable disabilities like cleft lip and clubfoot. *See* Sarah-Kate Templeton, *Babies Aborted for Minor Disabilities*, TIMES (London), Oct. 21, 2007, at **X**, *available at* http://www.timesonline.co.uk/tol/news/uk/health/article2689787.ece. It may be that the same cause that has yielded different responses in the two contexts produced different levels of controversy.

community into vocal advocacy, while the right-to-life lobby has taken less of a special interest in the issue of selective termination.[104] Yet disability rights groups declared their categorical opposition to selective non-treatment prior to the emergence of the Baby Doe case.[105] Although right-to-life advocates may have propelled the disability community into action in response to Baby Doe, they did not set the disability rights agenda.

Another possibility rests on shifting social contexts informing the two debates, either in the form of internal changes in the disability rights movement or broader social change. With respect to changes in the disability rights movement, it may be that growing fragmentation amongst disability groups has inhibited collective action and debate.[106] Or it is possible that disability rights advocates are more broadly committed to individual autonomy today than they were in the early 1980s. On a broader social scale, it may be that society is more hostile to disability rights today than it was in the early 1980s given the backlash against the ADA and civil rights more broadly.[107] Or it may be that the acceleration of society and the advance of medical technology have strengthened social views that life with a disability is a fate worse than death.[108]

These responses also prove unsatisfying. Temporal lines between the non-treatment issue and the abortion issue are blurry; disability advocates had taken notice of selective abortion by the time of the Baby Doe controversy.[109] Moreover, there are few indications that significant changes took place. The disability rights movement has never demonstrated much cohesion; it is an open question if it has become more fragmented in recent years.[110] There is no indication, moreover, that the disability rights community has developed a more fervent commitment to individual autonomy if its position on physician-assisted suicide is any indication.[111] Moreover, if relevant social changes have taken place more broadly, one wonders why disability advocates would be so unanimously resigned in the face of selective termination when they have not been with respect to other issues.

We are left, therefore, without a clear explanation for the divergent approaches disability advocates have taken in these two contexts. Perhaps the answer lies in some complex interaction of the doctrinal, social, and political possibilities discussed above. Even so, these possibilities strain to explain why disability advocates would cast

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[104] *See* Paige & Karnofsky, *supra* note 16, at 260 (quoting Evan Kemp, director of the Disability Rights Center in the early 1980s, arguing that to spring into action in the Baby Doe controversy, "[t]he disability rights movement needed the prodding of the right-to-life movement"). This is not to say, however, that anti-abortion groups haven't reached out to disability rights groups. *See* Laura Hershey, MS. MAGAZINE, July/August 1994, at 27 (noting that "antiabortion a groups are courting the disability community").

[105] *See infra* notes 147-151 and accompanying text.

[106] This is a consistent gripe among disability advocates. *See, e.g.*, GARY L. ALBRECHT, THE DISABILITY BUSINESS: REHABILITATION IN AMERICA 281 (1992) (noting that disability groups "do not constitute a unified lobby" and instead are often "competing with one another for resources").

[107] For disability rights concerns along these lines, see generally MARY JOHNSON, MAKE THEM GO AWAY: CLINT EASTWOOD, CHRISTOPHER REEVE & THE CASE AGAINST DISABILITY RIGHTS (2003).

[108] For a discussion of the rise of biological determinism in recent years, see generally RICHARD C. LEWONTIN, BIOLOGY AS IDEOLOGY: THE DOCTRINE OF DNA (1993).

[109] *See supra* notes 45-46 and accompanying text.

[110] *See* Samuel R. Bagenstos, *The Americans with Disabilities Act as Welfare Reform*, 44 WM. & MARY L. REV. 921, 1008-13 (2003) (describing the traditional division among disabilities groups organized around particular impairments and arguing that the civil rights movement and welfare reform helped unify these disparate groups).

[111] *See* Bagenstos, *supra* note 73, at 457-62.

disability as a neutral form of human variation in one context and reluctantly cast it as an inherently undesirable trait in another. How could sociopolitical forces so thoroughly and irrevocably alter the disability community's professed understanding of disability? Is either view appropriate or principled? The next Part develops an understanding of disability that encapsulates both of these apparently contradictory views. It contends that our understanding of disability is permeated by profound feelings of ambivalence.

II. Ambivalence and Disability Rights

In psychoanalytic thought, ambivalence denotes contradictory sentiments directed toward a single object.[112] According to one classic formulation, ambivalence refers to "love and hatred toward the same person at the same time."[113] Given the "dual orientation of man as an individual and as a member of society," love for another may inflame "the narcissistic nucleus of the personality" to hate the loved object.[114] Ambivalence does not typically produce a stable balance of competing sentiments. Rather, one attitude is embraced and the other denied.[115] Drawing again on the example of love and hate, "there is perhaps no more perplexing situation than to hate whom you love or to love whom you hate."[116] In different circumstances, therefore, ambivalence may achieve expression in apparent contradiction.[117] It also may shape the social understandings that fuel our conflicting views.[118]

Social responses to selective non-treatment and selective abortion reflect a deep ambivalence about disability. This ambivalence pervades the disability community itself. Disability advocates at once value disability as a neutral trait vital to personal identity and simultaneously devalue it as an undesirable impairment. The discomfort wrought by this contradiction has provoked the disability community to deny its ambivalence and embrace a singular view of disability as wholly neutral. In the neonatal context, disability advocates have advanced a view of disability consistent with this denial. Yet beneath the surface lie powerful doubts. In the prenatal context, these doubts have not been quite as powerfully suppressed. Instead, they have revealed an uneasy acceptance that disability may indeed be so undesirable as to render life not worth living.

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[112] For a discussion of different classifications of ambivalence, see Ihor V. Zielyk, *On Ambiguity and Ambivalence*, 9 Pac. Soc. Rev. 57 (1966).

[113] FRANZ ALEXANDER, FUNDAMENTALS OF PSYCHOANALYSIS 107 (1948).

[114] *Id.*

[115] For an instructive case study, see Patricia W. Linville & Edward E. Jones, *Polarized Appraisals of Out-Group Members*, 38 J. PERSONALITY & SOC. PSYCH. 689 (1980)

[116] ALEXANDER, supra note 113, at 107.

[117] That is, the same ambivalent feelings may lead to diametrically opposed views in the presence of different social stimuli. *See* Icek Ajzen, *Nature and Operation of Attitudes*, 52 ANN. REV. PSYCH. 27, 39-40 (2001) (reviewing research that priming subjects had a significant effect on the consequences of their ambivalence about a given object).

[118] *See* Ingrid Arnet Connidis & Julie Ann McMullin, 64 J. OF MARRIAGE & FAM. 558, 565 (2002) ("Individuals experience ambivalence when social structural arrangements collide with their attempts to exercise agency when negotiating relationships…. Managing ambivalence in daily life shapes the very social structures that produce ambivalence in the first place, through either reproduction of the existing order or its transformation.").

A. Ambivalence and Selective Non-treatment

The dilemma of selective non-treatment did not first arise with Baby Doe. Until recently, many tribal groups and major civilizations actively encouraged the practice of infanticide in cases of neonatal disability.[119] In the West, the acceptance of infanticide in ancient Greece and Rome is well documented. Aristotle and Plato argued that the practice was not merely justifiable but imperative for infants with disabilities; they reasoned that such infants were a burden on their families and the state.[120] The Roman Twelve Tables echoed this view in its exhortation that a "dreadfully deformed child shall be killed."[121] So did Roman philosophers like Seneca, who described infanticide on the basis of disability as an act of "reason that separates the harmful from the sound."[122] These societies, however, simultaneously embraced the practice and disavowed it. Individual acts of infanticide remained hidden from public view and subject to moral censure.[123]

Modern societies have placed infanticide under more explicit moral and legal sanction, yet they have continued to tolerate the practice. Prohibitions on infanticide have consistently preserved socially obscured outlets for it. After the rise of Christianity, for example, Roman law proscribed the direct killing of infants, but did not mention abandonment. Contemporary observers described exposure by abandonment as relatively commonplace during this period.[124] With the consolidation of church power, institutionalized processes of abandonment arose to further obscure these practices; wet nurses and foundling hospitals allowed parents to dispose of infants under the pretence of procuring treatment.[125] More modern prohibitions against abandonment have simply not been enforced.[126] In the United States, the law has made no special provisions for infanticide. Few cases are ever brought.[127]

Traditional mythology around infanticide on the basis of disability reflects powerful social efforts to both assuage moral doubts about the practice and obscure it from public view. Perhaps most striking is a myth of the Nuer tribe of east Africa, which held that infants with disabilities were hippopotamuses mistakenly born to human

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[119] For an overview of these practices, see Kathryn L. Moseley, *The History of Infanticide in Western Society*, 1 ISSUES L. & MED. 345 (1986).

[120] *See* ARISTOTLE, POLITICS 443 (Trevor J. Saunders ed. & T.A. Sinclair 1981) ("With regard to the choice between abandoning an infant or rearing it, let there be a law that no cripple child be reared."); PLATO, REPUBLIC 186 (Albert A. Anderson ed. & Benjamin Jowett trans., 2001) ("The officers in charge, whether male or female… will be responsible for taking the children of the good parents to a pen in a separate area within the republic and turn them over to nurses who live there. The offspring of the inferior—especially any that are deformed—will be concealed in some secret and unnamed place.").

[121] The Twelve Tables, Table IV, §1.

[122] Quoted in ROBERT F. WEIR, SELECTIVE NONTREATMENT OF HANDICAPPED NEWBORNS: MORAL DILEMMAS IN NEONATAL MEDICINE 9 (1984).

[123] *See id.* at 5-6.

[124] *Id.* at 10-11. Nevertheless, the rise of Christianity has been described as an important cause of the decline of the practice. *See* KUHSE & SINGER, *supra* note 72, at 111-17.

[125] LYON, *supra* note 7, at 62-63.

[126] For a discussion of this phenomenon in modern England, see Tony Ward, *Legislating for Human Nature: Legal Responses to Infanticide*, *in* Infanticide: Historical Perspectives on Child Murder and Concealment, 1550-2000, at 249 (Mark Jackson ed., 2002).

[127] For an overview of the prosecution of infanticide crimes in the United States, see Michelle Oberman, *Mothers Who Kill: Coming to Terms with Modern American Infanticide*, 8 DEPAUL J. HEALTH CARE L. 3, 24-58 (2004).

parents. Nuer parents could simply "return" these infants to their natural parents by throwing them into a river.[128] In Europe, religious superstition long held that infants with disabilities were demonic creatures temporarily substituted for a human child. Following folklore, parents might put these children through violent and sometimes murderous trials in hope that the devil would take pity on the substituted creature and return the original child.[129] This type of reasoning entered the common law as well; according to Blackstone, infants with disabilities were "monster[s]" that had no inheritable blood and could not be heirs to land.[130]

Despite these efforts, the practice has sporadically emerged from the public's collective subconscious amidst considerable controversy. With the rise of the medical profession in the 19th century, the birth process and attendant considerations about infanticide increasingly fell under the purview of physicians.[131] The profession largely disclaimed the practice, yet withheld treatment under a veil of silence.[132] At the height of the eugenics movement in the 1910s and 1920s, the issue nevertheless rose into public view. The case of the Bollinger Baby, an infant with severe disabilities refused food and water by her parents and physician, captivated the nation.[133] The case made national news and inspired a propagandist motion picture, which attempted to justify selective infanticide by casting the child as a monster that would undermine social order.[134] In its wake, the country engaged in a brief but spirited debate about the propriety of euthanasia. Shortly thereafter, the practice once again vanished from public discourse.[135]

The modern disability rights movement began to coalesce amidst another public glimpse into selective infanticide in the 1970s. The 1971 film "Who Shall Survive" dramatized the plight of an infant with Down syndrome refused treatment for esophogal blockage at the Johns Hopkins Hospital.[136] Funded by the Joseph P. Kennedy, Jr. Foundation, the film garnered national media coverage.[137] Perhaps influenced by the emergent visibility of abortion practices, a number of physicians simultaneously broached the issue in medical journals.[138] The reports indicated that a significant majority

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[128] WEIR, *supra* note 122, at 21.
[129] *Id.*, at 11.
[130] 2 WILLIAM BLACKSTONE, COMMENTARIES *246-47 ("A monster, which hath not the shape of mankind, but in any part evidently bears the resemblance of the brute creation, hath no inheritable blood, and cannot be heir to any land, albeit it be brought forth in marriage: but, although it hath deformity in any part of its body, yet if it hath human shape, it may be heir.").
[131] *See* Joseph F. Kett, *Science and Controversy in the History of Infancy in America*, *in* WHICH BABIES SHALL LIVE?: HUMANISTIC DIMENSIONS OF THE CARE OF IMPERILED NEWBORNS 23, 26-27 (Thomas H. Murray & Arthur L. Caplan eds., 1985).
[132] For a discussion of the medical profession's evolving treatment of death and abortion in the mid-19th century, see BURT, *supra* note 4, at 47-58 (2002).
[133] *See* MARTIN S. PERNICK, THE BLACK STORK: EUGENICS AND THE DEATH OF 'DEFECTIVE' BABIES IN AMERICAN MEDICINE AND MOTION PICTURES SINCE 1915, at 3-17 (1996).
[134] *Id.* at 143-58.
[135] *Id.* at 159-67.
[136] For an extensive discussion of the film, see Armand Matheny Antommaria, *'Who Should Survive?: One of the Choices on Our Conscience': Mental Retardation and the History of Contemporary Bioethics*, 16 KENNEDY INST. ETHICS J. 205 (2006).
[137] *Id.* at 214-217.
[138] *See, e.g.*, R.B. Zachary, *Ethical and Social Aspects of Treatment of Spina Bifida*, 2 LANCET 274 (1968); John Lorber, *Results of Treatment of Myelomeningocele: An Analysis of 524 Unselected Cases, with Special Reference to Possible Selection for Treatment*, 13 DEV. MED. & CHILD NEUROLOGY 279 (1971).

of pediatricians and pediatric surgeons supported non-treatment in at least some circumstances.[139] They also indicated that the practice was relatively common. Most prominently, Raymond S. Duff and A.G.M. Campbell recounted a series of infant deaths at Yale-New Haven Hospital after parents and physicians "concluded that prognosis for meaningful life was extremely poor or hopeless."[140]

The resulting discourse, culminating in the Baby Doe controversy, reflected a powerful social ambivalence about the practice. On the poles, social commentators both condemned and embraced it. Led by right-to-life and disability groups, one set of activists cast selective non-treatment as an immoral act that could not be tolerated under any circumstances.[141] Led by the medical profession, another set argued that selective non-treatment was in the best interests of many infants with disabilities and their families.[142] Opponents denied that disability could be sufficiently undesirable to render life not worth living. They focused on Baby Doe and ignored infants with more severe disabilities like anencephaly and Tay Sachs.[143] Proponents denied traditional concerns about the inherent wrongfulness of the act. They focused on the imputed suffering of the child and cast infants with severe disabilities as less than fully human.[144]

Beneath this apparent clarity, however, lay conflicting sentiments. Those who defended the propriety of selective non-treatment struggled to fit the practice within clearly defined moral boundaries. Many acknowledged that the empathic gulf between physician, family, and infant made these efforts impossible; one could only guess about the best interests of a given child or family.[145] In advocating for parental autonomy and individualized decision-making, physicians sought to bury these dilemmas within

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This is not to say that a scholarly silence existed previously. *See, e.g.*, Donald M. Glover & Frank McA. Barry, *Intestinal Obstruction in the Newborn*, 130 ANNALS OF SURGERY 480, 480-481 ("Many of the babies with intestinal anomalies are born prematurely and are poor candidates for any sort of operative procedure. The coincidence of other anomalies in these infants is also high. As surgeons we can offer little help to improve this factor.")

[139] *See, e.g.*, I. David Todres et al., *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 PEDIATRICS 197 (1977); Anthony Shaw, Judson G. Randolph & Barbara Manard, *Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588 (1977).

[140] Raymond S. Duff & A.G.M. Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 NEW ENG. J. MED. 890, 890 (1973). The study reported that of 299 consecutive deaths in the special-care nursery, 43 were related to withholding of treatment. *Id.*

[141] *See* supra notes 21-33 and accompanying text. For similar views from within the academy, see, for example, PAUL RAMSEY, ETHICS AT THE EDGES OF LIFE 192 (1978) ("We have no moral right to choose that some live and others die, when the medical indications for treatment are the same").

[142] *See, e.g.*, George P. Smith, *Murder, She Wrote Or Was It Merely Selective Nontreatment?* 8 J. Contemp. Health L. & Pol'y 49 (1992) (arguing that "acts of selective non-treatment can never be considered as acts of murder but rather as courageous acts of more humane and enlightened kindness, or even love.")

[143] For criticism of this denial, see Arthur L. Caplan, *Hard Cases Make Bad Law: The Legacy of the Baby Doe Controversy*, *in* COMPELLED COMPASSION: GOVERNMENT INTERVENTION IN THE TREATMENT OF CRITICALLY ILL NEWBORNS 111-18 (Arthur L. Caplan, Robert H Blank & Janna C. Merrick eds., 1992).

[144] *See, e.g.*, Richard A. McCormick, *The Quality of Life, The Sanctity of Life*, 8 Hastings Center Rep. 30, 35 (1978) ([T]here are times when preserving the life of one with no capacity for those aspects of life that we regard as *human*, is a violation of the sanctity of life itself."); MICHAEL TOOLEY, ABORTION AND INFANTICIDE 407-12 (1983) (concluding that infants under three months of age are quasi-persons subject to lesser moral concern than persons).

[145] For an expression of this understanding, see Joan E. Hodgman, *Withholding Treatment from Seriously Ill Newborns: A Neonatalogist's View*, *in* Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients 242, 243-44 (A. Edward Doudera & J. Douglas Peters eds., 1982).

individual cases. Amidst rhetoric that cast disability as a source of suffering incompatible with a worthwhile life, however, more than a few expressed unease with past recommendations for non-treatment in cases where treatment was appropriate in retrospect.[146] Although these cases did not dissuade defenders of the practice, they underlined the uncertainty and possible wrongdoing that accompanied it.

The disability community also betrayed doubts beneath its categorical opposition to selective non-treatment. Advocacy groups issued statements opposing the practice in wake of the 1971 film out of Johns Hopkins.[147] As additional revelations came to light in the 1970s, however, they remained largely silent. Even after Baby Doe's death in 1982, advocates acknowledged that they "needed the prodding of the right-to-life" movement to mobilize.[148] As one activist explained, Baby Doe was "a very emotional issue" for the community.[149] Although the disability rights movement would oppose selective non-treatment under all circumstances, its rhetoric buried this position behind more extensive discussions of misperceptions about the quality of life enjoyed by individuals with disabilities.[150] Rather than emphasize the neutrality of disability, these statements sought to justify the worth of those living with disabilities.[151]

Individual treatment decisions present these ambivalent sentiments in particularly stark relief. Consider, for example, the choice to terminate treatment for Baby Doe. The child's parents agonized over the decision and continued to visit his bedside until the bitter end.[152] The physicians, split by the decision, never wavered. Dr. James Schaffer, the physician most strongly pushing treatment, took measures shortly before the child's death to violate the court's order and save the baby. At the last second, however, he abandoned those measures.[153] The studies that sought to expose non-treatment practices in the 1970s reported similarly conflicting emotions on the part of those involved in

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[146] *See, e.g.*, Arthur L. Caplan, *Hard Cases Make Bad Law: The Legacy of the Baby Doe Controversy*, *in* COMPELLED COMPASSION: GOVERNMENT INTERVENTION IN THE TREATMENT OF CRITICALLY ILL NEWBORNS 105, 119-21 (Arthur L. Caplan, Robert H. Blank & Janna C. Merrick eds., 1992) (describing the case of a newborn for whom doctors aggressively recommended non-treatment who subsequently became "a vivacious, charming, and outgoing kid"). Caplan describes the reaction of the child's doctors: "The prospect that she might have been allowed to die filled them with nothing but dread. The fact that I had concurred with those, six years earlier, who said she would be better off dead left me with the same feeling." *Id.* at 120.

[147] Turnbull, *supra* note 22, at 370-71 (describing the statements issued by the American Association on Mental Deficiency and the Association for Retarded Citizens).

[148] Paige & Karnofsky, *supra* note 16, at 260.

[149] *Id.* (quoting Evan Kemp, director of the Disability Rights Center).

[150] *See Treatment of Infants Born with Handicapping Conditions: Hearing on H.R. 6492 Before the H. Comm. on Education and Labor*, 97th Cong. 52-53 (1982) (statement of The Association for Retarded Citizens).

[151] *See id.* at 52 ("Although the ARC recognizes the many difficulties encountered by parents and physicians… we know of a great many situations where parents facing dilemmas similar to Baby Doe have made the decision to proceed with medical treatment and the child has thrived, living a life full of ups and down [sic] as we all have.").

[152] LYON, *supra* note 7, at 27-33.

