

Engineering Perfect Offspring: Devaluing Children and Childhood

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American law permits withholding otherwise life-saving medical treatment from newborn children who are seriously ill or disabled when treatment is virtually "futile" or "inhumane" in prolonging the child's life.¹ Hence, when newborn children's genetic or congenital abnormalities would so impair them, or their lives would be so fleeting in all events, parents and physicians may legally choose the child's likely near-term death over life-prolonging treatment.² When exercising this choice, parents and physicians estimate the degree of impairment and likely duration of an abnormal child's life.³ They can abide by the law, though, only by comparing these

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1. See Child Abuse Prevention and Treatment Act, 42 U.S.C.A. §§ 5101-02, 5106a(b)(2)(B), 5106g(6) (West Supp. 1997). The Act requires states to respond to reports of "medical neglect," "including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions," but "the term 'withholding of medically indicated treatment' . . . does not include the failure to provide treatment . . . to an infant when . . . (B) the provision of such treatment would . . . (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of survival of the infant and the treatment itself under such circumstances would be inhumane." 42 U.S.C.A. § 5106g(6).

2. For this interpretation of the effect of the federal legislation, see, for example, *Bowen v. American Hosp. Ass'n.*, 476 U.S. 610 (1986); Steven R. Smith, *Disabled Newborns and the federal Child Abuse Amendments: Tenuous Protection*, 37 HASTINGS L.J. 765, 822 (1986); *Developments in the Law—Medical Technology and the Law*, 103 HARV. L. REV. 1519, 1584-614 (1990) [hereinafter *Developments in the Law*].

3. See *Developments in the Law*, *supra* note 2.

estimates with an unarticulated standard. That is, when we ask whether a child's life experience will be too inhumane or too short, we must compare that child with someone else: Too inhumane or too short compared with whose life experience? Will this child never see, hear, speak, or move as you or I do? Will this child suffer and die before reaching maturity as you or I have not? To whom, if anyone, should we compare seriously ill or disabled newborn children? The legal standards, not formally articulated,⁴ beg the question, what sort of a life is worth living?

Of course, the answer to that question depends on your perspective. Different people using different points of comparison and different perspectives will answer differently. Parents who are themselves seriously ill or disabled or experienced with some other adversity may view their children's struggles differently from those parents who are not. Likewise, religious convictions will inform the perspectives of some parents. By declining to articulate standards, the law permits different parents to choose differently, at least for those newborn children for whom life-prolonging medical treatment is "inhumane" or "virtually futile."⁵ I would not suggest that the law now remove from parents the authority to withhold inhumane or virtually futile medical treatment from their children. Still, the expectations and standards which inform parents' decisions should concern us all.

In particular, our jurisprudence and legal culture instill in parents the expectation and aim that children learn, mature, and grow to become self-sufficient, independent adults. American liberties and our related market economy both rely on this expectation that we all function sooner or later

4. The federal legislation requires states to adopt protocols for response to the withholding of medical treatment from disabled newborns as possible medical neglect penalized under the states' child abuse and neglect laws. 42 U.S.C.A. § 5106g(10) (1988). The criteria for determining medical neglect remain as vague as they were prior to the enactment of the federal legislation, then, in order to accommodate parental and physician discretion in hard cases. See Nelson Lund, *Infanticide, Physicians, and the Law: The "Baby Doe" Amendments to the Child Abuse Prevention and Treatment Act*, 11 AM. J.L. & MED. 1, 27-28 (1985). Because "there is no real national consensus on the underlying moral questions," Congress has not articulated legal standards which provide answers in the more complex—and more numerous—cases requiring parents and physicians to decide whether to terminate treatment or to prolong a disabled child's life. *Id.*

Commentators have observed that the continuing vagueness of the legal standards effectively authorizes parents to choose nontreatment of disabled newborn children who, with treatment, would in fact survive. See, e.g., Robert H. Mnookin, *Two Puzzles*, 1984 ARIZ. ST. L.J. 667, 668-71 (1984). The "law in action" as parents choose not to treat disabled newborn children thus diverges radically from "the law on the books" defining such nontreatment as medical neglect. See *id.* at 668.