[153] *Id.* 36-38. Schaffer repeatedly visited the child with an IV bottle in his hands to begin intravenous feeding. He placed a telephone call to a nearby hospital to ask if they would send a helicopter for the baby if he resuscitated it. In later interviews, Schaffer first denied that he would have tried to physically overpower another doctor to get to the child, and then stated that he would "have gone past anyone who tried to interfere." *Id.*

decisions.[154] Scholars have characterized these reactions as imbued at once with a desire to dedicate oneself to the welfare of one's child and a desire to deny one's relationship to the child. The resulting guilt, these scholars have argued, push some parents toward overprotection of the child and others toward rejection of the child.[155]

Disability advocates have echoed this ambivalence, though in more guarded fashion. Perhaps the best example is Harriet McBryde Johnson, a lawyer and disability advocate born with spina bifida. A member of the disability group Not Dead Yet, Johnson famously debated Peter Singer on the topic of selective non-treatment.[156] Writing about her encounter, Johnson initially conceives of Singer as something of a monster.[157] As she gets to know him, however, Johnson develops an uncomfortable liking for the man.[158] Johnson defends Singer's views against the criticism leveled by other members of Not Dead Yet and her own family,[159] and she increasingly struggles to confront his view that disability could render a life not worth living.[160] Ultimately, she

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[154] *See* Duff & Campbell, *supra* note 140, at 891 ("The penetrating questions and challenges, particularly of knowledgeable parents (such as physicians, nurses, or lawyers), brought increasing doubts about the wisdom of many of the decisions that seemed to parents to be predicated chiefly on technical considerations.").

[155] *See* Albert J. Solnit & Mary H. Stark, *Mourning and the Birth of a Defective Child*, *in* PHYSICAL ILLNESS AND HANDICAP IN CHILDHOOD: AN ANTHOLOGY OF THE PSYCHOANALYTIC STUDY OF THE CHILD 181, 185 (Ruth Eissler ed., 1977) ("At the one extreme is the guilt feeling leading to the mother's manifest dedication of herself unremittingly and exclusively to the welfare of the retarded child. At the other extreme is the parents' manifest intolerance of the child and the almost irresistible impulse to deny their relationship to the child. The underlying narcissistic injury is intolerable."); Philip Roos, *Parents of Mentally Retarded Children—Misunderstood and Mistreated*, *in* Parents Speak Out: Views from the Other Side of the Two-Way Mirror 13, 19 (Ann. P. Turnbull & H. Rutherford Turnbull III eds., 1978) ("The mixed feelings of love and anger typically experienced by parents toward their children are usually greatly intensified toward a retarded child. The greater the frustration generated by the retarded child's irritating behavior and failure to learn, the more likely are the parents to feel anger and resentment. Fantasies of the child's death are not uncommon. Since these feelings are typically accompanied by guilt, some parents may react with overprotection while others tend to reject their child.").

[156] *See* HARRIET MCBRYDE JOHNSON, TOO LATE TO DIE YOUNG: NEARLY TRUE TALES FROM A LIFE 201-28 (2005). Not Dead Yet opposes physician-assisted suicide and euthanasia.

[157] *Id.* at 204. Upon meeting Singer, Johnson reports thinking, "I shouldn't shake hands with the Evil One." She does, however. *Id.*

[158] At one point, Johnson goes for a stroll with Singer on the Princeton campus, passing the spot where members of Not Dead Yet famously protested his appointment to the faculty appointment. She remarks, "My brothers and sisters were here before me, and behaved far more appropriately than I am doing." *Id.* at 217.

[159] When another member of Not Dead Yet arrives and refers to Singer as a ghoul, Johnson tells him, "It's not like that. We are monstruously civil. And you need to fall into the program and be civil, too." She then remarks internally, "I hear an unpleasant stridency in my voice. I've invited a card-carrying lunatic into a delicate situation and now I wonder if I should have." *Id.* at 218. For a similar discussion with Johnson's sister, see *id.* at 224-227.

[160] Johnson engages in an extended internal dialogue defending Singer's views from her own attacks. Part of her wonders how she can defend a man who thinks she should not have been born. The other part has few answers. She concludes: "If I define Singer's kind of disability prejudice as an ultimate evil, and him as a monster, then I must so define all who believe disabled lives are inherently likely to be less happy, or that a life without a certain kind of consciousness lacks value. That would make monsters of many of the people with whom I move on the sidewalks, do business, break bread, swap stories, and share the grunt work of politics. The definition would reach some of my family and most of my nondisabled friends, people who show me enormous kindness and who somehow, sometimes manage to love me through their

cannot reconcile her own views. She concludes that her only response is to "invoke the muck and mess and undeniable reality of disabled lives well lived," unsatisfying though it may be.[161]

Given the pervasive reach of these sentiments, it is unsurprising that the Baby Doe controversy yielded a structurally ambivalent legal outcome. The Child Abuse Amendments explicitly condemned selective non-treatment on the basis of disability. In practice, however, they appear to have had a limited impact.[162] Non-compliance carries a threat of the withdrawal of a miniscule set of federal funds under the Child Abuse and Prevention Treatment Act.[163] More importantly, the Amendments delegated enforcement authority to state child protective services, which have abdicated their investigative responsibilities to internal hospital review committees.[164] According to the U.S. Commission on Civil Rights, the Department of Health and Human Services has failed to appropriately investigate non-treatment decisions.[165] Few disputes have emerged; physicians tend to deliberate about difficult treatment decisions amongst themselves and present a unified front to acquiescent parents.[166]

In a sense, therefore, the Amendments constituted a symbolic compromise to chill political heat more than a definitive movement in any policy direction.[167] Once again the issue of selective non-treatment emerged in a fiery moment and then vacated the public consciousness.[168] As was the case prior to the controversy, a distant threat of social condemnation and criminal sanction informs the boundaries of a largely veiled doctor-patient relationship. Infants with Down syndrome almost universally receive the treatments denied Baby Doe.[169] The advance of medical technology, however, continues to expand the set of salvageable premature babies, many of whom have disabilities.[170] In

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ignorance. I can't live with a definition of ultimate evil that encompasses all of them. I can't refuse the monster-majority basic courtesy, respect, and human sympathy." *Id.* at 227-28.

[161] *Id.* at 228. Johnson cannot come up with a clear principle. She can only "trust in the fact that, while we struggle, we must also live with our theories and with one another. As a shield from the terrible purity of Singer's vision, I'll look to the corruption that comes from interconnectedness." *Id.*

[162] This was predicted at the time of passage. *See, e.g.*, Thomas H. Murray, *The Final, Anticlimactic Rule on Baby Doe*, 15 HASTINGS CENTER REP. 5, 7 (1985) ("[T]he impact of this legislation will be minimal.").

[163] *See* Kathryn Moss, *The 'Baby Doe' Legislation: Its Rise and Fall*, 15 POL'Y STUD. J. 629, 641 (1987).

[164] *See* U.S. COMMISSION ON CIVIL RIGHTS, MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES 7-9 (1989).

[165] *Id.* at 10-11.

[166] *See* RENE ANSPACH, DECIDING WHO LIVES: FATEFUL CHOICES IN THE INTENSIVE-CARE NURSERY 93-99 (1993). A few scholars claim, however, that the Amendments have produced overtreatment. *See, e.g.*, Joy Hinson Penticuff, *The Impact of the Child Abuse Amendments on Nursing Staff and Their Care of Handicapped Newborns*, *in* COMPELLED COMPASSION 267, 268 (arguing that the amendments have fostered "the instrumentalist attitude… that life must be saved at all costs in all circumstances).

[167] *See* Janna C. Merrick, *Federal Intervention in the Treatment of Handicapped Newborns: Baby Doe Regulations and the 1984 Child Abuse Amendments*, 8 POL'Y STUD. REV. 405, 417 (1989) ("There was considerable public debate and a good deal of emotion, but not much of a problem at the outset nor much of a change in the aftermath.").

[168] For a discussion of the cyclical quality of debates concerning selective non-treatment, see PERNICK, *supra* note 134, at 167-168.

[169] *See* Anthony Shaw, *Baby Doe and Me: A Personal Journey*, *in* COMPELLED COMPASSION 200 ("The Baby Doe of the 1990s is no longer an infant with Down syndrome.").

[170] *See* Neil Marlow et al., *Neurologic and Developmental Disability at Six Years of Age after Extremely Preterm Birth*, 352 NEW ENG. J. MED. 9 (2005) (finding a higher rate of cognitive disability among extremely premature children).

keeping with traditional patterns, the medical profession and disability advocates have remained largely silent about the issue.

B. Ambivalence and Selective Abortion

The same pattern of ambivalence pervades the history of selective abortion. Although the practice of abortion stretches back as far as the practice of infanticide, selective abortion is a relatively recent phenomenon.[171] The emergence of methods to monitor fetal disability, first through ultrasound and x-rays and later through amniocentesis and chorionic villus sampling, fueled an accelerating demand for accurate tests and abortion.[172] At the same time, medical evidence that particular maternal illnesses and injuries might produce fetal disability fueled supporters of liberalized abortion laws, particularly during the rubella epidemic in California in the 1960s.[173] Abortion advocates presented instances of fetal disability among the least morally ambiguous cases for abortion.[174] Physician practices prior to state abortion reforms silently reflected that view, including fetal disability within the realm of permissible reasons for abortion.[175]

Yet abortion on the basis of disability also provoked moral doubts. Opponents of abortion rights presented instances of fetal disability or presumed disability among the least morally ambiguous cases against abortion rights.[176] Such practices, the reasoning went, presented a particular threat to the sanctity of all forms of human life. California Governor Ronald Reagan specifically excised the provision of the state's abortion reform statute that would have allowed abortion in cases of "fetal indications" of disability.[177] In so doing, Reagan pushed the original catalyst for the statute back under the rug; California physicians would instead include fetal disability under the statute's provision for abortion in cases that threatened the "mental health" of the mother.[178] Although the

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[171] For a global history of abortion practices, see generally JOHN M. RIDDLE, EVE'S HERBS: A HISTORY OF CONTRACEPTION AND ABORTION IN THE WEST (1997)

[172] *See* Powell, *supra* note 37, at 44-46.

[173] *See* KRISTIN LUKER, ABORTION AND THE POLITICS OF MOTHERHOOD 76-91 (1984); *see also id.* at 34-35 (discussing the acknowledgment of "fetal indications" in late 19th century America). For a broader view of causes for abortion reform, see generally DONALD T. CRITCHLOW, THE POLITICS OF ABORTION AND BIRTH CONTROL IN HISTORICAL PERSPECTIVE (1996).

[174] *See* LUKER, *supra* note 173, at 79-80 ("The costs of bringing a damaged child into the world—costs to the child itself, to its family, and to its community—were seen to be so high as to make abortion the obvious moral choice."). Individuals who generally disfavor abortion may make an exception for fetal disability. *See* Judith F. Daar, *Selective Reduction of Multiple Pregnancy: Lifeboat Ethics in the Womb*, 25 U.C. DAVIS L. REV. 773, 812-15 (1992).

[175] LUKER, *supra* note 173 at 81-82.

[176] *Id.* at 80 ("They had been willing to tolerate a situation where what they thought of as being the life of one person (an embryo) was sacrificed to save the life of another (a woman). But it posed enormous logical (as well as ethical) problems to argue that an individual must be sacrificed for its own good.").

[177] *Id.* at 88-91.

[178] *Id.* at 89-90.

Model Penal Code contained a "fetal indications" clause,[179] federal abortion reform achieved a result in line with California's statute.

Selective abortion did not garner special treatment under *Roe* or *Casey*, and resulting legislation has harbored considerable unease and contradiction.[180] A small minority of states allows third trimester abortions in cases of fetal disability.[181] However, most state statutes make no special provisions for selective abortion except with regard to funding.[182] The federal government and some state governments provide limited funding for genetic testing, but these measures generally do not pay for abortion procedures. The federal government has refused to allow its funds to pay for abortion except in cases of rape, incest, or threat to the life of the woman.[183] States have preferred to separate legislation about testing from legislation about abortion. For example, Missouri will pay for genetic testing for families disposed toward specified genetic diseases and disabilities, but it forbids referral for abortion in the event of a positive diagnosis unless the life of the woman is threatened.[184]

The social ritual around prenatal testing likewise reflects a powerful ambivalence about testing and selective abortion. In the past 35 years, prenatal testing has become a routine part of prenatal care.[185] Obstetricians and prospective parents engage in a circuitous dance to avoid the moral dilemmas that circumscribe the testing process.[186] Like so many state statutes, these discussions typically focus on the test rather than its consequence, namely the possibility of a choice between abortion and a child with a disability.[187] In study after study, parents explain their choice to procure testing as an effort to ensure the health of their child and reassure themselves about the health of their

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[179] MODEL PENAL CODE § 230.3(2) (1962) ("[a] licensed physician is justified in terminating a pregnancy if he believes there is substantial risk that continuance of the pregnancy would gravely impair the physical or mental health of the mother or that the child would be born with grave physical or mental defect").

[180] For a summary of the law's approach to prenatal testing, see Ellen Wright Clayton, *What the Law Says about Reproductive Genetic Testing and What It Doesn't*, *in* WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 131 (Karen H. Rotherberg & Elizabeth J. Thomson eds., 1994) and Pilar N. Ossorio, *Prenatal Genetic Testing and the Courts*, *in* PRENATAL TESTING AND DISABILITY RIGHTS 308.

[181] *See, e.g.*, TEX. HEALTH & SAFETY CODE ANN. § 170.002 (Vernon 2008) (allowing third term abortions if "the fetus has a severe and irreversible abnormality, identified by reliable diagnostic procedures."); UTAH CODE ANN. § 76-7-301.1 (West 2008) ("a woman may terminate the pregnancy if the unborn child would be born with grave defects").

[182] *See* Clayton, *supra* note 180, at 134-35.

[183] *Id.* at 136-38.

[184] *Id.* at 147-51.

[185] For a discussion of this evolution, see Suter, *supra* note 38, at 241-54. According to Suter, testing is "so accepted a part of pregnancy… that women who reject [it] must be prepared with explanations and justifications. People ask 'why not?' No one asks 'why?' We all know why, and many would make the same decision." *Id.* at 241.

[186] *See* Michael J. Malinowski, *Coming Into Being: Law, Ethics, and the Practice of Prenatal Genetic Screening*, 45 Hastings L. J. 1435, 1451-52 ("[W]e have warmly embraced the technological capability to test for genetic abnormalities, almost without question."); Nancy Press, *Assessing the Expressive Character of Prenatal Testing*, in PRENATAL TESTING AND DISABILITY RIGHTS 214, 219 ("For some women, the identity of meaning between standard prenatal care and prenatal testing was so complete that [maternal serum alpha fetoprotein] was described in terms of helping to protect the fetus.").

[187] For a classic discussion on this phenomenon, see BARBARA KATZ ROTHMAN, THE TENTATIVE PREGNANCY: PRENATAL DIAGNOSIS AND THE FUTURE OF MOTHERHOOD 86-115 (1986).

child.[188] Popular books on pregnancy advance the same reasoning.[189] These rationales raise an obvious question: what if these parents hear what they are not expecting? Only then does abortion explicitly enter the picture.

Legal and social expressions of ambivalence about selective abortion have proved mutually reinforcing. In the absence of clear statutory provisions on the issue, the law's regulation of selective abortion lies primarily in the torts of wrongful birth and wrongful life.[190] These actions hold physicians liable for failing to diagnose a prenatal disability if they deviated from the standard of care and the parents would have aborted the child but for the malpractice.[191] Courts have expressed profound unease with both forms of action, particularly wrongful life claims; roughly half of the states recognize a cause of action in wrongful birth, but only three recognize wrongful life.[192] For the most part, even states that recognize one of the causes of action have proceeded with trepidation. The actions stretch the concept of the harm inflicted in tort law and require a peculiar disaffirmation of the child in open court.[193] Yet the threat of wrongful birth suits has prompted the medical profession to further routinize procedures and to pressure parents to undergo testing.[194]

Social debates about this state of affairs have split between two poles. Led by disability advocates, critics of selective abortion have drawn parallels between the practice and the ideals espoused by the American eugenics movement.[195] Like the "old eugenics," the "new eugenics" obscures common humanity and dignity in its pursuit of

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[188] *See* Saxton, *supra* note 52, at 157 ("Women are increasingly pressured to use prenatal diagnostic testing under a cultural imperative that undergoing these tests is the 'responsible thing to do.' Strangers in the supermarket, even characters in TV sitcoms, readily ask a woman with a pregnant belly, 'Did you get your amnio?' While the ostensible justification is 'reassurance that the baby is fine,' the underlying communication to the mother is clear: screening for fetuses with disability traits is the right thing, 'the healthy thing,' to do.").

[189] *See, e.g.*, VICKI IOVINE, THE GIRLFRIEND'S GUIDE TO PREGNANCY: OR EVERYTHING YOUR DOCTOR WON'T TELL YOU 87 (1995) ("All amnio will do for you, in all likelihood, is relieve you of some of your phantom worries about your unborn baby.").

[190] *See* Ossorio, *supra* note 180, at 309-24.

[191] Wrongful life claims accrue to the child, while wrongful birth claims accrue to the parents.

[192] These claims predate the routinization of prenatal testing. For early discussions, see Note, *The Right to Recover for Prenatal Injuries*, 44 YALE L. J. 1468 (1935) (asserting that denials of wrongful death claims for prenatal injuries are misguided); Note, *The Impact of Medical Knowledge on the Law Relating to Prenatal Injuries*, 110 U. PA. L. REV. 554 (1962) (noting the development of prenatal tort claims and arguing for more expansive recoveries).

[193] For a recent and critical summary of the current state of the law, see Wendy F. Hensel, *The Disabling Impact of Wrongful Birth and Wrongful Life Actions*, 40 HAR. C.R.-C.L.L. REV. 141, 150-62 (2005).

[194] *See* Ossorio, *supra* note 180, at 309 ("If only a fraction of parents sue when their child is born with a disability but few or none sue when too many tests are done, the legal system will provide incentives for physicians to offer every feasible prenatal genetic test. The system will participate in constituting a medical norm of offering tests, and once this norm becomes common practice, physicians will face legal duties to offer the tests.").

[195] *See, e.g.* Sonia M. Suter, *A Brave New World of Designer Babies*, 22 Berkeley Tech. L. J. 897, 969 (2007) ("Neoeugenics as a practice should trouble us if the underlying intent is not focused on the best interests of the child or family, but instead is built on discriminatory attitudes, concerns about prestige, or narrow conceptions of the full value of the future child."). For a history of the Anglo-American eugenics movement, see generally DANIEL J. KEVLES, IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY (1985).

an elusive and oppressive perfection.[196] These critics have warned that genetic engineering threatens to erode the individual freedom guaranteed by origins and characteristics that are not at human disposal.[197] Defenders of the practice have cast aside concerns of renewed eugenic excesses in their appeals to individual autonomy; absent the coercive state power involved in the "old eugenics," they argue, eugenic decisions are unobjectionable if not morally imperative.[198] Some scholars have asserted a parental duty to ensure that newborns possess a minimum genetic endowment such that birth is not "unfair" to the child.[199]

These polar views belie a pervasive uncertainty about the morality of the practice. Critics have not pursued significant restrictions on either genetic testing or selective abortion. Joined by disability advocates, they have called for measures to ensure that decisions are fully informed.[200] These critics have also argued for restrictions on prenatal torts[201] and questioned the constitutionality of laws that relax limits on abortion in cases of fetal disability.[202] Such approaches abstain from the larger ethical question about selective abortion answered implicitly in comparisons to the eugenics movement. Nor do they reflect a robust effort to reign in the practice; legal enforcement of informed consent constitutes a weak tool at best, and limitations on prenatal torts would affect little more than the pressure on doctors to push for testing.[203] We are left with a chorus of concerns about the morality of the practice, yet few clear statements of when it may be acceptable.

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[196] *See generally* Michael J. Malinowski, *Choosing the Genetic Makup of Children: Our Eugenics Past-Present, and Future?* 36 CONN. L. REV. 125 (2003).

[197] JURGEN HABERMAS, THE FUTURE OF HUMAN NATURE 58-60 (2003); *see also* MICHAEL SANDEL, THE CASE AGAINST PERFECTION: ETHICS IN THE AGE OF GENETIC ENGINEERING 85 (2007) ("The problem with eugenics and genetic engineering is that they represent the one-sided triumph of willfulness over giftedness, of dominion over reverence, of molding over beholding.").

[198] *See* ALLEN BUCHANAN ET AL. FROM CHANCE TO CHOICE: GENETICS AND JUSTICE 60 (2000) ("Reprehensible as much of the eugenic program was, there is something unobjectionable and perhaps even morally required in the part of its motivation that sought to endow future generations with genes that might enable their lives to go better."); RONALD DWORKIN, SOVEREIGN VIRTUE: THE THEORY AND PRACTICE OF EQUALITY 452 (2000) ("[I]f playing God means struggling to improve our species, bringing into our conscious designs a resolution to improve what God deliberately or nature blindly has evolved over eons, then the first principle of ethical individualism commands that struggle.").

[199] *See, e.g.*, Bonnie Steinbock & Ron McClamrock, *When is Birth Unfair to the Child*, 24 HASTINGS CENTER REP. 15, 20 (1994) ("[B]efore embarking on so serious an enterprise as parenthood, people should think about the consequences for their offspring. Some circumstances may be so awful that birth is unfair to the child."); Ronald M. Green, *Parental Autonomy and the Obligation Not to Harm One's Child Genetically*, 25 J. L. MED. & ETHICS 5, 10 (1997) ("Parents have a *prima facie* obligation not to bring a child into being deliberately or negligently with a health status likely to result in significantly greater disability or suffering, or significantly reduced life options relative to the other children with whom he/she will grow up.").

[200] *See, e.g.*, Dixon, *supra* note 42, at 27 (arguing for informational requirements because "screening is being left largely to the discretion of the medical profession and is being performed for the benefit of prospective parents, not their fetuses").

[201] *See, e.g.* Darpana M. Sheth, *Better off Unborn? An Analysis of Wrongful Birth and Wrongful Life Claims Under the Americans with Disabilities Act*, 73 TENN. L. REV. 641 (2006) (arguing that wrongful birth and wrongful life claims violate the ADA).

[202] *See, e.g.*, Field, *supra* note 78, at 97-101 (arguing that such laws violate the Equal Protection Clause).

[203] *See* Peter H. Schuck, *Rethinking Informed Consent*, 103 YALE L.J. 899, 959 ("Although no one contests [informed consent's] goals of patient autonomy and improved decisionmaking, its present effectiveness in achieving those goals is quite limited; indeed, its most sophisticated advocates accept this fact, even while condemning the informed consent gap, which is a measure of this failure.").

Among defenses of the practice, Ruth Schwartz Cowan's recent account provides a particularly instructive glimpse into the uncertainty that lurks beneath statements of moral clarity. Cowan recalls her decision to undergo prenatal testing as one fraught with ambivalence about the morality of the practice given its eugenic overtones.[204] After decades of research, however, Cowan proclaims that she now feels capable "of giving my full assent, without guilt, without ambivalence, without apology."[205] She explains that eugenicists sought to improve the human race through oppression of the genetically unfit, while modern geneticists seek to relieve human suffering through aid to the genetically unfit.[206] For such a profound refutation of decades-old ambivalence, this is a profoundly unconvincing distinction. Simply stated, benevolent intentions need not translate into morally unambiguous behavior. Nor does Cowan's account withstand historical scrutiny; eugenicists portrayed their project as an effort to relieve human suffering and viewed measures like sterilization as aid to the genetically unfit.[207]

Once again, individual decisions present conflicting sentiments about selective abortion with exceptional clarity. A growing body of scholarship has begun to document pervasive feelings of guilt and uncertainty in these decisions.[208] Women report hoping that they will miscarry naturally and thus avoid the decision presented by a positive diagnosis.[209] Marsha Saxton and Carole Browner found that pregnant women express "upbeat, strongly positive, and almost romanticized attitudes" about individuals with disabilities, but "extremely fearful and negative attitudes regarding the possibility that their own child might be disabled."[210] Women appear to exaggerate the needs of children with disabilities and exaggerate social prejudices such children would encounter in order to rationalize their choices to proceed with abortion.[211] Yet guilt is a common thread. As one woman lamented, she had been wrong to "bow before the false god of intelligence," and yet she would have been wrong "to bring into the world a child the world so clearly does not want and will not care for."[212]

Disability advocates betray the same internal turmoil. Adrienne Asch condemns selective abortion as an instrument of social prejudice and argues forcefully that most forms of disability are inherently neutral. Yet Asch refuses to accept that women who choose selective abortion are anything more than misguided; she explicitly rejects the

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[204] RUTH SCHWARTZ COWAN, HEREDITY AND HOPE 226 (2008).
[205] *Id.* at 227.
[206] *Id.* at 236 ("The reproductive goals of medical geneticists are thus precisely the opposite of those of eugenics. Eugenicists wanted to ensure that the people they defined as genetically unfit did not reproduce; that is why they pushed for sterilization and segregation. Genetic screening was developed by medical geneticists to help the genetically 'unfit,' precisely the people the eugenicists would have sterilized, have as many children as they wanted.").
[207] For a particularly stark example these views, see PAUL POPENOE & E.S. GOSNEY, STERILIZATION FOR HUMAN BETTERMENT: A SUMMARY OF RESULTS OF 6,000 OPERATIONS IN CALIFORNIA, 1909-1929, at 30-38 (1929). For an overview of the connections between modern genetics and the eugenics movement of the first part of the 20th century, see KEVLES, *supra* note 195, at 251-301.
[208] For the most searching study into these sentiments, see ROTHMAN, *supra* note 138.
[209] Judith L.M. McCoyd, *"I'm Not a Saint": Burden Assessment as an Unrecognized Factor in Prenatal Decision Making*, 18 Qualitative Health Res. 1489, 1492 (2008).
[210] Saxton, *supra* note 52, at 226.
[211] *Id.* at 227.
[212] Barbara Katz Rothman, *Prenatal Diagnosis*, *in* ETHICAL ISSUES IN MODERN MEDICINE 379, 384-85 (John D. Arras & Bonnie Steinbock eds., 1995)

argument that their decisions are immoral.[213] Family members have expressed this ambivalence both in their decisions with respect to testing and in their efforts to address the ethical content of testing. It appears that many parents of children with genetic conditions choose to avoid prenatal testing so as to avoid the possibility of a decision about abortion.[214] In a series of letters with her son, Eva Feder Kittay betrays a similar ambivalence in a struggle to reconcile her love for her daughter Sesha and the pain she associates with Sesha's profound needs. Although Kittay initially condones testing and writes that the decision to have a child like Sesha "is not one that I could easily endorse,"[215] she concludes with profound doubts about what testing might have meant for Sesha and her family.[216]

The Prenatally and Postnatally Diagnosed Conditions Awareness Act reflects another structurally ambivalent legal outcome. The Act expresses social concerns about the practice in general terms, yet it skirts the difficult ethical questions at its core. Like the delicate dance conducted by physicians and expectant women, the Act limits its concern to testing and makes no mention of abortion. Though the Act may assuage some concerns in the disability community about informed consent, it offers no enforceable means to affect individual decisions. Nor does it promise much more than an ideal of informed consent; proposed funding, though significant, would have to cover a near limitless array of diagnosable conditions and a dynamic set of changing technologies. More than anything else, the Act provides a public statement of moral uncertainty that we may privately ignore.

C. Ambivalence and Disability

To say that we are ambivalent about selective non-treatment and selective abortion does not address the source of our mixed emotions about those practices. One possibility lies in ambivalence about death. Writing on social efforts to control the medical administration of death, Robert Burt has argued that we view death as at once inherently wrongful and a desirable release from suffering at the edge of life.[217] Efforts to

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[213] Adrienne Asch, *Can Aborting "Imperfect" Children Be Immoral? in* ETHICAL ISSUES IN MODERN MEDICINE 386, 389. ("Although I have serious moral qualms about selective abortion for sex or disability, I do not have moral objections."). This distinction may be logically plausible, but it does not seem to follow from Asch's harsh denunciation of the practice.

[214] *See* Susan E. Kelly, *Choosing Not to Choose: Reproductive Responses of Parents of children with Genetic Conditions or Impairments*, 31 Soc. Health & Illness 81 (2008). Kelly describes this pattern as a product of "a deep ambivalence regarding the choices and consequences" testing entails. *Id.* at 86.

[215] Eva Feder Kittay & Leo Kittay, *On the Expressivity and Ethics of Selective Abortion for Disability: Conversations with My Son, in* PRENATAL TESTING AND DISABILITY RIGHTS 165, 168.

[216] *Id.* at 189 ("Maybe, and it is hard to think of it, I would have aborted. And we would never know Sesha. And that loss seems unimaginable. But I may have given birth to another child, whose nonexistence would seem equally unfathomable, and I would have wondered about the child I aborted. I would have stopped every time I saw a mentally retarded child or adult and wondered, with tears in my eyes. Just as now, with tears in my eyes, I think about the young woman of twenty-seven who might be a graduate student like my wonderful graduate students, or be thinking about marriage, or be out on the ski slopes with you. In each case there is a loss. It is a human tragedy.")

[217] BURT, *supra* note 4, at 5 ("[D]eath in itself provokes ambivalence, no matter how fervently we wish it were not true. I believe that the struggle to deny ambivalence—by efforts to control's one's own death or

overcome our moral doubts about the infliction of death, he argues, merely inflame and intensify these doubts.[218] Burt suggests that these efforts produce needless suffering both for patients forced to endure futile treatments and patients dealt premature death.[219] As Burt acknowledges, disability plays an important role in this dynamic. We might view death to be a justifiable choice in the face of life with a disability, and yet harbor doubts about the morality of inflicting death.[220]

We must be careful, however, to disentangle ambivalence about death from ambivalence about disability. Social discourse concerning selective abortion and selective non-treatment has not merely betrayed doubts about the propriety of inflicting death. It has expressed doubts about the disability-specific justification for choosing death. This justification inflames views that disability is a neutral form of human variation. To our unease, it suggests that less able is somehow less worthy of human dignity or legal protection. Yet the justification remains a powerful one. It captures our understanding that most disabilities are inherently undesirable traits that one would reasonably avoid. More than that, it gives voice to our concern that disability may yield pain and difficulty beyond our powers to address. We feel discomfort in decisions to inflict death on the basis of disability because we see these decisions as at once wrongful and justifiable.[221]

Both of these views have origins deep within our cultural constructs. Let us first consider understandings of disability as inherently undesirable. We define disability as a marker of human deviation and limitation. It is a blemish upon socially idealized forms, a locus at the boundary of our notions of purity and impurity.[222] The range of devalued forms renders generalization difficult if not impossible. However, a few trends emerge. Socially, disability confers stigma and rejection; it embodies Erving Goffman's notion of spoiled identity and Mary Douglas' notion of pollution.[223] It is a form of difference that threatens our self-conceptions and our social norms. Biologically, disability confers frailties and weaknesses beyond those we must typically endure. It is not just difference; it is undesirable difference that carries the threat of dependency, poverty, and coercion.[224]

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the death of others, to find moral justification and emotional satisfaction in embracing death for oneself or for others—can never be more than a temporary palliative.").

[218] *Id.* ("I believe that to banish ambivalence by rigidly embracing the positive valuations in the ideals of autonomy, of a good death, or of physicians' benevolence leads ultimately to the intensified eruption of their inherent negative valuations into guilt-ridden, hurtful conduct.").

[219] Burt details these possibilities most notably in the contexts of abortion, physician assisted suicide, and withdrawal of life-sustaining treatment, and the death penalty. He concludes that the "intentional, unambiguous infliction of death in any context should be rigorously avoided and socially disapproved," and that when death cannot be avoided, "ambivalence about its moral status is also unavoidable and should, accordingly, be self-consciously and visibly honored through the design of practical techniques for highlighting and even amplifying its inevitable presence." *Id.* at 158.

[220] For example, see his discussion of the *Repouille* case. *Id.* at 27-46.

[221] Although the preceding discussion of Burt's work combines normative and descriptive elements, this Part will limit itself to a descriptive discussion of ambivalence about disability. Part III will delve into the normative implications of this descriptive analysis.

[222] Here I mean to describe the motivations behind classifications of disability rather than characterize the absolute desirability or undesirability of those classifications.

[223] *See generally* ERVING GOFFMAN, STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY (1963); MARY DOUGLAS, PURITY AND DANGER: AN ANALYSIS OF THE CONCEPT OF POLLUTION AND TABOO (1966).

[224] For a somewhat jarring discussion to this effect, consider Dax Cowart's stated reasons for his desire to commit suicide rather than endure life with a disability. ROBERT A. BURT, TAKING CARE OF STRANGERS:

Much though we may try to deconstruct these dynamics, our understandings of disability and our understandings of the "good" are codependent and mutually reinforcing.[225]

On an individual level, disability arouses deep-seated aversions to illness, aging, and death. The push toward disability is nearly as inevitable as the push toward death, and it serves as both a reminder and a threat of mortality.[226] Like illness, disability represents an "ontological assault" on the self. It threatens to transform the life we have known into a life we can scarcely imagine.[227] Like death, disability has the power to destroy us altogether. It threatens to transform consciousness into a nothingness as unfathomable and empty as death.[228] Individual efforts to conceive of life with a disability approach an empathic gulf; we struggle to imagine the new self that would emerge on the other side.[229] We assume individuals with disabilities lead lives of relentless suffering and despair. We imagine theirs a fate not much better than death, if not worse.[230] We quarantine them in private homes, back wards, and isolated outposts. And we turn to divinity and to science in hopes of treatment and cure.[231]

On a societal level, disability inflames our basic orientations toward subsistence and social order. The limitations wrought by disability do not only affect individuals with disability; they also impose unwanted burdens on caregivers and society more broadly.[232] These burdens have been dramatized in portrayals of disability as evidence of divine sanction and as an augury of famine, disease, and misfortune.[233] They have been portrayed further in myriad depictions of disability as a marker of immorality and

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THE RULE OF LAW IN DOCTOR-PATIENT RELATIONS 174-180 (1979) (Cowart was denominated "David G" in Burt's book, but has since publicly revealed his identity).

[225] That is, classifications of disability depend upon our conceptions of what is desirable, and their classification both enshrines and reinforces those conceptions.

[226] For a powerful statement to this effect, see ROBERT F. MURPHY, THE BODY SILENT 116-17 (1990) ("The disabled serve as constant, visible reminders to the able-bodied that the society they live in is a counterfeit paradise, that they too are vulnerable. We represent a fearsome possibility.").

[227] *See* Edmund D. Pellegrino, *Toward a Reconstruction of Medical Morality: The Primacy of the Act of Profession and the Fact of Illness*, 4 J. MED. & PHIL. 32, 44 (1979) ("The person who becomes a patient suffers what is nothing less than an ontological assault. In our usual state we see ourselves identified with our bodies, facing the world and acting on it in essential unity. In illness the body is interposed between us and reality—it impedes our choices and actions and is no longer fully responsive.")

[228] *See* MICHEL FOUCALT, MADNESS AND CIVILIZATION: A HISTORY OF INSANITY IN THE AGE OF REASON 16 (Richard Howard trans., 1965) ("The substitution of the theme of madness for that of death does not mark a break, but rather a torsion in the same anxiety. What is in question is still the nothingness of existence, but this nothingness is no longer considered an external, final term, both threat and conclusion; it is experienced from within as the continuous and constant form of existence.")

[229] For an eloquent description of the personal reinvention that may accompany the acquisition of a disability later in life, see REYNOLDS PRICE, A WHOLE NEW LIFE: AN ILLNESS AND A HEALING 178-86 (1994).

[230] Indeed, recent empirical work suggests that we overestimate the decreased perception of quality of life that accompanies disability. For a recent survey of these findings, see John Bronsteen, Christopher Buccafusco & Jonathan S. Masur, *Hedonic Adaptation and the Settlement of Civil Lawsuits*, 108 COLUM. L. REV. 1516, 1526-35 (2008).

[231] For a historical overview of these forces, see FOUCALT, *supra* note 228, at 241-78.

[232] This is not to say that care giving responsibilities are always unwanted; they are often the source of great satisfaction. It is to say that disability often yields unexpected and heightened responsibilities we would often prefer to avoid.

[233] *See* WAYLAND D. HAND, MAGICAL MEDICINE 57-64 (1980).

wickedness.[234] Individuals with disabilities have been cast as less than fully human, as animals and monsters not subject to the laws that govern human ordering.[235] They have been portrayed as life unworthy of life, as social parasites predisposed to laziness, criminality, and sexual predation.[236] And they have been subject to a persistent urge to eliminate disability altogether, if not by cure then by segregation, institutionalization and murder.[237] Such impulses have fueled a consistent pattern of deprivation.

More broadly, disability threatens our understanding of humanity and ourselves. In individuals with disabilities, we confront people who defy our present social orderings. Disability provokes fears and anxieties about the foreign and the strange, but it does more than that.[238] It challenges our efforts to order the world. It blurs the boundaries between social member and social outcast, social good and social evil, human and inhuman.[239] One response to such a challenge is to view the exclusion of the other as an affirmation of the prevailing social order. As Julia Kristeva writes, "the abject has only one quality of the object—that of being opposed to *I*."[240] In devaluing disability, social systems and social actors may confirm their own valuations.[241] The alternative, as Kristeva explains, is to occupy a "place where meaning collapses" and "the abject does not cease challenging its master."[242] In a sense, then, although the content of disability may change, its presence and devaluation is necessary for coherent social order.

Now let us turn to convictions that disability is a neutral element of individual identity. In challenging our self-perceptions, disability may elicit a wholly different response, that of veneration and exaltation. As Michel Foucalt has argued with respect to mental illness, disability may provoke not only devaluation but also a form of worship.[243] Traditionally, disability has evoked powerful associations with divinity and the

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[234] *See* Leonard Kriegel, *The Cripple in Literature*, *in* Images of the Disabled, Disabling Images 31, 31-38 (Alan Gartner & Tom Joe eds., 1987).

[235] For an overview of these portrayals, see HERBERT C. COVEY, SOCIAL PERCEPTIONS OF PEOPLE WITH DISABILITIES IN HISTORY 6-8 (1998).

[236] For an overview of such views in relation to the international eugenics movement, see KEVLES, *supra* note 195, at 70-84.

[237] The perfect storm of these urges occurred in the Nazi T-4 programs. For a history of the program and its antecedents, see ROBERT PROCTOR, RACIAL HYGIENE: MEDICINE UNDER THE NAZIS (1985).

[238] For an eloquent discussion of the far-reaching consequences of such fears see, for example, SANDER L. GILMAN, DIFFERENCE AND PATHOLOGY: STEREOTYPES OF SEXUALITY, RACE, AND MADNESS 20 (1985) ("We project [our] anxiety onto the Other, externalizing our loss of control…. The 'bad' self, with its repressed sadistic impulses, becomes the 'bad' Other; the 'good' self/object, with its infallible correctness, becomes the antithesis to the flawed image of the self, the self out of control.")

[239] This sentiment is well expressed in studies of the appeal of freak shows. *See, e.g.*, LESLIE FIEDLER, FREAKS: MYTHS AND IMAGES OF THE SECRET SELF 347 (1978) (arguing that the appeal of freak shows lay in part in the "experience for a moment out of time the normality of Freaks, the freakishness of the normal, the precariousness and absurdity of being, however we define it, fully human").

[240] JULIA KRISTEVA, POWERS OF HORROR: AN ESSAY ON ABJECTION 1 (Leon S. Roudiez trans. 1982).

[241] Once again, the appeal of freak shows proves illuminating. As Elizabeth Grosz argues, "[f]ascination with the monstrous is testimony to our tenuous hold on the image of perfection. The freak confirms the viewer as bounded, belonging to a 'proper' social category." Elizabeth Grosz, *Intolerable Ambiguity: Freaks as/at the Limit*, *in* FREAKERY: CULTURAL SPECTACLES OF THE EXTRAORDINARY BODY 55, 65 (Rosemarie Garland Thomson ed., 1996).

[242] KRISTEVA, *supra* note 240, at 2.

[243] This view is captured well by José Barchilon, who writes that Foucalt "feels that Freud's death instinct also stems from the tragic elements which led men of all epochs to worship, laugh at, and dread folly simultaneously." José Barchilon, *Introduction* to FOUCALT, *supra* note 228, at viii.

supernatural. Consider, for example, beliefs that the mentally ill can speak with gods and that the blind can foresee the future.[244] Such paradoxical visions of disability as both a curse and a sacrament pervade Henri-Jacques Stiker's intricate analysis of disability in Western history.[245] In her study on social pollution, Mary Douglas has likewise documented instances where even the most devalued pollution becomes, for an instant, a source of tremendous ritual power for good.[246] For Foucalt, mental illness reveals our true nature and knowledge beyond our powers of understanding; indeed, he argues, "madness fascinates because it is knowledge."[247]

Traditionally, however, exaltations of disability have been relatively rare and understated as compared to devaluations. Modern accounts emphasize the positive contributions people with disabilities make to a diversity of perspectives and experiences.[248] In this vein, scholars have explored the potential creative benefits associated with certain disabilities.[249] Such views push up against a broader vision of disability that recognizes its undesirability and yet affirms the inherent humanity of individuals affected by it. Glowing accounts of "super-crips," individuals who achieve great success despite their disabilities, celebrate the strength of the human spirit in overcoming disability rather than the disability itself.[250] Traditional beliefs that people should help those in need similarly affirm the humanity of individuals with disabilities while recognizing the undesirability of those disabilities.[251] Similar tendencies toward valuation of affected individuals emerge in primate groups as well.[252]

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[244] For an overview of these trends, see COVEY, *supra* note 235, at 8-9.

[245] HENRI-JACQUES STIKER, A HISTORY OF DISABILITY (William Sayers trans., rev. ed. 1999). Stiker's discussions of the valuation and devaluation of disability in the pre-modern period is particularly illuminating. *See id.* at 23-64.

[246] *See* DOUGLAS, *supra* note 223, at 203-04 ("In a given culture it seems that some kinds of behaviour or natural phenomena are recognised as utterly wrong by all the principles which govern the universe…. Most of the items receive varying degrees of condemnation and avoidance. Then suddenly we find that one of the most abominable or impossible is singled out and put into a very kind of ritual frame that marks it off from other experience."). For a discussion of madness in this regard, see *id.* at 217-18.

[247] FOUCALT, *supra* note 228, at 21. Foucalt explains further that "[w]hile the man of reason and wisdom perceives only fragmentary and all the more unnerving images of [truth], the Fool bears it intact as an unbroken sphere: that crystal ball for which all others is empty is in *his* eyes filled with the density of an invisible knowledge." Yet, Foucalt asks, "What does it presage, this wisdom of fools? Doubtless, since it is a forbidden wisdom, it presages both the reign of Satan and the end of the world; ultimate bliss and supreme punishment; omnipotence on earth and the infernal fall." *Id.*

[248] For a seminal statement to this effect, see WOLF WOLFENSBERGER, THE PRINCIPLE OF NORMALIZATION IN HUMAN SERVICES (1972),

[249] *See, e.g.*, MICHAEL FITZGERALD & BRENDAN O'BRIEN, GENIUS GENES: HOW ASPERGER TALENTS CHANGED THE WORLD (2007) (profiling historical figures thought to have had Asperger's syndrome, including Thomas Jefferson, Charles Darwin, and Albert Einstein); KAY REDFIELD JAMISON, TOUCHED WITH FIRE: MANIC DEPRESSIVE ILLNESS AND THE ARTISTIC TEMPERAMENT (1996) (chronicling the connection between depression and creativity).