5. See 42 U.S.C.A. §§ 5101-02, 5106a(b)(2)(B), 5106g(6). The overarching purpose of this federal legislation is, however, to ensure that all other seriously ill or disabled newborn children do receive life-prolonging medical treatment, regardless of their parents' or physicians' objections. See Lund, *supra* note 4, at 21-24 (describing the legislative history and its purpose of assuring the provisions of life-prolonging treatment to disabled newborn children).

as individual, autonomous adults.⁶ Indeed, the recognition that their seriously ill or disabled children—children with Down's syndrome, spina bi-

6. I anticipate that my characterization of the expectations of both our jurisprudence and our related market economy are readily recognizable. Following is a brief summation of the basis of my characterization:

As John Rawls has explicated in his comprehensive analysis of American constitutional justice, we comprehend legal personhood as the autonomous individual. JOHN RAWLS, *A THEORY OF JUSTICE* 142-50, 433-46, 513-20 (1971). That individual enjoys liberties of choice and, when exercising those liberties rationally, remains free of interference from either government or from private individuals. Hence, autonomous individuals act "from principles that we would consent to as free and equal rational beings," including freedom from the primary influence of "tradition and authority, or the opinions of others." *Id.* at 516. Constitutional precedent, in turn, reflects this legal understanding of personhood as autonomous individuality. Indeed, in landmark cases defining the legal import of childhood, the Supreme Court has consistently referred to the aim of childhood as producing the autonomous adult individual, an individual who enjoys both liberties to choose rationally and the autonomy of economic self-sufficiency. Hence, in *Plyler v. Doe*, 457 U.S. 202 (1982), the Court examined children's access to public school education with heightened scrutiny, *see id.* at 230, because education is a necessary predicate for competing in the economic marketplace and attaining economic autonomy, *see id.* at 223. Education is also a necessary predicate, the *Plyler* Court observed, for rationally exercising the liberty of enfranchisement. *Id.* at 222. Likewise, in *Wisconsin v. Yoder*, 406 U.S. 205 (1972), the Court analyzed the parental right to keep older children out of public school through reference to the children's eventual ability to become law-abiding adults capable of economic self-sufficiency. *Id.* at 221. In particular, the Court required assurance that the children removed from public schools would become, nonetheless, autonomous adults capable of relying on themselves rather than upon the state for economic support. *See id.* Our jurisprudence thus embodies a model of legal personhood characterized by individual autonomy, a model interpreted in the context of childhood as the potential for becoming economically self-sufficient and rationally independent adults. For further analysis and substantiation of this predominant jurisprudence of childhood, see Wendy Anton Fitzgerald, *Maturity, Difference, and Mystery: Children's Perspective and the Law*, 36 ARIZ. L. REV. 11, 22-33 (1994) (analyzing constitutional precedent); *id.* at 41-45 (analyzing child support law); *id.* at 64-71 (analyzing child custody law); *id.* at 84-99 (summarizing the jurisprudential model of children as potential autonomous, self-sufficient adults).

In turn, our cultural understanding of the import of childhood reflects this jurisprudential model of adult autonomy and self-sufficiency. As a society, we aspire for our children to become independent adults, both self-supporting and rationally choosing once vested with adult liberties. We understand education, then, as crucial to our children's eventual ability to compete and succeed in a technologically sophisticated labor market. Moreover, we characterize children as inheriting individual and political power as adults and therefore rationalize investment in children as investment in the responsible adult leadership of society's future. Indeed, legal autonomy, individuality, and economic self-sufficiency serve as the fundamental legal predicates for our capital market economy. Our economic system relies on the liberty of market participants to choose rationally in their own self-interest and consequently to enjoy the financial reward of meritorious choices or to suffer the financial penalties of individual failure. *See, e.g.,* RICHARD A. POSNER, *ECONOMIC ANALYSIS OF LAW*, 4th ed. (1992) (describing the manifestation in American jurisprudence—in constitutional and business law and in the American common law of property, contracts, family law, torts, and criminal law—of capital market economic principles and assumptions). Understanding economic dependence as the failure of the autonomous individual, then, our law provides no right to support from private individuals or from the state in dependent people, even children. We know, for example, from the Supreme Court's decision in *Bowen v. Gilliard*, 483 U.S. 587, 597 (1987), that children wield no vested right to support from their parents, for child support laws derive only from mutable legislative will. Nor, of course, do children or other

fida, or AIDS, for example—will face an often hostile society unprepared to accommodate their needs burdens parents' medical decision making. Not surprisingly, then, parents strive to birth and raise "perfect" offspring, children who will become independent adults, able to compete and excel in educational and, finally, commercial markets. No one can deny the utility of such goals for children. I suggest, however, that the goals of adult independence and self-sufficiency reflect an invidiously narrow perspective. From this perspective, life is worth living because of adult autonomy, and childhood is worth living as preparation for autonomous adulthood. This equation leaves no room for seriously ill or disabled newborn children who have little or no prospect of attaining self-sufficient adulthood.

In this essay, I observe that decision making about the medical treatment of children, whether or not to prolong their lives, reflects our cultural views on what sort of life is worth living. Our law and jurisprudence shape these views by valuing pre-eminently independence and self-sufficiency,⁷ attributes which seriously ill or disabled children do not enjoy. Of course, no child enjoys independence or self-sufficiency. Moreover, even the most "perfect" child with the best prospects for adulthood may meet an untimely death. Our law and jurisprudence seem bereft, however, of principles and perspectives capable of assuring that we value children, dependent as they are, even if they do not survive to autonomous adulthood. I hope that a critical examination of decision making for seriously ill or disabled children can help legal practitioners and scholars begin to articulate a more inclusive legal understanding of what sort of life is worth living. Indeed, I hope we can develop a legal perspective that values children and childhood, however short-lived or imperfect, without reference to our hopes for adulthood.

I begin that undertaking here, first by describing the legal context of medical decision making for genetically or congenitally abnormal children.

dependent people wield any right to support from the state as both the *Gilliard* Court, *id.* at 596, and the Court in *Deshaney v. Winnebago Department of Social Services*, 489 U.S. 189, 202 (1989), have observed. The parents of seriously ill or disabled newborn children, therefore, confront the prospect of raising children who will likely never conform to the expectations and standards of either the jurisprudential model of personhood or the economic system premised on that model.

Other critics before me have convincingly criticized the exclusivity of the jurisprudential model of personhood, the autonomous individual, and the consequences of their exclusion to women, people of color, and other people legally marginalized or left "outside" the predominant jurisprudential model. For discussion of such critics, see, for example, Fitzgerald, *supra*, at 18-19, 21, 24-25, 87-88, 91-98. In this essay, I seek to draw from the experience of medical treatment decision making for seriously ill or disabled children in order to further criticize that model and to urge its expansion to include dependent people, including children, however "able" or not they are.

7. See *supra* text accompanying note 6.

I suggest that the formal and practical law guiding these decisions reflects a devaluation of all children in our legal understanding of personhood. Second, I recount three cases of conjoined twins, including two cases of parents authorizing surgical separation of the twins with the hope of attaining for the children a more "normal" (or perfect) future. I see in these twins, as in other genetically and congenitally abnormal children, not so much physical defect and human tragedy as different, instructive, and often wonderful ways of being human. Third, I describe recent advances in genetic research and gene therapy and their popular reception. These advances coincide with a politically resurgent social Darwinism and confront us urgently with the question of whether to regulate, through law, individuals' options for genetically engineering their children. From these discussions I conclude that, culturally, socially, and legally, we promote an exclusive standard of perfection for our offspring which undermines tolerance for human difference and devalues all children.

I. The Legal and Jurisprudential Context of Medical Decision Making for Genetically and Congenitally Abnormal Children

The treatment of seriously ill or disabled newborn children has long challenged their parents and policy makers with deciding what it means to be human.⁸ Assessing the likely duration and quality of the child's life, as well as the burdens associated with caring for the child, parents and physicians have withheld otherwise life-saving medical treatment from children with pronounced genetic or congenital abnormalities.⁹ In the United States, for over a decade, federal statutes and case law have formally prohibited withholding medical treatment from abnormal children unless the treatment would be virtually futile or inhumane in significantly prolonging the child's life.¹⁰ Nonetheless, as commentators have observed, parents and physicians yet quietly withhold otherwise life-saving medical treatment from many other seriously ill or disabled newborn children, permitting them to die

8. See, e.g., Lund, *supra* note 4, at 16 nn. 68-69 & 73 (discussing "quality of life" criteria for medical treatment decisions for seriously ill or disabled newborn children, including some commentators' characterizations of such children as sub-human); Mary A. Crossley, *Of Diagnoses and Discrimination: Discriminatory Nontreatment of Infants with HIV Infection*, 93 COLUM. L. REV. 1581, 1622-25 (1993) (discussing "sanctity of life" versus "quality of life" criteria for medical treatment decisions for seriously ill or disabled newborn children).

9. See, e.g., Crossley, *supra* note 8, at 1581-87; Martha A. Field, *Killing "The Handicapped"—Before and After Birth*, 16 HARV. WOMEN'S L.J. 79, 82 (1993); Smith, *supra* note 2, at 822-23.