[250] *See* SHAPIRO, *supra* note 82, at 16-20.

[251] For a global view of these trends, see generally David Braddock & Susan L. Parish, *An Institutional History of Disability*, *in* AN INSTITUTIONAL HISTORY OF DISABILITY, *IN* DISABILITY AT THE DAWN OF THE 21ST CENTURY AND THE STATE OF THE STATES 3 (David Braddock ed., 2002).

[252] For a discussion of this phenomenon, see, for example, FRANS DE WAAL, GOOD NATURED: THE ORIGINS OF RIGHT AND WRONG IN HUMANS AND OTHER ANIMALS 52 (1997) (noting that disability may provoke teasing and abuse in primate groups, but that "[a]mong animals who have lived together for a long time, however, such maltreatment is not the rule. What is most striking about adjustment to handicapped

These tendencies no doubt derive in part from feelings of empathy and connection with individuals apart from their disabilities. The tension between valuing a person and disvaluing a defining personal characteristic like disability cannot be easily disentangled. Unlike death, we experience disability apart from its infliction or occurrence. Disability becomes a personal trait, a constitutive element of the self. Freak shows did not arouse such fascination merely as a product of affirming normality at the expense of deviance; they also aroused an uncomfortable recognition that even individuals so different from our conceptions of humanity could also be so human.[253] Modern scholarship indicates that social integration leads us to develop a richer understanding of individuals apart from their disabilities; interaction and exchange appears to prompt recognition of commonality and humanity.[254] Such views have elicited a persistent ideal of social integration expressed across a range of social orders and cultural frameworks.[255]

Attempts to distinguish between disability and neutral difference inflame these positive valuations. Our efforts to define disability face enough difficulties given the continuum of valuations that inevitably accompany any personal characteristic.[256] They are made more difficult, however, by concerns about the meaning of such classification. To cast a segment of society apart as undesirable is in some measure to deny that segment basic dignity and humanity.[257] Such devaluation contravenes the common humanity, empathic connection, and admiration we feel for individuals with disabilities. In devaluing these individuals, we at once affirm our humanity and compromise it. In exalting them we arrive at the same uncomfortable contradiction.[258] The discomfort wrought by these contradictions has yielded attempts to eliminate the notions of pollution that produce them. In casting disability as an unremarkable part of human variation and pursuing integration, we reach for the possibility of deconstructing our discomfort.[259]

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monkeys is that it so often takes the opposite form: instead of being torn to pieces or abandoned as a useless community member, the disabled individual receives extra tolerance, vigilance, and care.").

[253] *See* Grosz, *supra* note 241, at 65 ("The viewer's horror lies in the recognition that this monstrous being is at the heart of his or her own identity, for it is all that must be ejected or abjected from self-image to make the bounded, category-obeying self possible.").

[254] For an overview of these studies, see Timothy M. Cook, *The Americans with Disabilities Act: The Move to Integration*, 60 TEMP. L. REV. 393, 445-54 (1991). This also applies to severely disabled individuals who exhibit few characteristics we typically associate with humanness. *See* Robert Bogdan & Steven J. Taylor, *Relationships with Severely Disabled People: The Social Construction of Humanness*, 36 SOC. PROB. 135 (1989).

[255] *See generally* STIKER, supra note 245. For a statement to this effect, see David T. Mitchell, *Forward* to STIKER, *supra* note 245, at xi ("ironically, a professed will to integration characterizes most epochs' treatment of people with disabilities").

[256] For a discussion of the perils of classification see, for example, SUSAN WENDELL, THE REJECTED BODY: FEMINIST PHILOSOPHICAL REFLECTIONS ON DISABILITY 57-81 (1996).

[257] For a discussion of social separation and attributions of defilement see, for example, DOUGLAS, *supra* note 223, at 8-35.

[258] These two lines warrant an additional exposition. In devaluing disability we affirm our humanity in difference and yet compromise it by denying feelings of compassion associated with humanness. In exalting disability we affirm our humanity through our compassion and yet we compromise our humanity in blurring the boundaries of humanness.

[259] For a discussion of this phenomenon and a critique of its role in contemporary treatment of disability, see STIKER, *supra* note 245, at 126-58. Stiker describes the modern emphasis on rehabilitation as the culmination of "a culture that attempts to complete the act of identification, of making identical. This act will cause the disabled to disappear and with them all that is lacking, in order to assimilate them, drown them, dissolve them in the greater and social whole." *Id.* at 128. The goal, he argues, is that "[t]he face of

Given these competing sentiments, it is not surprising that ambivalence remains in decisions about disability even when we remove death from the picture. Consider Elizabeth Schiltz's exploration of how she would react if a scientist found a "cure" for her son's Down syndrome. She writes, "I almost certainly would give it to him. But I will admit that I would pause beforehand."[260] Schiltz explains that she would think hard about a conversation between a teenager with Down syndrome and her mother. The teenager reportedly asked her mother whether she would have Down syndrome in heaven. According to Schiltz, the mother replied that she thought not. The daughter replied, "But how will you know who I am then?"[261] Schiltz asks further "whether the world would really be a better place without my son's soft, gentle, deep, almond-shaped eyes."[262] Although Schiltz subscribes to a view of disability as inherently limiting, she struggles to reconcile this view with her love for a family member powerfully shaped by it.

Consider as well how individuals with disabilities respond to Schlitz's cure question. Nancy Weinberg asked a sample of individuals whether they would cure their disability if given the choice.[263] The sample split roughly in half. Among the responses, Weinberg discerned subjects "who were very bitter about being disabled," subjects who "enjoyed being disabled and embraced their disability," and a plurality of individuals with mixed sentiments.[264] Susan Wendell lends depth to the reaction of the last group. In considering whether she would choose to cure her chronic fatigue syndrome, Wendell reveals that her "resistance to the attitude that I need to be cured in order to be a whole or fully acceptable person infuses [her] desire for a 'cure' with ambivalence."[265] Wendell makes clear that she would welcome a cure for others, but that to "cure" her disability would forever annihilate a fundamental part of herself. She concludes, somewhat uncertainly, that she would "joyfully accept a cure, but I do not need one."[266]

A small body of empirical studies presents a broader picture of ambivalence about disability. Most prominently, researchers led by Irwin Katz have documented "contradictory feelings" toward people with disabilities in the form of simultaneous "hostility on the one hand" and "compassion on the other."[267] Katz conducted a series of controlled experiments testing the behavior of research subjects confronted with unfamiliar individuals with disabilities. Across a variety of settings, he found that subjects developed polar views based on stimulus events that reinforced either positive or negative sentiments.[268] Using similar methods, other scholars have traced comparable dynamics in reactions to the poor, the sick, the elderly, racial groups, and other socially

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society should not have any pimples. 'Would that we could all be the same!' Society's wish, as expressed through the treatment of disability, is to make identical, *without making equal*." *Id.* at 150.

[260] Elizabeth R. Schiltz, *Confessions of A "Genetic Outlaw,"* BUSINESS WEEK, July 20, 2006, at X, *available at* http:/www.businessweek.com/technology/content/jul206/tr20060720_148057.htm.

[261] *Id.*

[262] *Id.*

[263] Nancy Weinberg, *Another Perspective: Attitudes of People with Disabilities*, *in* ATTITUDES TOWARD PERSONS WITH DISABILITIES 141, 142 (Harold E. Yuker ed., 1988).

[264] *Id.* at 149.

[265] WENDELL, *supra* note 256, at 83 (1996).

[266] *Id.* at 84.

[267] Irwin Katz, R. Glen Hass & Joan Baily, *Attitudinal Ambivalence and Behavior Toward People with Disabilities*, *in* ATTITUDES TOWARD PERSONS WITH DISABILITIES 47, 47 (Harold E. Yuker ed., 1988).

[268] For a summary of these studies, see *id.*

marginalized populations.[269] In light of these findings, a few scholars have suggested that efforts to ensure unequivocal responses to disability and other traits leave insufficient room for the unavoidable reality of ambivalence.[270]

In addition to these studies, a few scholars have attempted to explain social responses to disability with reference to ambivalence. Leslie Fielder, for example, has detailed social responses that simultaneously devalue individuals with disabilities as "divinely sent omens of disaster" and value them "as if they were themselves divine."[271] She argues that these views at once confirm our common humanity and reflect our unease with impairment and deviance.[272] In a similar vein, a number of scholars have argued that the "fantasy of wiping out disability," yields simultaneous efforts to uplift and cure individuals with disabilities and to cast aside those individuals who defy normalization and repair.[273] For the most part, this scholarship has identified ambivalence about disability only to criticize societal failures to adequately address issues related to disability.[274] Accordingly, ambivalence about disability is worthy of little more than condemnation.

And yet even these scholarly responses also reflect ambivalence about disability. Scholars have long conceptualized disability with reference to an intractable pair of descriptive models. The medical model of disability describes disability as an undesirable deviation from normal species functioning.[275] The social model of disability describes disability as a socially constructed devaluation of otherwise inherently neutral human

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[269] *See generally* IRWIN KATZ, STIGMA: A SOCIAL PSYCHOLOGICAL ANALYSIS (1981); Peter Glick & Susan T. Fiske, *The Ambivalent Sexism Inventory: Differentiating Hostile and Benevolent Sexism*, 70 J. PERSONALITY & SOC. PSYCH. 491 (1996); Patricia W. Linville & Edward E. Jones, *Polarized Appraisals of Out-Group Members*, 38 J. PERSONALITY & SOC. PSYCH. 689 (1980).

[270] *See, e.g.*, Marten Soder, *Prejudice or Ambivalence? Attitudes Toward Persons with Disabilities*, 5 DISABILITY, HANDICAP & SOC'Y 227, 236 (1990) ("What these [studies] suggest is that there are at least two different valuations involved: the devaluation of disability as such on the one hand and a benevolent sympathy toward persons with disabilities on the other hand. This points to a situation that is not well understood in terms of prejudice.").

[271] Leslie A. Fiedler, *The Tyranny of the Normal*, 14 HASTINGS CENTER REP. 40, 40 (1984)

[272] *See id.* at 41-42 (arguing that disability "serves to remind, as the arts have long tried to do, of what we now find it difficult to confess except in troubled sleep: that those wretched caricatures of our idealized body image, which at first appear to represent what is most absolutely 'Other' (thus reassuring us who came to gape that we are 'normal') are a revelation of what in our deepest psyches we suspect we recognize as the Secret Self. After all, not only do we know that each of us is a Freak to someone else; but in the depths of our unconscious (where the insecurities of childhood and adolescence never die) we seem forever Freaks to ourselves.").

[273] Rosemarie Garland Thomson, *The Cultural Logic of Euthanasia: "Sad Fancyings" in Herman Melville's "Bartleby,"* 76 AMERICAN LITERATURE 777, 781 (2004). *See also* George S. Baroff, *Eugenics, "Baby Doe," and Peter Singer: Toward a "More Perfect Society,"* 38 MENTAL RETARDATION 73, X (2000) (arguing that disability "impedes the accomplishment of consensual adaptive goals and, in that sense, cannot be viewed without some wish that it were not present. It is, at least, this inherent ambivalence toward mental retardation or any disability that must be recognized and acknowledged.").

[274] *See, e.g.*, ANITA SILVERS, DAVID WASSERMAN, & MARY B. MAHOWALD, DISABILITY, DIFFERENCE, DISCRIMINATION: PERSPECTIVES ON JUSTICE IN BIOETHICS AND PUBLIC POLICY 19 (1998) (decrying the "ambivalence about whether people with disabilities should assume ordinary roles or be confined to specially protected ones [that] pervades the culture").

[275] No scholars have affiliated themselves with this model. Rather, it serves as a symbol created by disability advocates to capture the approach taken by opponents. This is not to say, however, that it does not accurately describe the views espoused by much of the public and the academy. *See* TOM SHAKESPEARE, DISABILITY RIGHTS AND WRONGS 15-16 (2006).

differences.[276] Whereas the medical model locates disability within biology, the social model locates disability in cultural practices that give content to biology.[277] To clarify the differences between these models, scholars often cite the example of an individual in a wheelchair unable to climb a set of stairs. According to the medical model, the individual is disabled because she is unable to walk like most people. According to the social model, it is society's failure to construct a ramp that transforms this individual's neutral impairment into a disability.[278]

It does not take long to recognize that both models represent ideal types in the Weberian sense. The social model makes a powerful contribution in its recognition that disability is a product of a complex interaction between biology and social context. It fails to address, however, the possibility that impairments may be inherently undesirable in any social context, limiting a person's capacity.[279] The medical model captures this latter point; we may organize social institutions so as to fully accommodate blind individuals, but these people will still be unable to see a beautiful sunset. Yet it fails to address the role of prejudice, stigma, and a social orientation toward normality that give impairments particular relevance.[280] Accordingly, a number of scholars have suggested conceptions of disability that combine elements from these approaches.[281] These suggestions have unsurprisingly generated a debate about the appropriate balance of social and biological forces in addressing disability.[282]

Nevertheless, the traditional dichotomy continues to form the foundation of discussions theorizing disability. Disability advocates have assessed the merits of legal developments by gauging their reliance on social or medical views of disability. This has been particularly apparent with respect to the ADA. Advocates initially heralded the Act as a victory for the social model;[283] as courts construed the legislation narrowly, many advocates blamed restrictive decisions on the continued pervasion of the medical model.[284] The persistence of the framework has prompted some disability advocates to

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[276] For early statements along these lines see, for example, Kai T. Erikson, *Notes on the Sociology of Deviance*, 9 SOCIAL PROBLEMS 307, 308 (1962) ("Deviance is not a property *inherent in* certain forms of behavior; it is a property *conferred upon* those forms by the audiences which directly or indirectly witness them); THOMAS S. SZASZ, THE MANUFACTURE OF MADNESS: A COMPARATIVE STUDY OF THE INQUISITION AND THE MENTAL HEALTH MOVEMENT (1970) (analogizing social constructions of mental illness to social constructions of witchcraft).

[277] For a classic statement of this perspective, see MICHAEL OLIVER, THE POLITICS OF DISABLEMENT: A SOCIOLOGICAL APPROACH 58 (1990) ("[T]he disabled individual is an ideological construction related to the core ideology of individualism and the peripheral ideologies related to medicalisation and normality. And the individual experience of disability is structured by the discursive practices which stem from these ideologies.").

[278] *See, e.g.*, Mary Crossley, *The Disability Kaleidoscope*, 74 NOTRE DAME L.R. 621, 654 (1999).

[279] For a thorough criticism of the social model from a disability rights perspective, see SHAKESPEARE, *supra* note 275, at 31-53.

[280] This criticism has fueled the modern disability rights movement. *See* SCOTCH, *supra* note 81, at 15-40 (1984).

[281] *See, e.g.*, SHAKESPEARE, *supra* note 275, at 55-67.

[282] For a trio of such efforts from a philosophical bent, see SILVERS, *supra* note 274.

[283] *See, e.g.* Cook, *supra* note 254, at 469 ("Congress's intent to prescribe the race discrimination standards under the Civil Rights Act of 1964 as the standards for disability discrimination under the ADA could not be clearer").

[284] *See, e.g.*, Harlan Hahn, *Accommodations and the ADA: Unreasonable Bias or Biased Reasoning?*, 21 BERKELEY J. EMP. & LAB. L. 166, 168-179 (2000).

counsel eschewing it altogether.[285] This dynamic once again reflects ambivalence about disability. Scholars have divided views of disability as either wholly undesirable or wholly neutral. Although they have recognized that this division does not reflect the world, scholars and advocates alike have denied their contradictory sentiments in favor of a singular view of disability.

This discussion suggests an alternative conception of disability rooted in the psychoanalytic concept of ambivalence. It is important that we define the content of that ambivalence with some precision. Katz suggests that our ambivalence about disability derives from two conflicting values: "individualism of the Protestant ethic variety and humanitarianism."[286] It is no wonder that Katz finds ambivalence across a wide swath of social groups; it is difficult to dispute that people, Protestant or otherwise, experience contradictory feelings of selflessness and selfishness when confronted with others in need.[287] Social responses to selective abortion and selective non-treatment suggest that ambivalence about disability stretches further than this, however. We devalue disability because it is generally undesirable both from social and biological standpoints. Yet we value disability as a constitutive element of personal identity. In disability, we see what we value in ourselves and we see what we disparage. In line with the social and medical models, we see disability as both inherently undesirable and inherently neutral.

It is worth addressing a few potential objections to this formulation. First, this conception considers disability as it affects individuals, not disability in the abstract. Few would characterize the infliction of biological impairment with reference to ambivalence.[288] We do not feel ambivalent about avoiding accidents or receiving good medical care or taking vaccines. It is only once a disability becomes constitutive of individual identity that we may feel strongly conflicting sentiments about it. Second, an approach to disability focused on ambivalence does not help us with the project of defining disability. The medical and social models do not do much better; although each model defines disability in some sense, they do so with such imprecision as to render them of little practical use.[289] This scheme does even less, though it might be able to shed light on the accuracy of classifications reached through other means.

Let us return, then, to the original puzzle. It would appear that the disability community expressed inconsistent visions of disability with respect to selective non-treatment and selective abortion in part because of its own ambivalence about disability. As discussed above, ambivalence may yield conflicting responses to the same basic question in the presence of different contextual forces. In both contexts, disability advocates faced the general question of when death may be an acceptable alternative to nascent life with a disability. In the neonatal context, advocates confronted a human face in Baby Doe and received powerful backing from the right-to-life movement. Accordingly, they gravitated toward a view of disability as inherently neutral. In the prenatal context, the same advocates confronted a faceless mass of ambiguous

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[285] *See, e.g.*, SHAKESPEARE, *supra* note 275, at 27.
[286] Katz et al, *supra* note 267, at 57.
[287] For a discussion to this effect, see Joseph Goldstein & Jay Katz, *Abolish the "Insanity Defense"—Why Not?* 72 YALE L.J. 853, 868-70 (1963).
[288] Indeed, this would turn the tort system on its head.
[289] The social model begs the question of what social constructions induce the label of disability, while the medical model begs the question of what impairments rise to the level of disability. The two conceptions may frame these inquiries, but they do little to answer them.

personhood and a more overtly hostile political environment. Accordingly, they adopted a more overtly ambivalent view of disability.

III. Baby Doe, Prenatal Testing, Ambivalence, and the Law

Thus far, this Essay has limited itself to descriptive goals. In seeking to explain seemingly contradictory positions taken by disability advocates, it has developed a theory of disability and ambivalence. This theory does not carry any a priori normative weight; it merely identifies a consistent pattern of social and individual responses to disability. In this regard, it is hardly distinct from either the social or medical models of disability. Although scholars who ascribe to one or the other of these models have traditionally reached similar normative conclusions, neither model expresses any core normative criteria.[290] Instead, they offer us a way of thinking about disability that may color our decisions in making normative tradeoffs or developing normative goals. Under the medical model, these goals often correspond to treatment and rehabilitation. Under the social model, they typically correspond to social reconstruction and antidiscrimination.[291]

This begs an obvious normative question: how should the law address ambivalence about disability? Traditionally, we have attempted to deny our ambivalence. As the last section showed, however, these efforts have not been particularly successful; the law concerning selective non-treatment and selective abortion constitutes a structurally ambivalent regime. This Part suggests that efforts to deny ambivalence about disability obscure difficult decisions and promote destructive eruptions of guilt and mistreatment. Rather than grasp for moral clarity, the law should encourage constructive expressions of ambivalence about disability. That is, the law should avoid singular visions of disability and singular visions of moral behavior with respect to disability. This is not to say that the law should ignore prejudice on the basis of disability. It is to say that we should reconsider what we mean by prejudice in this context.

A. A Normative Approach to Ambivalence and Disability

To date, legal scholars have pursued an elusive hyper-rationality in their efforts to address disability. Drawing on the descriptive dichotomy between the social and medical models, these scholars have built a normative dichotomy between a civil rights approach and a welfare approach to disability policy. The civil rights approach targets irrational bias through antidiscrimination law. The welfare approach targets real but unjust differences through legal entitlements.[292] Like the descriptive models, these normative approaches represent ideal types more than anything else; emerging legal debates concern the appropriate balance between the two approaches more than the substantive superiority

[290] *See* Adam M. Samaha, *What Good is the Social Model of Disability*, 74 U. CHI. L. REV. 1251 (2007) (arguing that neither model suggests normative prescriptions and outlining how various normative orientations might analyze disability).
[291] *See id.* at 1251-53.
[292] *See* Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L. J. 1, 10-23 (2004).

of either one.[293] In making these arguments, scholars have turned to broader principles that implicate both approaches. For example, we might look to questions of efficiency, anti-subordination principles, or conceptions of human rights.[294]

Yet there is something troubling about distinctions between irrational bias and real but unjust differences. With respect to irrational bias, what does it mean to act rationally with respect to disability? Disability elicits a complex set of conflicting emotions; how are we to choose which are rational and which are irrational? We might say that the law should treat people as they are and strive to counteract inaccurate assumptions and stereotypes.[295] Mark Kelman and Gillian Lester argue that we should ignore disability as a classification except insofar as it reveals pertinent information about a given individual. They contend that disability has no meaningful independent content, or more precisely, that independent meaning given to disability distorts policy decisions and should be avoided.[296] This may be the best of imperfect alternatives, but it begs the question of why it is any more "rational" to ignore our conflicting emotions than it is to accept them.