10. See generally, 42 U.S.C.A. §§ 5101-02, 5106a(b)(2)(B), 5106g(6) (West Supp. 1997); *Bowen v. American Hosp. Ass'n.*, 476 U.S. 610 (1986).

immediately.¹¹ For these parents and physicians, the children permitted to die would not have had a life worth living.

The substantive distinctions drawn for seriously ill and disabled children, though, remain elusive. For many decision makers, the unarticulated standard for comparison is a "normal" child, a child unimpaired and expected to survive through normal adulthood.¹² Once we articulate this standard for comparison, we can recognize medical decision making about seriously ill or disabled children as measurements of deviation from a norm. For many parents and physicians determining an abnormal child's treatment, the issue is whether the child's impairment is so different from a norm as to make the child's life, however long, not quite human, or at least not worth living. I would suggest instead that seriously ill or disabled children confront us with varieties of human difference,¹³ compelling us to re-think our tolerance for difference.

Among the myriad problems besetting children, medical decision making for seriously ill or disabled children does not loom so large as child poverty, abuse, racism, sexism, and other societal neglect.¹⁴ That we adults collectively countenance such mass maltreatment and neglect of children reflects, I believe, social, cultural, and moral devaluing of children as people. In turn, the law reflects the small value adults as a powerful collective attach to children. As other scholars have explicated, American law, for example, posits children as almost a species of parental property, subjecting them to their parents' plenary authority, for good or ill.¹⁵ The state may intrude on parental authority for a sufficiently important state interest, but

11. See, e.g., Crossley, *supra* note 8, at 1581-87; Field, *supra* note 9, at 83-84; Mnookin, *supra* note 4, at 670.

12. See, e.g., Crossley, *supra* note 8, at 1623-26; Lund, *supra* note 4, at 15-19.

13. My discussion of difference relies on Martha Minow's analysis in her *MAKING ALL THE DIFFERENCE: INCLUSION, EXCLUSION, AND AMERICAN LAW*, 299-310 (1990). See also Martha Minow, *The Supreme Court 1986 Term—Forward: Justice Engendered*, 101 *HARV. L. REV.* 10, 13-18 (1987) (explaining how legal decision makers mistake their own subjective perspective for objective, neutral norms, and arguing that all human "difference" is not innate, but rather determined from a particular perspective).

14. For a comprehensive description of the plight of children in the United States see, for example, *CHILDREN'S DEFENSE FUND, THE STATE OF AMERICA'S CHILDREN: 1997 YEARBOOK 9* (1997) (indicating that some 15 million American children live in poverty, with another million predicted to join them as welfare program reforms are implemented). Child abuse and neglect case numbers have risen, with approximately a million children confirmed abused or neglected annually. See *id.* at 51. The gap between white students and students of color in academic achievement has steadily widened since 1990, a gap which reflects the de facto racial and economic segregation in schools. See *id.* at 74-75.

15. See, e.g., Barbara Bennett Woodhouse, "Who Owns the Child?": *Meyer and Pierce and the Child as Property*, 33 *WM. & MARY L. REV.* 995 (1992) (demonstrating through analysis of landmark Supreme Court precedents that parents' constitutional rights protect not so much diverse parenting choices as parents' proprietary interests in children).

not in the interests of any particular child as a person.¹⁶ From the state's—or adult collective's—point of view, the most important interest in children is utilitarian or self-serving. The state should ameliorate child crime or illiteracy or malnutrition, for example, in order to secure the safety, self-sufficiency, and health of the adult population.¹⁷ From this perspective, childhood is crucial preparation for adulthood, but not especially valuable in and of itself. As a society, we invest in, nurture, and educate children so that they may become productive, self-sufficient adults.¹⁸ Children are the future, as people are wont to say, comprehensively defining the social, cultural, and legal value of childhood. Under our law, then, children are potential adults.

Seriously ill and disabled children confound this legal paradigm, of course, when they are unlikely to become self-sufficient, independent adults even if they survive to adulthood. These abnormal children deviate not only from the standard of the normal child, but also from the standard of children-as-potential-adults now animating American law. Indeed, seriously ill and disabled children differ mainly from normal children in that, unlike normal children, they will not become self-sufficient, independent adults.

Medically abnormal children require unusual financial investment and care giving, but in this regard they differ from other children only in degree. All children require substantial financial investment and care giving, as every parent and most state child services programs bear witness. Most children attain independence and economic self-sufficiency, though, upon emancipation into adulthood.¹⁹ Seriously ill and disabled children chal-

16. See, e.g., Sharon Elizabeth Rush, *The Warren and Burger Courts on State, Parent, and Child Conflict Resolution: A Comparative Analysis and Proposed Methodology*, 36 HASTINGS L.J. 461, 493-94 (1985) (discussing how parental rights limit state authority and interests); Fitzgerald, *supra* note 6, at 41-45, 64-71.

17. See e.g., Martha Minow, *Rights for the Next Generation: A Feminist Approach to Children's Rights*, 9 HARV. WOMEN'S L.J. 1, 6 (1986) (discussing collective adult self-interest driving the legal treatment of children); Fitzgerald, *supra* note 6, at 31-34 (arguing that adult utilitarian aims comprise the driving rationales for Supreme Court decisions regarding children's education); *id.* at 41-50 (discussing child support law); *id.* at 64-71 (discussing child custody law); Wendy Anton Fitzgerald, *Stories of Child Outlaws: On Child Heroism and Adult Power in Juvenile Justice*, 1996 WISC. L. REV. 495, 514-17, 521-23 (arguing that adult utilitarian aims drive juvenile justice reforms).

18. See *supra* note 6.

19. I would note that economic self-sufficiency in the United States actually entails intricate economic interdependence, necessary for survival, but rarely acknowledged. See William H. Simon, *Rights and Redistribution in the Welfare System*, 38 STAN. L. REV. 1431, 1434 (1986). Moreover, as Michael Sandel has observed, the predominant jurisprudential model of legal personhood, the autonomous individual, fails to comprehend a broad range of human interdependence, not only economic, but also informing people's very identity. See MICHAEL J. SANDEL, *LIBERALISM AND THE LIMITS OF JUSTICE* 175-83 (1982).

lenging medical decision making, however, present little prospect for attaining either independence or adulthood. Our law may therefore encourage parents and physicians to devalue the lives of seriously ill and disabled children and withhold life-prolonging treatment, not so much because the care is costly and care-giver intensive, but because these children will never become independent and hence legally valued adults.

If so, then the dilemmas of seriously ill and disabled children offer an important insight into the maltreatment and neglect of children generally. Culturally, socially, and legally, we define being human as independent, self-sufficient adulthood. In jurisprudential terms characterizing American law, for example, we value as human the "autonomous individual."²⁰ Children are valuable as potential autonomous adults, and if they lack that potential, they may not seem legally valuable at all. Moreover, so long as legal personhood hinges upon attainment of autonomous individuality, all children are inferior, less-than-legal people. Hence American law, as noted, consigns children to their parents' proprietary control, taking a public interest in children only in order to assure their eventual development into autonomous individual adults.

I have joined others in advocating the expansion of legal personhood to include children and the attributes of childhood. Critics of American jurisprudence—feminists, critical race theorists, and others—have comprehensively detailed how an unspoken norm permeates the law, a norm distinct for its exclusivity in gender, class, race, and other human differences.²¹ This narrow legal norm devalues as abnormal and inferior different human characteristics, among them, I have argued, childhood.²² Because children are dependent, immature, and not autonomous, they cannot meet the legal norm and are thus relegated to inferior legal status for the duration of childhood. Similarly, because seriously ill and disabled children will, even if they attain adulthood, likely *never* meet the narrow legal norm of individual autonomy, they may appear to parents and to physicians as forever relegated to an inferior legal status. Our law may thus influence medical decision makers to withhold life-prolonging treatment from abnormal children.

An attempt to comprehend children legally *as children* would help subvert the exclusive legal norm of individual autonomy and gain legal

20. See, e.g., RAWLS, *supra* note 6.

21. See, e.g., SANDEL, *supra* note 19, at 175-83 (arguing that the model of the autonomous individual in American law lacks the formative influences and relationships which, happily, shape actual people and their choices). See generally PATRICIA J. WILLIAMS, *THE ALCHEMY OF RACE AND RIGHTS* (1991); Mari J. Matsuda, *Liberal Jurisprudence and Abstracted Visions of Human Nature: A Feminist Critique of Rawls' Theory of Justice*, 16 N.M. L. REV. 613 (1986).

22. See Fitzgerald, *supra* note 6, at 84-109.

recognition for children's personhood.²³ That is, let us value children for themselves, not for their potential to become autonomous adults. Indeed, what if *most* children never survived to adulthood? Their lives, however short, dependent, and "childish" yet demand legal recognition and respect as human.