With respect to real but unjust differences, how are we to decide which differences rise to such a level of injustice as to require legal intervention? As a variety of commentators have noted, traditional theories of justice have been woefully inadequate in their treatment of disability. These theories have consistently excluded people with disabilities from consideration by assuming a minimum level of competence among subjects of justice.[297] Contemporary efforts to include disability within a unified theory of justice invariably return to questions about the boundaries of humanity. Martha Nussbaum's inquiry into the core capabilities required for a life worthy of human dignity reflects the intractability of these questions. In defining a precise list of capabilities, Nussbaum attempts to impose moral clarity on what makes life worth living.[298] The items on Nussbaum's list are worthy aspirations; they are desirable and enabling. In clarifying which human traits are desirable and which are not, however, they deny our conflicting sentiments about disability.[299]

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[293] *See, e.g.*, Matthew Diller, *Dissonant Disability Policies: The Tensions between the Americans with Disabilities Act and Federal Disability Benefit Programs*, 76 TEX. L. REV. 1003, 1055-1080 (1998).

[294] *See* MARK S. STEIN, DISTRIBUTIVE JUSTICE AND DISABILITY: UTILITARIANISM AGAINST EGALITARIANISM (2006) (arguing for a Rawlsian preference for utilitarianism); Samuel R. Bagenstos, *Subordination, Stigma, and "Disability,"* 86 VA. L. REV. 397 (2000) (arguing for an understanding of disability as subordination); Michael Ashley Stein, *Disability Human Rights*, 95 CAL. L. REV. 75 (2007) (combining elements of the social model, the human right to development, and Martha Nussbaum's capabilities approach to generate a disability human rights framework).

[295] For an argument to this effect see, for example, MARTHA MINOW, MAKING ALL THE DIFFERENCE: INCLUSION, EXCLUSION, AND AMERICAN LAW 50-78 (1990).

[296] MARK KELMAN & GILLIAN LESTER, JUMPING THE QUEUE 213-226 (1997).

[297] *See, e.g.*, MINOW, *supra* note 295, at 148-159 (examining the philosophical underpinnings of contemporary rights discourse); MARTHA C. NUSSBAUM, FRONTIERS OF JUSTICE: DISABILITY, NATIONALITY, SPECIES MEMBERSHIP 96-154 (2006) (critiquing social contractarian views of disability); Carlos A. Ball, *Autonomy, Justice, and Disability*, 47 UCLA L. REV. 599 (2000) (critiquing libertarian views of disability).

[298] NUSSBAUM, *supra* note 297, at 69-81 (defining and defending the core capabilities of a life worthy of human dignity).

[299] *See, e.g., id.* at 179-95. Much though Nussbaum strives for clarity, she struggles to apply her core capabilities to hypothetical individuals with disabilities. She argues that for Sesha Kittay, a just society would engineer genetic aspects of the womb "so that she would not be born with impairments so severe."

As we have seen, discomfort with attitudinal ambivalence often prompts the embrace of one set of conflicting sentiments at the expense of another. To that extent, prevailing efforts to rationalize disability are entirely understandable. These efforts are dangerous for two reasons, however. First, embracing a singular view of disability imposes abstraction that does not respond to individual circumstances. To deny the complex set of sentiments that informs our reactions to disability may obscure the difficult tradeoffs before us.[300] Second, denials of ambivalence threaten to provoke eruptions of hurtful expressions of guilt. In denying one sentiment, we tend to embrace an amplified version of the competing sentiment.[301] This "response amplification" extends to behavior as well; to rationalize and reinforce our denial, we may engage in extreme behavior toward the object of our ambivalence.[302] As circumstances change, therefore, we may swing from one set of extreme sentiments and behaviors to the other.[303]

The first of these dangers is fairly intuitive. Denials of ambivalence about disability provoke one variant of what Martha Minow has termed the "dilemma of difference." That is, in fixating on disabling traits or ignoring them, we fail to confront the situations before us.[304] Singular views of disability as undesirable fixate upon the trait such that it stands in for the whole. In so doing, these views ignore the totality of circumstances confronting particular individuals with disabilities and encourage inappropriately low expectations for such individuals. Singular views of disability as neutral ignore the trait and thereby fail to see the individual as a whole. The consequences are comparable to those that accompany views of disability as undesirable, albeit inverted. These views may prompt unfairly high expectations and in so doing ignore individual needs for support. In both instances, abstraction pushes us to treat these individuals in accordance with our fears or aspirations rather than reality.[305]

The second of these dangers requires a bit more explanation. As we have seen, understandings of disability's undesirability and neutrality are deeply rooted within our social structures. Accordingly, embracing a view of disability as either undesirable or neutral necessarily requires psychological suppression of the contrary view.[306] Actions premised on one polar view arouse subconscious doubts about the propriety of our conduct in service of that view. These unacknowledged doubts may provoke behaviors

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Id. at 193. However, she argues, "we do not say this about [individuals with Down syndrome or Asperger's] because there is a realistic prospect that [these individuals] will attain the capabilities that we have evaluated as humanly central." *Id.* A look at the core capabilities casts considerable doubt upon this statement, however. *Id.* at 76-77. Nussbaum hedges, stating that although the approach "does not entail engineering" these disabilities away, "it does not clearly speak against this either." *Id.* at 193.

[300] Studies have found that individuals with ambivalent attitudes engage in more systematic information processing than individuals with nonambivalent attitudes. *See, e.g.*, Klaus Jonas, Michael Diehl & Philip Bromer, *Effects of Attitudinal Ambivalence on Information Processing and Attitude-Intention Consistency*, 33 J. EXPERIMENTAL SOC. PSYCH. 190 (1997).

[301] For a summary of this phenomenon see, for example, Katz et al, *supra* note 267, at 48-49.

[302] *See* David W. Bell & Victoria M. Esses, *Ambivalence and Response Amplification: A Motivational Perspective* 28 PERS. & SOC. PSYCH. BULL. 1143 (2002).

[303] *See* Mark Conner et al, *Moderating Role of Attitudinal Ambivalence within the Theory of Planned Behavior*, 42 BRIT. J. SOC. PSYCH. 75 (2003).

[304] *See* MINOW, *supra* note 295, at 19-48.

[305] The analogue to Minow's dilemma is particularly apparent in her discussion of special education. *See id.* at 81-86.

[306] This dynamic is comparable to that described in Burt with respect to death. *See* BURT, *supra* note 4, at 11-26.

that reinforce the embraced pole and thereby suppress the contrary pole. Conversely, the same doubts may instead provoke eruptions of behavior that reflect the suppressed contrary pole.[307] As a result, polar views of disability's undesirability may elicit behaviors that magnify such convictions as well as behaviors that express guilt about them. The same goes for polar views of the neutrality of disability; such views may elicit behaviors that are reinforcing or behaviors that are antagonistic.

What form do these behaviors take? First consider instances where we embrace a neutral view of disability and suppress negative views. Reinforcing behaviors might include overprotection or overindulgence. We might ignore an individual's negative conduct or fail to hold him accountable for his actions. Antagonistic behaviors could include abuse, neglect, or violence toward individuals with disabilities. Caregivers as well as peers might lash out in the form of bullying or they might ignore prior obligations to provide supports.[308] Now consider instances where we embrace a negative view of disability and suppress neutral views. Reinforcing behaviors could include an array of abuse and harassment comparable to those described above. Antagonistic behaviors could include the same types of overprotection or overindulgence described above. In both of these examples, antagonistic behavior would likely include censure and hostility towards oneself or towards other visible proponents or emblems of the dominant view.

To the extent that the law encourages denials of ambivalence about disability, it may promote each of these dangers. Imagine that the law espoused a view of disability as neutral human difference. In accordance with the first danger, this view could encourage a denial of negative valuations of disability and a corresponding failure to address the biological needs of individuals with disabilities. In accordance with the second danger, it could also prompt eruptions of harmful behavior that would either reinforce views of disability as neutral or expose views of disability as undesirable. Now imagine that the law espoused a view of disability as an undesirable affliction. This view might encourage a denial of positive valuations of disability in a way that would stigmatize and dehumanize individuals with disabilities. It could also prompt harmful behaviors either embracing or disclaiming such polar views. Less explicit endorsements of a social consensus to either effect, moreover, could have the same consequences.

For concreteness, consider these issues with reference to selective non-treatment and selective abortion. Under the first regime, we might expect parents and prospective parents to choose life in situations where life is against the best interests of the neonate or fetus. Suppressed negative valuations of disability might prompt guilty uncertainty about these choices; they could also provoke eruptions of anger and resentment directed toward the child, the medical profession, or society more broadly. Under the second regime, we might expect parents and prospective parents to choose non-treatment in situations where

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[307] Freud describes this dynamic well with respect to feelings of love and hate. *See* 10 SIGMUND FREUD, *A Case of Obessional Neurosis*, *in* THE STANDARD EDITION OF THE COMPLETE PSYCHOLOGICAL WORKS OF SIGMUND FREUD 240 (James Strachey trans. 1955) ("We may suppose, then, that in the cases of unconscious hatred with which we are concerned the sadistic components of love have, from constitutional causes, been exceptionally strongly developed, and have consequently undergone a premature and all too thorough suppression, and that the neurotic phenomena we have observed arise on the one hand from conscious feelings of affection which have become exaggerated as a reaction, and on the other hand from sadism persisting in the unconscious in the form of hatred.").

[308] For a discussion of these forces, see, for example, DICK SOBSEY, VIOLENCE AND ABUSE IN THE LIVES OF PEOPLE WITH DISABILITIES: THE END OF SILENT ACCEPTANCE? 13-49 (1994).

non-treatment is against the best interests of the neonate or fetus. Suppressed positive valuations of disability could prompt the same guilty uncertainty about these choices and potentially the same eruptions of anger and resentment, albeit towards different targets. For example, parents and prospective parents might direct these eruptions toward living individuals with disabilities or their children without disabilities.

These examples may appear to oversimplify. The law does not espouse a singular view of disability as neutral or undesirable; it reflects a complex mixture of these views. Nevertheless, localized treatment of individuals with disabilities unavoidably conveys messages about the neutrality or undesirability of disability. For a particularly stark example, consider the issue of rationing medical care. Guidelines for rationing based on disability would require an attempt to separate forms of disability relevant to the decision from irrelevant forms. They would thereby force us to engage the question of whether disability constitutes neutral human difference or an undesirable affliction that would warrant a lesser or greater claim on scarce medical resources. We might try to avoid this issue and place discretion in doctors. Yet their choices would necessarily rely on the same judgments.[309] Accordingly, each of these approaches could provoke the dynamic of denials discussed above.

It appears, then, that the law may exacerbate the destructive consequences of our ambivalence about disability. How might it instead minimize or eliminate those consequences? Two interrelated avenues are readily apparent.[310] To reduce its own propensity to inflame denials of ambivalence, the law should avoid attempts at rational mastery of disability. That is, the law should not endorse visions of disability as either wholly neutral or wholly undesirable. This principle extends to both the law's systemic treatment of disability and individual legal doctrines. In line with the views of disability advocates, it suggests that the law should be wary of overt devaluations of disability and illusory attempts to eliminate it altogether. Less in tune with traditional disability advocacy, it also suggests that the law should not necessarily condemn negative valuations of disability. More than that, this principle would suggest caution about applying traditional rights frameworks to disability.

To reduce denials of ambivalence about disability more broadly, the law should consciously expose and accentuate that ambivalence. As we have seen, the law must struggle to avoid judgments about the neutrality or undesirability of disability in individual decisions. Nor is the law the sole source of social exegesis on the topic of disability; the controversies around selective non-treatment and selective abortion chronicle a variety of forces that may yield denials of ambivalence. In acknowledging our ambivalence about disability, we may be able to resist those forces. It appears that both purely cognitive and purely emotional forms of ambivalence yield to the embrace of a single fact or sentiment; studies suggest that individuals weigh competing facts and arrive at a conclusion, while it appears that few contradictory emotions can be maintained at

[309] This issue will be considered in more depth below. *See infra* notes 387-393 and accompanying text.
[310] These avenues draw their inspiration from Burt's analysis. *See supra* notes 218-220 and accompanying text.

once.[311] Instances in which cognitions conflict with emotions, however, may be maintained in a state of relative equilibrium.[312]

The difficulty, of course, lies in the details. To acknowledge ambivalence toward an entire social group may in itself suggest an unpardonable devaluation. Yet to ignore our ambivalence about disability promotes responses equally if not more synonymous with prejudice. To acknowledge ambivalence about disability threatens to abdicate responsibility for protecting the rights of individuals with disabilities. Yet to over-pursue that responsibility runs the risk of provoking abstraction and hurtful conduct. How are we to reconcile traditional views about human equality with a legal regime that actively encourages doubt about those views? These concerns require a close inquiry into particular legal doctrines that affect disability in a given context. The remainder of this Part addresses how the law should acknowledge disability in the contexts of selective non-treatment and selective abortion. Part IV turns to a broader set of contexts across disability law.

B. Acknowledging Ambivalence about Disability and Selective Non-treatment

As we have seen, the present regime governing selective non-treatment reflects social ambivalence about disability. This does not mean, of course, that the present regime addresses that ambivalence in optimal fashion. Rather than proceed immediately to the current law, it is worth considering the proposed legal approaches to the non-treatment dilemma in further detail. Broadly speaking, these proposed approaches fall into three categories. First, a variety of scholars have wrestled with appropriate substantive standards for treatment decisions. Second, a few scholars uncomfortable with clearly defined standards have turned their efforts toward a regime oriented more toward process than substance. Third, a smaller group has cast each of these approaches aside and embraced the present disconnect between law and practice. The normative framework developed above falls builds on the third approach.

The substantive standards put forward each display an effort to define the proper relevance of disability for non-treatment decisions. Traditional criminal law provides no excuse to the law's blanket condemnation of non-treatment as homicide.[313] Anti-discrimination standards either prohibit consideration of disability or raise the puzzling question of when an infant is "otherwise qualified" for medical treatment.[314] Futility standards like the Child Abuse Amendments raise the same issue in their definitions of futile treatment.[315] In line with family law and the incompetent patient's right to refuse

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[311] *See* Kari Edwards, *The Interplay of Affect and Cognition in Attitude Formation and Change*, 59 J. Personality & Soc. Psych. 202 (1990).

[312] *See* Howard Lavine, Cynthia J. Thomsen & Mark P. Zanna, *The Primacy of Affect in the Determination of Attitudes and Behavior: The Moderating Role of Affective-Cognitive Ambivalence*, 34 J. EXPERIMENTAL SOC. PSYCH. 398 (1998).

[313] *See* Robertson, *supra* note 10, at 217-235.

[314] For a discussion of these difficulties, see Mary A. Crossley, *Infants with Anencephaly, the ADA, and the Child Abuse Amendments*, 11 ISSUES L. & MED. 379, 399-406 (1996)

[315] *See* Nancy K. Rhoden, *Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts*, 58 S. CAL. L. REV. 1283, 1313-17 (1985) (arguing that the Child Abuse Amendments incorporate quality of life concerns).

medical treatment, a number of scholars have suggested a standard or mechanism that would follow the best interests of the child.[316] These efforts invariably return to difficult questions about what makes a life worth living. Perhaps the messiest approaches attempt to balance the rights and interests of the parties affected by the decision, namely the child, the family, the treating physician, and society at large.[317]

Each of these substantive approaches relies on some form of judicial review to ensure enforcement. Standards call upon judicial bodies to make judgments about the propriety of treatment decisions. Uneasy with these difficult determinations, many scholars have turned to procedural mechanisms like Infant Care Review Committees.[318] Combined with substantive standards, these committees provide an additional layer of process and a record for judicial review.[319] Set apart from those standards, committees might allow courts to limit their review to procedural requirements. To take a page from administrative law, courts could grant considerable deference to substantive solutions arrived under proper procedures.[320] Neonatal non-treatment decisions, however, are not well suited to either form of review. Time is short, enforcement would be difficult, and procedure could drift into mere formality.[321]

A third set of commentators, however, has expressed a preference for an ambiguous regime akin to the present one. These scholars proceed from the view that many non-treatment decisions are morally impenetrable; oftentimes, we simply cannot know the best interests of the child, the family, or society at large.[322] Under this premise, an appropriate set of substantive standards remains elusive. More than that, legitimating treatment decisions either through substantive standards or procedural requirements would threaten to diffuse responsibility for difficult decisions and devalue vulnerable members of society.[323] Accordingly, these scholars have embraced the "curious and discomforting discontinuity" that characterizes the present regime.[324] The law's formal condemnation preserves prevailing social mores, yet non-enforcement allows non-legitimated decisions against treatment. Moreover, the threat of social or legal sanction

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[316] *See, e.g.*, JOSEPH GOLDSTEIN, ANNA FREUD & ALBERT J. SOLNIT, BEFORE THE BEST INTERESTS OF THE CHILD, 91 (1977) (arguing for recognition of parental autonomy except in cases "when (1) medical experts agree that treatment is nonexperimental and appropriate for the child, and (2) denial of that treatment would result in death, and (3) the anticipated result of treatment is what society would want for every child—a chance for normal health growth or a life worth living").

[317] Such a standard is envisioned in KUHSE & SINGER, *supra* note 72, at 153-171.

[318] For an overview of the issues raised by these committees, see Robyn S. Shapiro & Richard Barthel, *Infant Care Review Committees: An Effective Approach to the Baby Doe Dilemma?*, 37 HASTINGS L.J. 827 (1986).

[319] *See* Susan M. Wolf, *Ethics Committees and Due Process: Nesting Rights in a Community of Caring*, 50 Maryland L. Rev. 798, 831-844 (1991) (describing ethics committees as reinforcing due process and effective review).

[320] The most obvious analogue would be to hard look review. *See* Motor Vehicle Mfrs. Ass'n v. State Farm Mut. Auto. Ins. Co., 463 U.S. 29 (1983).

[321] This aspect of procedurally oriented review has been subject to criticism. *See, e.g.*, Steven R. Smith, *Disabled Newborns and the Federal Child Abuse Amendments: Tenuous Protection*, 37 Hastings L.J. 765, 766 (1986) (describing ethics committees as "cumbersome and unworkable in emergencies").

[322] *See* Robert H. Mnookin, *Two Puzzles*, 1984 ARIZ. ST. L.J. 667, 677-81.

[323] *See* Robert A. Burt, *Authorizing Death for Anomalous Newborns*, *in* GENETICS AND THE LAW 435, 440 (Aubrey Milunsky & George J. Annas eds., 1976).

[324] Mnookin, *supra* note 322, at 684.

focuses responsibility for individual decisions.[325] We are left, then, with an uncomfortable equilibrium "all the more attractive because unacknowledged."[326]

The normative principles developed above provide a basis for the intuitions expressed by the third set of commentators. It is easy to see that faithfully enforced substantive standards threaten to provoke denials of ambivalence about disability. This is perhaps most clear for standards that wholly proscribe non-treatment or allow it unrestricted. The potential standards between these poles likewise require some determination of the relevance of disability in treatment decisions. Although such standards would surely leave gray areas, they would necessarily project an affect of moral clarity about the content of disability in individual cases. Equally troubling, purely procedural requirements present the same difficulty. In some contexts, relying on procedure rather than substance might preserve the moral ambiguity of the conduct in question.[327] In the present context, however, the law traditionally frowns upon non-treatment of newborns as neglect if not homicide. To ignore this principle and legitimate individual non-treatment decisions would convey a profoundly different principle, and an equally unambiguous one.

That these legal regimes would provoke denials of ambivalence does not necessarily favor a disjunction between law and practice akin to that endorsed by the third view described above. To the extent that individual disputes always provoke denials of ambivalence on some level, we can only seek to limit the destructive potential of these denials rather than eliminate it entirely. In this context, however, some disjunction appears to be the best means of avoiding that potential.[328] Given traditional legal presumptions, to legitimate non-treatment on the basis of disability would convey a message of profound gravity about the undesirability of disability. Attempts to distinguish between types of disability might diffuse this message to some degree, but these distinctions would be difficult to maintain in the face of understandings of disability as a coherent whole.[329] More than that, such distinctions would likely further stigmatize those characteristics considered the most undesirable.

Broadly speaking, there are two possible disjunctive regimes from which to choose. The law might condemn selective non-treatment in principle yet allow it in practice. This describes the present regime. Alternatively, the law might allow selective non-treatment in principle yet condemn it in practice. A regime like this might give parents complete deference over treatment decisions and yet convey a clear message that

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[325] *See* Burt, *supra* note 323, at 445 ("The possibility of criminal liability should force these physicians to give of themselves, to identify both with the family and with the newborn child as if the suffering of each were the physicians' own.")

[326] Carl E. Schneider, *Rights Discourse and Neonatal Euthanasia*, 76 CAL. L. REV. 151, 176 (1988).

[327] In administrative law, for example, placing questions of substance in the hands of agencies may allow courts to duck ethical questions. Of course, the law may still convey a message about the conduct in question by virtue of the agency action. However, procedural review may leave the substantive legitimacy of that conduct uncertain.

[328] By disjunction, I mean to refer to inconsistency between law and practice. For a common example, consider speeding limits that are not enforced to the letter.

[329] That is, characteristics traditionally classified as disabilities would likely remain classified as such even if we distinguished between them on the basis of severity.

non-treatment is morally abhorrent.[330] Each of these regimes could avoid clear judicial statements about the content of disability, leaving decisions to parents and their doctors. In accordance with the first normative principle advanced above, both regimes would avoid attempts at rational mastery over disability. Under the second normative principle, the question then becomes which disjunctive regime would best encourage social actors to acknowledge their ambivalence about disability. This choice extends both to the type of disjunction and the underlying content of that contradiction.

The present disjunction between law and practice appears the better of the two alternatives. A regime that legally allowed non-treatment but condemned it in practice would have the benefit of simultaneously affirming views of disability as neutral and undesirable. In contrast, a regime like the present one displays a uniform view of disability as neutral while allowing that view to be undermined. The former regime would expose our ambivalence about disability where the present regime obscures it.[331] There are reasons to question the stability of a regime that legally permitted non-treatment, however. Given that all but a few commentators agree that non-treatment should be an extremely rare occurrence, there likely would be a powerful push to root out the inconsistency between public condemnation and legal recognition.[332] Moreover, a departure from traditional limits on parental autonomy—even with a social counterweight—might encourage devaluation of disability where a regime consistent with traditional presumptions would not.

Our task, then, is to select the appropriate details of a disjunctive regime akin to the one governing selective non-treatment at present. The law possesses a variety of tools to condemn non-treatment; the differences lie in the severity, scope, and clarity of the sanction. It might threaten criminal sanctions or civil sanctions. It might target parents, physicians, hospitals, or some combination. It might explicitly refer to disability or leave it conspicuously absent. The law could ignore some forms of non-compliance but strike at others. It could leave all details to doctors and parents, or it could intervene to prevent clear departures from social mores. In approaching these possibilities, we must ask ourselves which would best allow doctors and parents to grapple with their own ambivalence. Too great or slight a sanction might yield the illusion of moral clarity rather than moral uncertainty. So might a threat of enforcement, even if distant.

As a start, it seems to me that the appropriate balance would formally condemn non-treatment on the basis of disability and carry a real though distant threat of legal sanction. The Child Abuse Amendments provide a formal legal statement against non-treatment, though the threat of sanction for non-compliance remains more social than legal. Occasional application of the criminal law or antidiscrimination law could provide the added threat necessary to encourage acknowledged ambivalence. Although many cases would be morally indistinct, some would be sufficiently against social mores as to

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[330] This moral disapproval could be overt, understated, or somewhere in between. The law might require waiting periods or distribute informational materials about disability, adoption, or the like. Or it might overtly condemn the morality of the practice but withhold legal sanctions.

[331] This is because only a few parties recognize the disjunction within the present regime, while the disjunction in the former would be readily apparent.

[332] Even those who defend the present disjunction do so with some unease. *See, e.g.*, Mnookin, *supra* note 322, at 683 ("I feel very uncomfortable suggesting that we should muddle through and live with a striking dichotomy between the law on the books and the law in action rather than developing more precise standards or adopting new procedures.").

warrant formal sanction. A system of administrative oversight could serve this function, though excessive oversight could also prompt excessive compliance with the formal law. The problem of doctor-parent communication would remain a problem, however; a united front of physicians obscures the treatment dilemmas altogether. This might spare parents some guilt, but it also imposes abstraction on decisions and undermines parental interests in both caretaking and self-determination.

Although an orientation toward ambivalence highlights the gravity of doctor-parent communication, it does not help us resolve the tendency toward coercion in doctor-patient relationships rather than mutual respect. Beyond the law's typical trouble regulating these relationships,[333] a commitment to structural ambivalence about disability in treatment decisions could make it even more difficult to promote communication about disability.[334] Therefore, these issues may be better addressed on a systemic level with respect to doctor-patient relations or with respect to how doctors address communication about disability generally.[335] Localized efforts could alternatively push for expanded disclosure requirements, internal mechanisms for counseling and mediation, and perhaps prerequisite training for physicians concerning how to deliver diagnoses. To avoid disrupting the ambivalent balance of the regime, these localized efforts might be best approached through the encouragement of professional guidelines.

It may appear incongruous that an effort to expose ambivalence about disability would yield a regime largely obscured from public view. Perhaps it is. However, the present legal regime governing parental autonomy and the dispensing of death casts doubt on whether an outwardly ambivalent arrangement would be sustainable. The next best thing is to ensure that the actors engaged in treatment decisions at the edge of life recognize their own ambivalence about disability. This requires a disjunction between law and practice that may seem disingenuous even if necessary. Such is the character of a tragic choice; in the words of Calabresi and Bobbit, "it is honesty which allows us to see clearly, and occasionally appreciate, the ways, some subtle and some not honest, by which societies must cope."[336] In addressing our ambivalence about disability, we must navigate powerful and yet inconsistent social values. To build an appropriate regime, we must honestly confront that reality; yet that regime will not necessarily broadcast it so honestly.

C. Acknowledging Ambivalence about Disability and Selective Abortion

Selective abortion occupies a markedly different legal constellation. The default rule under *Roe* allowed nearly unbridled discretion for prospective parents until the third

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[333] For the seminal treatment of this difficulty, see JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT (1984).

[334] That is, legal efforts to promote communication about disability in this context should not convey a view of disability as either undesirable or neutral.

[335] Physicians report receiving little training about disability in medical school and residency. *See* Steven J. Ralston, *Reflections from the Trenches: One Doctor's Encounter with Disability Rights Arguments*, *in* PRENATAL TESTING AND DISABILITY RIGHTS 334, 335 ("In general, what I was taught in medical and in my training is that disability—no matter what its form—is a bad thing and to be avoided at all costs.").

[336] GUIDO CALABRESI & PHILIP BOBBIT, Tragic Choices 26 (1978).

trimester.[337] Although *Casey* scaled back that discretion in allowing further state regulation pre-viability, it preserved a robust right.[338] Selective abortion and selective non-treatment, therefore, occupy inverted legal contexts. In one, prospective parents may choose fetal death for nearly any reason; in the other, parents may choose neonatal death for few if any reasons. Nevertheless, scholarly commentary on legal treatment of selective abortion roughly mirrors commentary on legal treatment of selective non-treatment. Some advocate substantive regulation, while others would rather duck substantive questions in favor of procedural safeguards. The disjunctive quality of the law's treatment of selective abortion has garnered less support, however. It will receive more support here.

The proffered substantive standards to regulate selective abortion do not differ much from those proffered to regulate selective non-treatment. Pursuant to *Casey*, the law might restrict or ban prenatal technology.[339] It also might develop antidiscrimination standards under the ADA or only allow abortion on the basis of prenatal diagnosis under a futility standard.[340] Alternatively, the law could impose a best interests standard for fetuses or balance the benefits and burdens of the social actors affected by these decisions These approaches might be individualized or based on a precise schedule of diagnoses.[341] As it does at present, the law could remain largely silent about the practice, leaving it subject to prevailing abortion jurisprudence and tort law.[342] Others have suggested that the law promote selective abortion to advance a sound system of public health.[343] This might be achieved through the protection of a right to be born with sound mind and body or through government subsidies.[344]

As was the case with selective non-treatment, enforcing these substantive standards would require procedural mechanisms that would pierce the doctor-patient relationship. Alternatively, scholars have once again turned to procedure to avoid the difficult substantive questions presented by selective abortion. The mantra of informed consent has not been limited to disability advocates.[345] To ensure that prospective parents grapple with the decisions before them, scholars have proposed requirements for genetic

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[337] Roe v. Wade, 410 U.S. 113 (1973).

[338] Planned Parenthood of Southeaster Pennsylvania v. Casey, 505 U.S. 833 (1992).

[339] *Casey* upheld a 24-hour waiting period, parental consent requirements for minors, and reporting requirements. *Id.*

[340] I am not aware of any scholars pushing this view.

[341] For a discussion of these possibilities, see Dorothy C. Wertz, *Drawing Lines: Notes for Policymakers*, *in* PRENATAL TESTING AND DISABILITY RIGHTS 261, 263-78.

[342] For such views, see Ronen Perry, *It's a Wonderful Life*, 93 CORNELL L. REV. 329 (2008) (arguing for greater recognition of wrongful life suits); Note, *Father and Mother Know Best: Defining the Liability of Physicians for Inadequate Genetic Counseling*, 87 YALE L. J. 1488, 1515 (1978) (arguing that these suits vindicate "the social interest in ensuring tha prospective parents have access" to appropriate information for abortion).

[343] *See, e.g.* Jennifer H. Yen, *Is My Baby "Defective"? Fetal Genetic Testing as Part of a Public Health Care Plan*, 36 SUFFOLK U. L. REV. 391, 395 (2003) (arguing that prenatal testing should be part of any serious health plan to combat inequities in its availability).

[344] *See* Lois Shepherd, *Protecting Parents' Freedom to Have Children with Genetic Differences*, 1995 U. ILL. L. REV. 761, 769 (critiquing conceptions of "an emerging right to be born with a sound body and mind"); Eric Rakowski, *Who Should Pay for Bad Genes*, 90 CAL L. REV. 1345, 1408-12 (2002) (examining government subsidies to test for conditions that make "life not worth living").

[345] *See* Suter, *supra* note 38, at 260-70 (arguing for reform to repair the informed consent mechanism in prenatal testing).

counseling, information disclosure, physician training, and mediation.[346] Despite the weighty literature decrying the effectiveness of informed consent actions, these scholars have envisioned a mechanism of enforcement largely propelled by private litigation.[347] To address the traditional pitfalls of informed consent actions, the law might also engage in administrative enforcement or provide incentives for physician groups to adopt professional guidelines.[348] Absent heavy administrative involvement, it is unlikely that informed consent actions would have much of an effect on practice.[349]

Few if any scholars have voiced support for the ambivalent state of the present law. This may be due to the relative dearth of discussion on the topic of selective abortion as compared to selective non-treatment. It may also stem from the fact that the ambivalent quality of the law concerning selective abortion is less readily apparent than it is for selective non-treatment.[350] In any case, attempts at substantive or procedural clarity once again risk inflaming denials of ambivalence about disability. Regimes that either encourage selective abortion or forbid it altogether provide the most obvious examples. Faithfully enforced substantive standards would also run the risk of conveying a singular view of disability in their attempt to define the appropriate relevance of disability in decisions for abortion. Procedural mechanisms, moreover, could not avoid substantively legitimating selective abortion as a legally cognizable practice. This state of affairs presents obvious parallels with that concerning selective non-treatment.

Importantly, however, the prevailing legal regime differs in this context. A purely procedural approach would not depart significantly from the standard legal approach to abortion more broadly. In this sense, it would not necessarily convey much of a message about disability at all. To the extent that these mechanisms would require judicial oversight, however, they would further expose the practice to the public. Procedural requirements might cast some moral doubt upon the practice, but they would formally legitimate it within defined parameters. Perhaps the law could avoid this problem by simply avoiding the issue altogether.[351] Amidst growing public recognition of the practice and rising abortion rates for particular diagnoses, however, it would be difficult to imagine that the law is merely abstaining from passing judgment on the issue.[352] Moreover, legal silence would leave in place a perfunctory and unexamined process. It appears, then, that a disjunctive regime would best avoid hurtful denials of ambivalence.

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[346] *See generally*, Angela M. Hannemann, *A New Routine: Assisting Patients in Responding to Prenatal Diagnosis*, 90 MARQ. L. REV. 337 (2006).

[347] *See* Dixon, *supra* note 42, at 46-50.

[348] *See* Michael J. Malinowski, *Coming into Being: Law, Ethics, and the Practice of Prenatal Genetic Screening*, 45 HASTINGS L. J. 1435, 1518-25 (1993) (outlining a proposal for a commission to regulate prenatal testing).

[349] *See* Dixon, *supra* note 42, at 46-50 (identifying pitfalls for informed consent requirements for prenatal testing).

[350] It is also more recent. Until the passage of the Prenatally and Postnatally Diagnosed Conditions Awareness Act, the law simply passed on the issue. This state of affairs was ambiguous if not necessarily ambivalent.

[351] The law could theoretically feign ignorance of the subject and neither legitimate nor condemn the practice. Complete abstention would be difficult given present legal doctrines concerning prenatal torts, however.

[352] Prenatal testing has slowly begun to make its way into national news outlets. *See, e.g.*, Elizabeth Weil, *A Wrongful Birth?* N.Y. TIMES MAG., Mar. 12, 2006, at X.

The question then becomes what form this disjunction should take. Once again, two broad options emerge. The law might allow selective abortion yet raise moral doubts about it, or it might disallow selective abortion yet ignore some proportion of the practice through lax enforcement. A formal disavowal of the practice would be consistent with the regime proposed above for selective non-treatment. It would cut against present law and practice with respect to abortion and selective abortion, however. In light of the prevalence and public acceptance of selective abortion, a formal presumption against the practice also would likely prove unstable, at least in the immediate future. To the extent that we feel less connected to a fetus than a neonate, the difference with selective non-treatment makes sense.[353] Formal restrictions on selective abortion would also contravene the presumption of the prevailing abortion regime. The unambiguous message about disability conveyed by a reversal of this presumption could provoke denials of ambivalence.

This suggests that the law allow selective abortion yet disapprove of the practice. As with selective non-treatment, this prescription need not recommend the specifics of the present regime. With respect to allowing selective abortion, the options are relatively few. The law might overtly signal its approval of the practice, or it might subsume disability-related motives within the sea of legally recognized yet unsolicited reasons for abortion. With respect to disapproving of the practice, the possibilities have few bounds. As a starting point, the law could impose informational requirements like those sought by procedurally oriented proponents of reform. It might require independently certified genetic counselors or additional training for physicians involved in decisions.[354] These mechanisms could help ensure that physicians and counselors accurately portray the limitations of relevant disabilities and make explicit the connection between testing and abortion. Similarly, the law might require that prospective parents receive information about families and professionals available to discuss the relevant disability in more detail.[355]

Although informational requirements could indicate some level of legal disapproval, they would convey an ambiguous message at best. The law might additionally restrict government funding to abortion generally or to selective abortion in particular. It might prohibit temporal extensions for abortion on the basis of disability as discrimination. Taking a page from the selective non-treatment context, this might take the form of a child abuse standard for viable fetuses. [356] In a similar vein, the law could

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[353] The perceived distance between fetus and neonate appears to be widening. For one account of this dynamic, see ROTHMAN, *supra* note 138, at 1-15. This distance will likely widen further with the advance of prenatal testing technology. *See* Carolyn Jacobs Chachkin, *What Potent Blood: Non-Invasive Prenatal Genetic Diagnosis and the Transformation of Modern Prenatal Care*, 33 AM. J. L. & MED. 9, 9 (2007) ("Someday soon, virtually any pregnant woman will be able to learn—with 98-99% accuracy—whether her fetus has contracted a serious genetic disorder by undergoing nothing more than an inexpensive, non-invasive blood test.").

[354] Physicians tend to push prenatal testing harder than genetic counselors, and they tend to leave questions about the relative merits of directive counseling and non-directive counseling unexamined. *See* Dixon, *supra* note 42, at 21-27.

[355] Parents of children with prenatally diagnosable disabilities have begun making parent networks available to prospective parents who receive a diagnosis. *See, e.g.*, Amy Harmon, *Prenatal Test Puts Down Syndrome in Hard Focus*, N.Y. TIMES, May 9, 2007, at X.

[356] Like the Child Abuse Amendments, such a standard might disallow selective abortion except in cases where treatment will be futile at birth.

abolish wrongful birth and wrongful life claims, limit their awards, or replace these actions with a more ambiguous regulatory regime like worker's compensation.[357] Further, the law might expand and publicize options for parents to give up children with disabilities for adoption. Aggressive social programs for families and children with disabilities would dramatize that selective abortion need not be a preordained conclusion. Legislative and administrative bodies could also articulate more overt if unbinding concerns about the ethical viability of the practice itself.[358]

This is an admittedly rough set of possibilities. Our task is to strike an appropriate balance between condoning and condemning selective abortion. Given the legitimating quality of the law, overt approval of selective abortion would render achieving this balance a difficult task. This suggests a regime that does not inquire overtly into the disability-related motives driving selective abortion. The appropriate form of legal censure presents a more delicate set of tradeoffs. To best encourage doctors and prospective parents to grapple with their moral doubts, it might well be necessary to combine all the possible elements described above. Available evidence about these decisions suggests as much; the routinization of prenatal testing and selective abortion has carefully eschewed expressions of uncertainty and ambivalence. Although the 2008 statute provides a start, the law should aim for a broader statement of moral uncertainty about selective abortion.

It is worth emphasizing the social contingency involved in structuring this regime. The source of the differences between the approaches proposed for selective non-treatment and selective abortion rests on different social understandings of the appropriate administration of death for fetuses and newborns. If those social understandings were to change, the task of promoting structural ambivalence about disability in these contexts would as well.[359] Repudiation of abortion rights would require a near total shift in the context of selective abortion, perhaps to a regime comparable to the regime proposed here for selective non-treatment. Conversely, an affirmation of parental rights to forms of infanticide would require similar shifts in the legal framework governing selective non-treatment. Perhaps a more troubling question concerns how these regimes would respond to shifts in social understandings of genetic enhancement. This is particularly true for selective abortion, which is associated with those issues in the public mind.[360]

For our present purposes, it suffices to say that legal measures to affirm, repudiate, or qualify practices of genetic enhancement would raise many of the same issues as selective non-treatment and selective abortion.[361] Efforts at rational mastery of

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[357] For such a proposal, see Field, *supra* note 78, at 190-93.

[358] The Prenatally and Postnatally Diagnosed Conditions Awareness Act is one example of this approach. Legislation could be more unequivocal in its condemnation, if not its legal sanctions.

[359] Such change is unlikely, but the importance of context that this reveals will be instructive as we address ambivalence about disability in other areas of the law.

[360] Indeed, objections to prenatal testing and selective abortion suggest other technologies to avoid having children with disabilities. One prominent method is preimplantation genetic diagnosis. For a summary of the moral and legal issues raised by that practice see Jason Christopher Roberts, *Customizing Conception: A Survey of Preimplantation Genetic Diagnosis and the Resulting Social, Ethical, and Legal Dilemmas*, 2002 DUKE L. & TECH. REV. 12.

[361] *See, e.g.*, Alicia R. Oullette, *Insult to Injury: A Disability-Sensitive Response to Smolensky's Call for Parental Tort Liability for Preimplantation Genetic Interventions*, 60 HASTINGS L.J. 397 (2008) (advancing a disability rights critique of prenatal torts in the realm of preimplantation genetic diagnosis).

disability in the context of genetic enhancement would likely provoke the same denials of ambivalence. They might also spill over into social understandings of selective abortion and selective non-treatment. In a sense, this muddies the waters still further; considering each of these regimes in relative isolation preserves the illusion of their mutual independence. The point here is not merely that the law should be wary of unambiguous responses to questions concerning genetic enhancement. It is rather that efforts to expose ambivalence about disability in individual contexts rely on broader social understandings of disability. Accordingly, it is necessary to look at the structural construction of ambivalence about disability in the law more broadly.

III. Ambivalence, Disability, and the Law

This Part considers three broad substantive areas of federal disability law: education, employment, and healthcare. The law's approach to disability reaches considerably further. In keeping with the issues raised by selective non-treatment and selective abortion, we might look narrowly at the role of ambivalence about disability in physician assisted suicide and refusal of life-sustaining treatment. To take a more traditional tack, we might address questions of capacity to contract, constructions of disability in tort, or the treatment of disability in the mens rea requirements of criminal law. The three broad areas discussed here, however, occupy the center of modern scholarly discourses in disability.[362] In part by virtue of their generality, moreover, these regimes allow us to develop a broader understanding of what addressing ambivalence about disability suggests for the law generally.

Scholars have often lamented the lack of a unifying principle to govern these areas, and I do not purport to offer one here.[363] The idea is merely to explore what an eye toward ambivalence may suggest for disability policy writ large. That is, how might ambivalence about disability help us understand current legal approaches to disability and how might this understanding help us suggest more appropriate policies? The complexity of these areas of law viewed both in isolation and in concert cautions against anything more than a preliminary framing of the issues. Yet a few themes emerge. Like the law governing selective abortion and selective non-treatment, each of the three regimes discussed below presents a structural pattern of ambivalence about disability. They also suggest the same destructive urge for clarity about disability. To diffuse this dynamic, the law would do best to consciously expose our ambivalence.

A. Education and the IDEA

[362] *See* Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 54-83 (2004) (focusing on these three areas in making prescriptions for the future of disability law).

[363] Indeed, this lament has encouraged denials of ambivalence about disability. For a minority view arguing against approaches that draw on a set of first principles for disability policy, see Jerry L. Mashaw, *Against First Principles*, 31 SAN DIEGO L. REV. 211 (1994).

The educational system must run the gauntlet between expecting too much and too little of its students.[364] Singular views of disability as either neutral or undesirable run the risk of placing students in one of these imperfect situations. This result carries more than the probable misfortune of a set of educational objectives inappropriate for a student's particular capabilities.[365] It also raises the possibility of destructive expressions of guilt on the part of parents, teachers, and peers responding to the inconsistencies between their private views and the public ideal. For parents and teachers, this could take the form of abusive behavior or overprotection.[366] For peers, it could take the form of social ostracizing, bullying, or babying.[367] Such a dynamic would have ramifications beyond the treatment of individual students with disabilities. The educational system also gives content to how young people and parents approach disability more broadly.

To address these potential consequences, it once again appears that the law should avoid casting disability as either a neutral difference or an undesirable affliction. A view toward the neutrality or undesirability of disability could produce a variety of possible policy outcomes. We might think that a neutral approach to disability in education would provide students with disabilities with no specialized treatment, regardless of individual needs.[368] Or we might think that a neutral approach would ensure equal opportunity to benefit from educational services, even if that required unequal services.[369] Alternatively, the law could strike down educational curricula that disproportionately disadvantage individuals with disabilities under a form of traditional disparate impact analysis. The list

[364] For an intricate analysis of this point, see MINOW, *supra* note 295, at 23-40.

[365] This is the overriding concern of the present law. *See* H. RUTHERFORD TURNBULL III, MATTHEW J. STOWE & NANCY E. HUERTA, FREE APPROPRIATE PUBLIC EDUCATION: THE LAW AND CHILDREN WITH DISABILITIES 153-204 (7th ed. 2000).

[366] For an expression of this possibility, see Reginald L. Jones & Samuel Guskin, *Attitudes and Attitude Change in Special Education*, *in* Attitudes and Attitude Change in Special Education: Theory and Practice 1, 11 (Reginald L. Jones ed., 1984) ("A teacher may feel that a handicapped child will complicate his teaching job, but if such a child is placed in the classroom he may demonstrate effective effort in working with her. On the other hand, a teacher may express highly desirable values about integration and yet show unhappiness with and hostility toward a child who has serious emotion and learning problems."). The history of educational services for people with disabilities is littered with instances of abuse. State institutions for the mentally retarded provide the most graphic example. *See generally* BURTON BLATT & FRED KAPLAN, CHRISTMAS IN PURGATORY, A PHOTOGRAPHIC ESSAY ON MENTAL RETARDATION (1966). For a more recent set of abuses, see GOVERNMENT ACCOUNTABILITY OFFICE, SECLUSIONS AND RESTRAINTS: SELECTED CASES OF DEATH AND ABUSE AT PUBLIC AND PRIVATE SCHOOLS AND TREATMENT CENTERS 5-7 (2009) (detailing deaths arising out of improper use of restraints in special education).

[367] For a particularly troubling and extreme example, see *Boy Convicted of '£5 Bet' Murder*, BBC NEWS, Jan. 22, 2008, http://news.bbc.co.uk/2/hi/uk_news/england/wear/7202351.stm (last visited June 5, 2009) (detailing the murder of a young man with disabilities by a trio of young men who bet on which of them could knock him out first).

[368] This roughly characterizes the legal regime prior to the enactment of the Education for All Handicapped Children Act.

[369] For an early view to this effect, see, for example, Note, *Enforcing the Right to an "Appropriate" Education: The Education for All Handicapped Children Act of 1975*, 92 Harv. L. Rev. 1103, 1125-26 (1975) (arguing that courts should interpret the EAHCA such that "an appropriate education for a particular child would require services aimed at developing the child's intellectual capacity to the same degree that the school sought to develop the 'normal' abilities of its nonhandicapped students").

could go on; perhaps more than in the contexts of selective abortion and selective non-treatment, efforts for neutral treatment rely on lower order conceptions of neutrality.[370]

A view of disability as inherently undesirable yields comparably indeterminate policy prescriptions. Negative views of disability prompted the wholesale exclusion of students with disabilities from public schools until Congress passed the Education for All Handicapped Children Act in 1975.[371] Segregated educational settings available at parental expense or through charity coincided with segregated institutional settings and broader social exclusion of individuals with disabilities.[372] Similarly negative views of disability could prompt a wholly different approach committed to government assistance, either through monetary or in-kind supports. The resulting questions revolve around the appropriate levels of assistance and the appropriate means of classification. Beneath these lie broader social conceptions of justice.[373] The law might not aspire for equal opportunity or full citizenship, but it could seek some level of assistance.

In practice, legal regulation of the education system reflects a structurally ambivalent view of disability. The 1975 Act, since renamed the Individuals with Disabilities Education Act,[374] nominally advances a view of disability as a neutral form of human variation. The original legislation drew on a pair of federal court decisions finding that the exclusion of students with disabilities from public education violated the Equal Protection Clause.[375] It codified their requirement that every child receive a "free public program of education and training appropriate to his capacities."[376] The findings of the Act make clear that disability "is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society."[377] Accordingly, the Department of Education has defined an "appropriate education" as one designed "to meet individual educational needs of handicapped persons as adequately as the needs of nonhandicapped persons are met."[378]

Courts have shied away from this interpretation, however, which does not appear within the Act itself. In lieu of clear substantive requirements, the Act set forth an extensive set of procedural mechanisms geared to ensure that parents and schools agree to appropriate programs.[379] The Supreme Court seemingly eviscerated the Act's non-discrimination mandate in *Board of Education v. Rowley*, holding that an "appropriate education" solely required "sufficient support services to permit the child to benefit

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[370] Indeed, debates over those conceptions of neutrality have driven much of the legal discourse concerning the EAHCA and the IDEA. *See generally* Mark C. Weber, *The Transformation of the Education of the Handicapped Act: A Study in the Interpretation of Radical Statutes*, 24 U.C. DAVIS L. REV. 349 (1990).
[371] Pub. L. No. 94-142, 89 Stat. 773 (1975).
[372] *See generally* MARGRET WINZER, THE HISTORY OF SPECIAL EDUCATION: FROM ISOLATION TO INTEGRATION (1993)
[373] For an appeal to examine these conceptions apart from identity politics, see KELMAN & LESTER, *supra* note 296, at 196-97.
[374] Pub. L. No. 101-476, 104 Stat. 1103 (1990).
[375] Pennsylvania Ass'n for Retarded Children v. Pennsylvania, 334 F. Supp. 1257 (E.D. Pa. 1971); Mills v. Bd. of Educ., 348 F. Supp. 866 (D.D.C. 1972).
[376] 334 F. Supp. 1257 at 1258.
[377] Pub. L. No. 105-16, 111 Stat. 37, 38 (1997).
[378] 34 C.F.R. §104.33(b)(1).
[379] These procedures are particularly important in the development of individualized education programs. For an overview, see TURNBULL et al, *supra* note 365, at 160-173.

educationally" from instruction.[380] The Court categorically denied that the Act "required anything more than equal access."[381] Although lower courts have consistently distinguished *Rowley* and subsequent acts of Congress have imposed a broader, if still ambiguous, substantive floor,[382] courts continue to conceive of the Act as a provision of social welfare services more than a guarantor of some notion of equal rights.[383] In the same vein, public debates and recent legislation have built on the Act's connection with social welfare programs.[384]

Once again, the law espouses seemingly contradictory views of disability. It advances an ideal of disability as neutral difference and does not follow that ideal to its logical conclusion. The question then becomes whether this method of expressing ambivalence about disability is optimal in this context. The shadow of death made such decisions fairly clear in the contexts of selective abortion and selective non-treatment. Here, the range of realistic possibilities stretches further. Theoretically, the law could espouse even less equivocal antidiscrimination ideals that would go even less enforced than the present ones.[385] Or it could orient itself explicitly toward a system of monetary entitlements and rely more heavily on broader antidiscrimination regimes like the ADA.[386] Among moderate regimes like the present one, moreover, the enormous complexity of the educational system could allow for a variety of outcomes.

My object here is not to identify the educational regime that would best express ambivalence about disability. This is a complex inquiry subject to prevailing social understandings of the law's role in education and a multiplicity of empirical questions. Rather, I intend to suggest that the contradictory quality of the present regime is not necessarily undesirable; more than that, it may be advantageous. The law should not seek to capture equality in some strict sense with respect to disability, nor should it pursue a clear vision of justice to redress the undesirability of disability. In constructing this body of law, the appropriate inquiry would consider how to express each of these conflicting views of disability appropriately without fully embracing either. In the contexts of selective abortion and selective non-treatment, formal ambiguity was not a plausible

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[380] Bd. of Educ. of Hendrick Hudson Central School District v. Rowley, 458 U.S. 176, 189 (1982).
[381] *Id.* at 200.
[382] For a careful tracing of this retreat, see Weber, *supra* note 370. For a discussion of the modern standard, see Scott F. Johnson, *Reexamining Rowley: A New Focus in Special Education Law*, 2003 B.Y.U. EDUC & L.J. 561, 585 (arguing that "the 1997 amendments to the IDEA make clear that the foundation underlying *Rowley*'s reasoning is no longer present).
[383] *See* Mark C. Weber, *The IDEA Eligibility Mess*, 57 BUFF. L. REV. 83, 153 (2009) (arguing that "courts should appreciate… that they are being led on a misguided search for the 'truly disabled,' a search that the IDEA does not require, but that instead threatens to undermine the goals of the statute.")
[384] *See* H. Rutherford Turnbull III, *Individuals with Disabilities Education Act REauthroization: Accountability and Personal Responsibility*, 26 REMEDIAL & SPECIAL EDUC. 320, 320 (2005) (describing the 2004 reauthorization of IDEA as "social reform on a large scale—more like a '*welfare state*' reform law than a civil rights or school reform law").
[385] For example, it might require educational programs meet a strict disparate impact requirement yet leave that requirement unenforced.
[386] This could be achieved through a school voucher system. Many scholars have expressed concern that such a system would leave individuals with disabilities worse off, however. *See, e.g.*, Martha Minow, *Choice or Commonality: Welfare and Schooling after the End of Welfare as We Knew It*, 49 DUKE L.J. 494, 528 (1999) (arguing that school choice programs will "leave the most vulnerable children from the least-engaged and least-solid families in the worst schools").

solution given prevailing legal regimes. Here, ambiguities like the IDEA's "free appropriate public education" standard may be our best guide.[387]

Upon electing a structurally ambivalent regime, the task remains to order that regime such that it exposes individual feelings of ambivalence. The procedural and individualized orientation of the present regime ideally requires parents and professionals to grapple with the particular circumstances of the child at issue.[388] A truly collaborative and informed process would expose the conflicting views of disability held by the relevant parties and more particularly their conflicting impulses toward the child. To do so, however, such a process would need to correct for the imbalance of power between parents and professionals.[389] It is well established that many parents feel intimidated and only nominally included in the IEP process.[390] As in the medical context, this may be inevitable to some extent; however, further procedural safeguards, a broader set of substantive presumptions, and additional efforts to educate parents about their rights could help promote a more genuine dialogue.

This is an admittedly broad prescription. To make matters more concrete, the IDEA's presumption in favor of the least restrictive environment strengthens parental bargaining power and combats traditional impulses to warehouse students in segregated settings.[391] It acknowledges, however, that segregated settings may be appropriate in certain circumstances and does not proscribe them altogether.[392] This presumption provides only one tool for parents; schools could comply with the presumption and nevertheless standardize IEP processes into mere formalities. Additional requirements for IEP meetings, parent counsel, independent evaluation, expedited administrative review, or the like, could give parents more bargaining chips.[393] With respect to judicial review, the Supreme Court recently held that the IDEA does not place the burden of proving the appropriateness of an educational program on schools, nor does it allow parents to

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[387] That is, in those contexts the prevailing legal order precludes the adoption of overtly ambiguous standards because of the shadow of death. The complexity of the educational system welcomes such overtly ambiguous standards. Indeed, they have long befuddled courts and commentators.

[388] For a discussion of the parent-professional dynamics involved in the IEP process, see Sue Goldstein et al, *An Observational Analysis of the IEP Conference*, 46 EXCEPTIONAL CHILDREN 278 (1980). For a more systemic view of the potential of parent-professional collaboration, see ANN P. TURNBULL ET AL, FAMILIES, PROFESSIONALS AND EXCEPTIONALITY: POSITIVE OUTCOMES THROUGH PARTNERSHIP AND TRUST (5th ed. 2005).

[389] For a summary of research on this imbalance, see Lynn M. Daggett, 8 U.C. DAVIS J. JUV. L. & POL'Y 1, 23-29 (2004).

[390] *See* David M. Engel, *Law, Culture, and Children with Disabilities: Educational Rights and the Construction of Difference*, 1991 DUKE L.J. 166, 192-194.

[391] For a discussion of the power of this presumption, see Mark C. Weber, *The Least Restrictive Environment Obligation as an Entitlement to Educational Services: A Commentary*, 5 U.C. DAVIS J. JUV. L. & POL'Y 147, 158 (arguing that "in special education law, the least restrictive environment obligation has a unique role as a positive obligation to provide services").

[392] For an argument questioning the scope of the integration presumption and its origins in thinking about race discrimination, see Ruth Colker, *The Disability Integration Presumption: Thirty Years Later*, 154 U. PENN. L. REV. 789 (2006).

[393] This is not to say that parents do not have bargaining chips at present; indeed, that is the purpose of the IDEA's safeguards. I merely intend to draw attention to possible measures that might level the playing field. This is a frequent topic of discussion in special education law. My aim is to reconceptualize the purpose of promoting a genuine discussion between parents and professionals.

recover expert witness fees.[394] An act of Congress to the contrary would likewise shift the balance toward parents.[395]

There are surely other means to expose ambivalence about disability in this context, depending on the broader structure of the regime. Instead of looking at the process for setting educational programs, we might look at the methods of classification used to determine eligibility for protection. We might eliminate disability classifications altogether and provide all children with an individualized education program.[396] Feasibility aside, this approach could capture views about both the neutrality and undesirability of disability. Perhaps more realistically, context specific inquiries into the need for special education services might do better at avoiding singular views of disability than more categorical approaches based on diagnosis. Once again, my aim is only to frame the range of issues rather than to answer them. Issues of classification, moreover, point to important overlaps with the ADA and federal benefit programs.

B. Employment, Federal Disability Benefits, and the ADA

The bulk of modern legal scholarship concerned with disability addresses federal regulation of employment. For the most part, this work focuses on the ADA's protections against employment discrimination. However, a growing set of scholars has begun to explore the interaction between antidiscrimination mandates and federal disability benefits.[397] By most accounts, legal reforms in the past two decades have yielded a series of puzzling and frustrating failures. The sweeping antidiscrimination rhetoric embodied in the ADA did not prevent courts from construing the Act narrowly and prompting Congress to issue a harsh rebuke in the ADA Amendments Act of 2008.[398] Eligibility requirements for federal benefit programs tend to encourage individuals with disabilities to remain out of the workforce. For these reasons or perhaps others, the national employment rate for individuals with disabilities has remained stagnant in the two decades since the passage of the ADA.[399]

Attention to our ambivalence about disability helps to explain these outcomes and suggest appropriate reforms. As in the educational context, federal regulation of employment must walk a fine line between expecting too much of individuals with

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[394] Arlington Cen. School Dist. Bd. of Educ. v. Murphy, 548 U.S. 291 (2006); Schaffer ex rel. Schaffer v. Weast, 546 U.S. 49 (2005).

[395] *See* Kelly D. Thomason, Note, *The Costs of a "Free" Education: The Impact of Schaffer v. Weast and Arlington v. Murphy on Litigation Under the IDEA*, 57 DUKE L.J. 457, 485-86 (2007).

[396] Along these lines, some scholars have argued for an approach based on the relationships between students that would yield something approaching a universally designed classroom. *See, e.g.*, MINOW, *supra* note 295, at 83-86.

[397] *See, e.g.*, Matthew Diller, *Dissonant Disability Policies: The Tensions between the Americans with Disabilities Act and Federal Disability Benefit Programs*, 76 TEX. L. REV. 1003, 1008 (1998) (arguing that "attempts to divide the ADA and the disability benefit programs into two mutually exclusive policy spheres are based on misunderstandings of both statutory schemes").

[398] Pub. L. No. 110-325, 122 Stat. 3553.

[399] For an overview of empirical work on this question, see Richard V. Burkhauser & David C. Stapleton, *A Review of the Evidence and Its Implications for Policy Change, in* THE DECLINE IN EMPLOYMENT OF PEOPLE WITH DISABILITIES: A POLICY PUZZLE 369 (David C. Stapleton & Richard V. Burkhauser eds., 2003).

disabilities and expecting too little. Singular views of disability threaten to yield inappropriate employment outcomes that ignore individual needs and circumstances. These outcomes might take the form of unduly high expectations for employees with disabilities or, alternatively, unduly low expectations for those employees.[400] They might instead appear in underemployment of capable individuals with disabilities or, indeed, inefficient overemployment of individuals with disabilities who do not possess the appropriate skills for the job.[401] Tensions between these outcomes and underlying feelings of ambivalence also carry the power to elicit destructive expressions of guilt. For example, this might produce abusive or overprotective employment relationships.[402]

The present regime rests upon each of these singular visions of disability, albeit with different visions controlling different contexts. A view of disability as inherently neutral underpins the antidiscrimination approach of the ADA and Section 504 of the Rehabilitation Act.[403] The findings of the ADA conspicuously placed the act within the antidiscrimination framework contained in Title VII and constitutional protections for "discrete and insular" minorities "subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness."[404] The Act cast the social position of individuals with disabilities as a product of prejudice and animus. Although framed in the seemingly new language of reasonable accommodation, it endeavored to eliminate the effects of implicit and explicit bias through standard antidiscrimination prohibitions against relevant forms of disparate treatment and disparate impact.[405] Disability advocates accordingly applauded the act as a victory for the social model of disability.[406]

Federal disability benefit programs maintain a quiet coexistence with the federal antidiscrimination regime. Beneath these programs lies a view of disability as inherently undesirable, often to the consternation of disability advocates.[407] Federal disability

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[400] Sheltered workshops typically provide an instructive example of unduly low expectations. For a criticism of these institutions, see Jacobus tenBroek, *Sheltered Workshops for the Physically Disabled*, 44 J. URB. L. 39 (1966). Unduly high expectations are more rare and harder to define with certainty given social prejudice and imperfect scientific understanding of impairments.

[401] Few scholars have argued that the employment rate for people with disabilities is inefficiently high. *But see* RICHARD EPSTEIN, FORBIDDEN GROUNDS: THE CASE AGAINST EMPLOYMENT DISCRIMINATION LAWS 485-488 (1995) (raising this possibility, at least in the foreseeable future under the ADA).

[402] For vignettes about some such abusive relationships, see MARK C. WEBER, DISABILITY HARASSMENT 1-9 (2007). Sheltered workshops represent an effort at an overprotective environment.

[403] This may overstate the case. Antidiscrimination law need not presume that suspect classifications are inherently neutral. The point here is that disability advocates pursued antidiscrimination law behind a rallying cry that cast disability as a neutral form of human variation. *See* Samaha, *supra* note 290, at 1278-84

[404] 42 U.S.C. § 12101(a)(7) (2000).

[405] For a discussion stressing the novelty of the reasonable accommodation standard, see Pamela S. Karlan & George Rutherglen, *Disabilities, Discrimination, and Reasonable Accommodation*, 46 DUKE L.J. 1 (1996). For a view of the parallels between reasonable accommodation and disparate impact, see Christine Jolls, *Antidiscrimination and Accommodation*, 115 HARV. L. REV. 642 (2001).

[406] *See, e.g.*, Robert L. Burgdorf Jr., *"Equal Members of the Community": The Public Accommodations Provisions of the Americans with Disabilities Act*, 64 TEMP. L. REV. 551, 580 (1991) ("ADA access requirements represent a crystallization of societal conviction that, at this point in our development, we have enough understanding of the significant life limitations imposed by attitudinal, architectural, and communications barriers on millions of our citizens to recognize that continued toleration of such barriers is folly.").

[407] For a description of the disability community's historical reaction against these views, see SHAPIRO, *supra* note 82, at 184-210.

benefits have a much longer history than antidiscrimination mandates, rooted in pensions for war veterans.[408] Modern Social Security benefits reflect dual aims of social insurance and public assistance for individuals with disabilities.[409] For the most part, benefits are only available to those completely unable to work as defined by the statutory scheme.[410] Some disability advocates question this formulation and assert that all individuals with disabilities are capable of working given adequate supports and appropriate employment.[411] For them, disability benefits constitute an excuse not to work and a system that entrenches learned helplessness and dependency.[412] In any event, federal disability benefits envision a regulatory regime segmented between those able to work and those unable to do so.[413]

Placed in context, these regimes make up a larger system characterized by structural ambivalence about disability. In one doctrinal area, disability is a neutral form of difference protected against discrimination. In the other, it is an undesirable affliction addressed by government largesse and social insurance. Of course, the two regimes are not quite as distinct as we might imagine. For example, people with disabilities capable of employment do not only garner government aid from antidiscrimination law; they may also benefit from vocational rehabilitation services, community programs, affirmative action, and the like. These services are consistent with a view of disability as a neutral difference subject to social prejudice, but they could just as well reflect a view of disability as an inherently undesirable affliction that requires social supports. It is the organizing principle, not necessarily specific policies, that separates the two spheres and betrays our ambivalence.

The interaction between federal disability benefits and federal antidiscrimination law is not the only reflection of ambivalence about disability in the employment context. Each of the two spheres also reflects its own brand of ambivalence about disability. Courts, academics, and the public at large have often construed the ADA as if it were a public assistance measure rather than an antidiscrimination measure.[414] The strong parallels between reasonable accommodation claims under the ADA and disparate impact

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[408] *See* Peter David Blanck & Michael Millender, *Before Disability Civil Rights: Civil War Pensions and the Politics of Disability in America*, 52 ALA. L. REV. 1 (2000) (contesting that view that disability rights advocacy did not mobilize until the civil rights movement).

[409] *See* Matthew Diller, *Entitlement and Exclusion: The Role of Disability in the Social Welfare System*, 44 UCLA L. Rev. 361, 370-383 (1996)

[410] *See* Diller, *supra* note 397, at 1060-1062.

[411] *See, e.g.*, Patricia Rogan, Michael Callahan & David Hammis, *Toward Full Citizenship: New Directions in Employment for People with Significant Disabilities*, *in* MAKING THE DAY MATTER: PROMOTING TYPICAL LIFESTYLES FOR ADULTS WITH SIGNIFICANT DISABILITIES 35, 35 (Pamela Walker & Patricia Rogan eds., 2007) (summarizing research that "people with high support needs *can* work if the job is matched to their abilities and interests, and if they are provided with the necessary supports").

[412] For a classic statement to this effect, see Jacobus tenBroek & Floyd W. Matson, *The Disabled and the Law of Welfare*, 54 CAL. L. REV. 809, 831 ("It is the agency of welfare, not the recipient, who decides what life goals are to be followed, what ambitions may be entertained, what services are appropriate, what wants are to be recognized, what needs may be budgeted, and what funds allocated to each.").

[413] For a discussion of the distinction between conceiving of welfare as an excuse not to work and as recognition of inability to work, see Mark C. Weber, *Disability and the Law of Welfare: A Post-Integrationist Experiment*, 2000 U. ILL. L. REV. 889, 924-29.

[414] *See* Matthew Diller, *Judicial Backlash, the ADA, and the Civil Rights Model*, 21 BERKELEY J. EMP. & LAB. L. 19, 48-51 (2000)

claims under Title VII continue to elude academics.[415] Perhaps more troubling for disability advocates, public discomfort with the antidiscrimination paradigm of the Act has prompted something of a backlash against the ADA and disability rights more broadly.[416] Courts have interpreted the definition of disability under the Act as though it were a gateway to public benefits rather than a classification protected against discrimination.[417] The rhetoric of neutrality captured in the Act, then, does not quite match the reality.

Federal disability benefit programs also betray a structural ambivalence about disability. Matthew Diller has documented a curious dynamic in the coverage and extent of disability benefits. Programs that employ broad definitions of disability tend to yield benefits comparable to those offered to the poor generally, while programs that employ narrow definitions tend to yield higher and non-punitive benefits.[418] Inclusive definitions of disability, then, prompt social views that disability cannot be separated from other reasons for poverty and should be irrelevant in considerations of social justice. Narrow definitions, on the other hand, prompt an embrace of the view that disability is undesirable and worthy of services beyond those of the poor.[419] In both situations, eligibility requirements must divide the population of individuals with disabilities between those for whom disability should be neutral and those for whom it cannot be. This uncomfortable task exposes conflicting views about disability.[420]

Given these layers of structural ambivalence, the question becomes whether the current regime diffuses ambivalence about disability in optimal fashion. This is unlikely. Although non-enforcement might make sense in the prenatal or neonatal contexts, the ADA constitutes a highly visible regime fraught with considerable litigation. Our system of federal disability benefits must draw lines with respect to coverage, but it does not have to divide between those capable and incapable of working. An alternative regime might simply acknowledge the relationship between the two spheres discussed above. The judges who interpreted the ADA as though it were a benefits statute may simply need education and guidance about the different paradigms operating in these two spheres. The public and the academy would surely benefit from the same guidance. This shift might be achieved through a formalized legal recognition of the distinct approaches of these areas or through social activism.[421]

The trouble with this approach is that it would only structure ambivalence in an extremely broad sense. Although this might influence the legal constructions of the individual spheres, it might not. It may be necessary, therefore, to pursue different expressions of ambivalence in each of those spheres. In the antidiscrimination context, this could involve legislative measures that highlight the undesirability of disability. For

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[415] For discussions of this phenomenon, see Jolls, *supra* note 405, at 651-71 (2001)

[416] For an attempt to understand the narrowness of judicial interpretations, see, for example, Diller, *supra* note 414. For a broader treatment from a disability rights perspective, see JOHNSON, *supra* note 107.

[417] *See* Diller, *supra* note 414, at 23 (arguing that the ADA "appears to judges as a kind of subsidy conferred on a class of people singled out by Congress for special treatment"). For a doctrinal overview, see *id.* at 47-51.

[418] *See generally* Diller, *supra* note 409.

[419] *Id.* at 364.

[420] This is particularly the case in light of the contrast with the ADA. Absent that statute, the task could prompt denials of ambivalence.

[421] The ADAAA represents one step in this direction.

example, the law could implement an indefinite and non-remedial affirmative action program, relax of particular standards for employees with disabilities, or grant government subsidies for employers who provide reasonable accommodations.[422] In the benefits context, we might eschew the line between those capable and incapable of working in favor of a continuum and partial disability benefits that do not penalize employment or income.[423] In the same vein, we might develop an analogue to the earned income tax credit for disability.[424] Admittedly, there are a variety of other possibilities that could promote these ends; my goal here, as in the discussion of education above, is merely to frame the issues.

Once we arrive at a conclusion about how to best to avoid legally prompted denials of ambivalence in the employment context, an additional task remains. How should the law expose ambivalence about disability in this realm? In both the hiring process and the workplace, reactions to disability color a multitude of interpersonal relationships and managerial decisions.[425] Recognizing that mixed feelings about disability are understandable if not desirable may help employers and employees best address issues related to disability in the workplace. However, the law does not intrude into employment decision-making in quite the way it does in the IEP process.[426] This renders measures to expose ambivalence about disability a bit trickier. The best ways may lie in education and public recognition of the structural ambivalence that characterizes the employment regime more broadly.[427] This is an area where disability advocates might be best served by toning down rhetoric invoking traditional antidiscrimination law.

A call to acknowledge and accept ambivalence about disability in employment may seem to apologize for animus and prejudice. More than in the prior areas discussed here, the employment context invokes parallels with traditional antidiscrimination law and the persistent trouble of both explicit and implicit bias against minority groups in employment. Such an apology is not my aim. The goal here is to argue that overemphasis on views of disability as inherently neutral may yield destructive denials of ambivalence about disability. Indeed, this is one way to explain the backlash against disability rights after the passage of the ADA. Disability advocates may argue that prejudice and animus motivates reactions against the ADA just as it has propelled discrimination in the workplace. This may be true. But attention to our ambivalence about disability suggests that prejudice in the traditional sense is not the only factor at work here. In propounding a

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[422] For an argument about subsidizing reasonable accommodations, see Scott A. Moss, Daniel A. Malin, Note, *Public Funding for Disability Accommodations: A Rational Solution to Rational Discrimination and the Disabilities of the ADA*, 33 HARV. C.R.-C.L. L. REV. 197, 219-31 (1998).

[423] For an argument to this effect, see Weber, *supra* note 413, at 943-47.

[424] *See id.* at 947-50.

[425] Consider, for example, the facts in *Vande Zande v. State of Wisconsin Department of Administration*. In that case, a prominent part of the dispute concerned whether the defendant employer needed to lower break room countertops so that the plaintiff could wash her mug in the kitchen rather than the bathroom. The court did not consider how the prevailing setup would affect the interpersonal dynamics within the office. 44 F.3d 558, 545-56 (1995) (Posner, J.).

[426] Proposals for such a scheme have been advanced, however. *See, e.g.*, Susan Sturm, *Second Generation Employment Discrimination: A Structural Approach*, 101 COLUM. L. REV. 458 (2001).

[427] This would push together the two normative principles advanced here for the law to both avoid provoking ambivalence and consciously expose ambivalence.

strong view of the neutrality of disability in the employment context, disability advocates may be fueling denials of ambivalence that they then interpret as prejudice.

C. Medical Care, Life, and Death

Let us return to the realm in which we began, that of medical care. Denials of ambivalence about disability in this broad area carry many of the same dangers examined in the education and employment contexts. The dangers that arose with respect to selective abortion and selective non-treatment are emblematic if not exhaustive. At the edge of life and death, singular views of disability threaten either excess treatment or inadequate treatment, as physicians impose abstraction upon the individual patients before them.[428] The same danger exists for treatment decisions more generally. In doctor-patient relationships, singular views of disability threaten to exacerbate troubling dynamics of coercion and poor communication that afflict the medical profession. As merely one example of these difficulties, consider the history of institutionalization in this country. An initially benevolent enterprise quickly became an instrument of harm, coercion, and abuse in the name of medical treatment.[429]

In important ways, the healthcare system betrays a clear orientation toward a view of disability as undesirable. Physicians concern themselves in large part with efforts to cure and rehabilitate individuals with illnesses and disabilities. Research efforts aim to both improve these measures and to eradicate particular illnesses and disabilities altogether. These efforts are concerned with some metric to assess quality of life. They are, moreover, both a government project and a broader social project. Calls for a cure have animated charity organizations, longstanding fundraisers, and even disability groups.[430] The government actively promotes such efforts through research funding and a diverse public health regime. It recognizes the special medical needs that accompany disability through healthcare benefits and research funding priorities.[431] These efforts reflect an understandable push to improve individual and collective quality of life in the face of the undesirable consequences of disability.

At the same time, elements of legal regulation of the healthcare system espouse a view of disability as a neutral form of human difference. The ADA and Section 504 nominally apply to a variety of healthcare decisions.[432] Courts have applied these statutes to strike down denials of access to healthcare and failures to provide auxiliary aids

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[428] For discussions to this effect, see Part III.B and Part III.C.

[429] *See generally* DAVID J. ROTHMAN, THE DISCOVERY OF THE ASYLUM: SOCIAL ORDER AND DISORDER IN THE NEW REPUBLIC (1971).

[430] Among the most prominent is Jerry Lewis' annual telethon to raise money for muscular dystrophy. For a critical view, see JOHNSON, *supra* note 156, at 47-75. In recent years, the disability group Autism Speak has been particularly motivated by the search for a cure. *See* Bob Wright & Suanne Wright, A Message from Suzanne and Bob Wright, Co-Founders Autism Speaks http://www.autismspeaks.org/founders.php ("This disease has taken our children away. It's time to get them back.").

[431] For an overview of these issues, see CHARLES E. DRUM ET AL, DISABILITY AND PUBLIC HEALTH (2009).

[432] For an overview, see Lawrence O. Gostin, *The Americans with Disabilities Act and the Corpus of Antidiscrimination Law: A Force for Change in the Future of Public Health Regulation*, 3 HEALTH MATRIX 89 (1993).

necessary for access.[433] Cases of differential treatment on the basis of disability have been more infrequent and opaque. In cases where physicians provided differential treatment on the basis of disability and disability was entirely irrelevant to the decision at hand, courts have been quick to find invidious discrimination.[434] They have been more wary of cases in which the need for medical treatment is related to the patient's disability. These cases raise uncomfortable questions about reasonable medical judgment and the best interests of the patient.[435] Questions like these are even starker in cases of healthcare rationing on the basis of disability.

The few courts that have wrestled with these issues convey a familiar pattern of ambivalence about disability. In cases concerning physician refusals to provide requested care, the courts have arrived at bipolar conclusions. One interpretation, emerging out of the Baby Doe controversy, holds that Section 504 only applies to treatment decisions unrelated to a patient's disability. This approach would seem to remove rationing decisions related to disability from judicial scrutiny.[436] A second interpretation, espoused in *In re Baby K*, holds that under the ADA quality of life is an impermissible consideration in treatment decisions.[437] The Department of Health and Human Services drew on this interpretation in opposing a rationing regime proposed for Oregon's Medicaid program.[438] In the absence of much additional case law, we are left with views of disability as both inherently undesirable and a neutral form of human difference.

This dynamic is also evident outside of the antidiscrimination context. Consider, for example, the present regime governing physician-assisted suicide. In *Glucksberg*, the Supreme Court placed considerable emphasis on the importance of protecting vulnerable groups like people with disabilities from what could become coercive euthanasia.[439] Yet the Court's decision did not condemn the practice altogether, nor its relation to quality of life considerations; rather, it left the issue to the states.[440] Oregon's regime expresses a similar ambivalence. It sidesteps issues of disability and quality of life by drawing eligibility requirements with reference to a definition of terminal illness tied to life expectancy.[441] Competency requirements nominally preclude the option of suicide for

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[433] *See* Mary Crossley, *Becoming Visible: The ADA's Impact on Health Care for Persons with Disabilities*, 52 ALA. L. REV. 51, 57-63 (2000)

[434] *Id.*

[435] *See* Philip G. Peters, Jr., *When Physicians Balk at Futile Care: Implications of the Disability Rights Laws*, 91 NW. U. L. REV. 798, 825-42 (1997).

[436] *See* United States v. University Hosp., 729 F.2d 144, 156-59 (2d Cir. 1984) (finding that section 504 does not apply to medical treatment decisions). The court in *University Hospital* stated further: "one would not ordinarily think of a newborn infant suffering from multiple birth defects as being 'otherwise qualified' to have corrective surgery performed." *Id.* at 156. For a comparable analysis under the ADA, see Johnson v. Thompson, 971 F.2d 1487, 1493-94 (10th Cir. 1992).

[437] In re Baby K, 832 f. Supp. 1022, 1029 (E.D. Va. 1993) ("the plain language of the ADA does not permit the denial of ventilator services that would otherwise keep alive an anencephalic baby when those life-saving services would otherwise be provided to a baby without disabilities at the parent's request") *aff'd*, 16 F.3d 590 (4th Cir. 1994).

[438] *See* Peters, *supra* note 435, at 816-17.

[439] Washington v. Glucksberg, 521 U.S. 702, 732 (1997) ("The State's assisted-suicide ban reflects and reinforces its policy that the lives of terminally ill, disabled, and elderly people must be no less valued than the lives of the young and healthy, and that a seriously disabled person's suicidal impulses should be interpreted and treated the same way as everyone else's.").

[440] *Id.* at 735-36.

[441] Or. Rev. Stat. 127.805 § 2.01 (2008).

persons with intellectual disabilities, but these requirements are meager at best.[442] The statute thereby assumes away negative valuations of disability while simultaneously allowing those valuations to enter the analysis unacknowledged.

Alternatively, consider the present regime governing the practice of refusing life-sustaining treatment. In protecting a right to refuse treatment, the Court has explicitly referenced the state's interest in protecting vulnerable groups that might be victimized by its use.[443] Individuals who refuse treatment must meet competency requirements either at the time of their choice or at the time they make a directive.[444] Yet the law largely ignores the relevance of quality of life considerations in decisions to refuse treatment. The court in *Bouvia v. Superior Court* recognized these concerns in its careful enumeration of the maladies that drove the plaintiff to consider refusing treatment.[445] In *Cruzan v. Director*, however, the Supreme Court stressed that states could "properly decline to make judgments about the 'quality' of life that a particular individual might enjoy" and instead assert general interests in human life.[446] State statutes and the Uniform Health-Care Decisions Act ignore the relevance of such concerns, once again allowing them to enter decisions without state endorsement.[447]

The question is whether these regimes appropriately diffuse and expose ambivalence about disability. With respect to differential treatment and rationing healthcare, it may be best to maintain the present doctrinal uncertainty. That leaves each of these practices on weak footing and subject to the possibility of condemnation. This uncertainty might push physicians to reduce their disclosure of information to patients and their families, which could suggest that the law should pay particular attention to the doctor-patient relationship when disability is present. This would be a complex task, though it might look to heightened disclosure or procedural requirements. Such measures could serve the dual purpose of structuring ambivalence into the regime and exposing it to physicians. So could efforts to educate physicians about the social experience of disability apart from medical diagnoses. Ideally, physicians would take quality of life into account but do so in a manner that acknowledged their conflicting emotions.

In the context of physician-assisted suicide, the same concerns suggest a comparably conflicted and uncertain legal doctrine. The role of disability in decisions to end life could recommend a disjunctive regime that bans assisted suicide and yet allows some amount of its practice to go unnoticed. Alternatively, a regime that legalized physician-assisted suicide in some form would do best to follow Oregon's lead and avoid direct confrontation with the acceptable role of disability in decisions. To further expose our ambivalence about disability in this context, the law might require patient education about disability on top of competency requirements. This could take the form of required

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[442] *Id.* § 1.01 ("'Capable' means that in the opinion of a court or in the opinion of the patient's attending physician or consulting physician, psychiatrist or psychologist, a patient has the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available.").
[443] Cruzan v. Director, 497 U.S. 261, 281 (1990).
[444] *Id.* at 270-72.
[445] Bouvia v. Superior Court, 179 Cal. App. 3d 1127, 1135-37 (1986).
[446] 497 U.S. 261 at 282.
[447] For a critical analysis of these laws as they affect people with disabilities, see Marah Stith, *The Semblance of Autonomy: Treatment of Persons with Disabilities Under the Uniform Health-Care Decisions Act*, 22 ISSUES L. & MED. 39 (2006).

informational materials or referrals to disability groups representing the disability in question. A patchwork of state regimes like the one emerging at present would also convey a concrete message of ambivalence about the practice. So would legislative, administrative, and professional statements of uncertainty. Present social efforts to capture the proper role of disability in these decisions, however, should be abandoned.[448]

The ambivalent character of the current regime governing withdrawal of life sustaining treatment also has much to recommend it. If the law retreated to the regime pre-*Cruzan*, the resulting ban on withdrawal of life sustaining treatment would run counter to prevailing views of consent, autonomy, and torts. The law's careful avoidance of questions about the relevance of disability in these decisions expresses a constructive ambivalence about disability. Given social understandings about the practice demonstrated in controversies like *Bouvia*, however, the law might further emphasize a vision of disability as neutral human difference.[449] As in the contexts discussed above, this might take the form of educational requirements about disability or referrals to individuals with the disability in question. It could also take the form of overt statements of concern about the practice. For disability advocates, this suggests an effort to ensure realistic portrayals of disability in these decisions rather than an effort to foreclose the availability of non-treatment altogether.

On a higher level of generality, diffusing ambivalence about disability in the field of medical care suggests that the law avoid overt attempts to eradicate disability as well as efforts to cast it as a classification irrelevant to treatment decisions. As in the contexts of education and employment, disability advocates should be wary of aggressive reliance on traditional antidiscrimination principles and rights discourse. However, the distrust of the medical profession so often expressed by the disability rights movement has considerable merit. This is particularly true with the rise of medical technologies aimed at preventing disability like prenatal testing and preimplantation genetic diagnosis. Disability advocates have reason to be wary about technological advances that militate the effects of disability; despite their promise, these advances may further a culture of cure. This is the troubling and imprecise line the law must walk. As we recognize the desirability of cure and prevention, we must also recognize the constitutive quality of disability and our limits of understanding.

Conclusion

This Essay has pursued a pair of objectives, one descriptive and the other normative. Descriptively, it has argued that our reactions to disability are understandably colored by pervasive feelings of ambivalence. These feelings are not limited to those

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[448] This goes for both sides of the debate. The general public remains largely split on the issue. For an overview of legislative efforts since *Glucksberg*, see Kathryn L. Tucker, *In the Laboratory of the States: The Progress of* Glucksberg's *Invitation to States to Address End-of-Life Choice*, 106 Mich. L. Rev. 1593 (2008). Disability groups are heavily opposed. For a summary of their recent efforts, see Alicia Ouellette, *Disability and the End of Life*, 85 OR. L. REV. 123, 128-145 (2006).

[449] For a critical discussion of the views of disability captured in the *Bouvia* case, see, for example, PAUL K. LONGMORE, WHY I BURNED MY BOOK AND OTHER ESSAYS ON DISABILITY 149-174 (2003). Longmore writes that the case dramatized "arguments for euthanasia, aid-in-dying, assisted suicide, and medical cost containment [that] simply rationalize the ultimate act of oppression." *Id.* at 168.

ignorant about disability, nor those prejudiced against people with disabilities. Rather, they pervade the disability rights movement and individuals with disabilities themselves. We view disability as at once inherently undesirable and inherently neutral; it is both an affront to individuality and community and a proponent of identity and connection. Normatively, this Essay has argued that the law should consciously structure legal regimes to diffuse and expose ambivalence about disability. Denials of ambivalence threaten to prompt behavior that does not respond to individual needs and circumstances. On both an individual and a systemic level, these denials may lead to overprotection of individuals with disabilities or devaluation of those individuals.

I have suggested a pair of inquiries to navigate this difficulty. First, the law should avoid giving content to disability as either inherently neutral or inherently undesirable. Instead, it should preserve uncertainty about the relevant content of disability through ambivalent expressions that capture both of these competing sentiments. This task requires close attention to context and a degree of comfort with legal ambiguity and disjunction. Second, the law should actively expose ambivalence about disability whenever possible. That is, the law should not only avoid provoking denials of ambivalence in its own right; it should seek to diffuse the traditional social push toward these denials. I have applied these two inquiries in a series of contexts. Although present regimes on the whole reflect social ambivalence about disability, they do not necessarily reflect the optimal expression of that ambivalence. I have identified some possible avenues of reform, though my primary objective has been to demonstrate how to analyze these areas with reference to ambivalence about disability.

For disability advocates, structuring legal regimes to reflect ambivalence about disability may seem a strange path toward equal rights. I would like to suggest that the formulation of equal rights, though an appealing one, threatens to obscure the difficult situations before us. The drive of the disability rights movement to examine the construction of difference is a desirable and important one. But we should not imagine that this process can produce a view of disability unhindered by profoundly mixed emotions. The same holds for those focused on eradication and cure of disability. Much though we may try to put disability into confined medical terms, it eludes our comprehension. Abstract notions of the proper content of humanity or equality do not get us far in analyzing disability; in fact, they make the analysis more difficult.

This does not suggest that past efforts to regulate disability through antidiscrimination law or social welfare law are inappropriate. It cautions, however, that these approaches must occupy a larger constellation of legal regulation that espouses structural ambivalence about disability. In many of the contexts examined here, the law would do best to strive for mud rather than crystals.[450] This may be an uncomfortable and troubling prescription. The law tends toward enough confusion in the absence of a genuine effort toward this end. Individual advocates, moreover, will be hard pressed to argue for structurally ambivalent regimes. My more modest hope is that disability advocates and policymakers more broadly will recognize their conflicting emotions about disability and relax their efforts to find coherent meaning within it. This will be a messy project. Yet it may allow us to move beyond our fixation on an individual's disability and approach a genuine understanding of that individual and of ourselves.

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[450] This metaphor draws its origins from Carol M. Rose, *Crystals and Mud in Property Law*, 40 STAN. L. REV. 577 (1988).