Seriously ill and disabled children urgently confront us with this demand. Many will not survive to adulthood, and yet their lives, however short, dependent, and childish yet require legal recognition and respect. Moreover, seriously ill and disabled children represent all children in this imperative. If we cannot legally recognize and respect the personhood of children bound to die, then we betray the morally unacceptable judgment that no child is valuable except as a potential autonomous adult.

Unfortunately, American law, both formal and practical, does indeed betray this morally unacceptable judgment. A widely-reported survey showed, for example, that while fewer than a quarter of all children born to HIV-infected mothers eventually manifest the virus, American doctors would withhold otherwise life-saving medical treatment from some or all such children, depending on the treatment.²⁴ In response, the researchers urged the usual treatment of all babies born to HIV-infected mothers because the virus cannot be detected in children until several months after birth.²⁵ Embedded in both medical approaches is the assumption that, in truth, we should not invest time, energy, and money into children who will not survive childhood, if only we could reliably identify which ones they were. Similarly, physicians now routinely counsel parents to abort fetuses identified as genetically or congenitally "defective," noting that many children with Down's syndrome, cystic fibrosis, or spina bifida rarely survive very long into adulthood, and they require costly, difficult care for their short lifetimes.²⁶ All these short lives are not worth saving, apparently, because they are comprised almost entirely of childhood with little or no hope of attaining autonomous adulthood. The law in practice informs parents, children, and all of our culture that autonomous adulthood and not dependent childhood, whether healthy or no, is the only recognized standard for legal respect and inclusion in personhood.

23. See *id.*; Fitzgerald, *Stories of Child Outlaws: On Child Heroism and Adult Power in Juvenile Justice*, *supra* note 17, at 525-38.

24. See Betty Wolder Levin et al., *The Treatment of Non-HIV-Related Conditions in Newborns at Risk for HIV: A Survey of Neonatologists*, 85 AM. J. OF PUB. HEALTH 1507, 1509-10 (1995).

25. See *id.* at 1512. Given recent medical advances resulting in an AIDS therapeutic drug "cocktail" enhancing the prognosis of HIV-infected people and their unborn children, neonatologists might respond differently were the survey repeated today.

26. See, e.g., Lund, *supra* note 4, at 9-12.

II. The Import of Recent Advances in Genetic Research and Therapies

Parents and medical practitioners have withheld treatment of genetically and congenitally abnormal children for centuries,²⁷ and infanticide is still common in some cultures throughout the world.²⁸ These practices constitute a kind of crude genetic-engineering, a post-hoc method for "improving" the human species by eliminating the least fit and preventing their procreation.²⁹ In the United States in the 1920s, political fervor for more concerted eugenic practices resulted in the enactment in many states of laws mandating the involuntary sterilization of "the feeble-minded" and convicted criminals.³⁰ The Supreme Court struck down one such statute in 1942 as violative of Equal Protection,³¹ and a myriad of studies repudiated the premise of a genetic cause of either mental retardation or criminality.³²

Nonetheless, several states maintain statutory authority for involuntarily sterilizing the "feeble-minded,"³³ and as recently as 1983 two states authorized sterilizing epileptics.³⁴ Popular enthusiasm for eugenic practices and the prevalence of underlying eugenic assumptions correspond, not surprisingly, with periods of social turmoil and political intolerance.³⁵ Our age appears to be one of these periods, and coincides as well with unprecedented scientific research in human genetics.³⁶

Indeed, the past decade has witnessed enormous strides both in fundamental scientific understanding of human genetics and in therapeutic technologies applying that new knowledge. The Human Genome Project, an international co-ordinated endeavor to "map" human DNA, for example, has located most of the genetic "markers" necessary for identifying human chromosomes.³⁷ International scientific efforts have located several single gene diseases, including Huntington's disease and one form of breast can-

27. *See id.* at 1.

28. *See id.* at 1 n.2.

29. *See id.* at 19-21.

30. *See, e.g.,* IRA MARK ELLMAN ET AL., FAMILY LAW: CASES, TEXT, PROBLEMS 1023-36 (2d ed. 1991) (describing and discussing engenic law in the United States).

31. *See* Skinner v. Oklahoma, 316 U.S. 535 (1942).

32. *See, e.g.,* ELLMAN ET AL., *supra* note 30, at 1033.

33. *Id.* at 1034.

34. *See id.* at 1033.

35. *See* DOROTHY NELKEN & SUSAN LINDEE, THE DNA MYSTIQUE: THE GENE AS A CULTURAL ICON, 126, 198-99 (1995).

36. *See, e.g., id.* at 5-9, 54-57.

37. *See* Laura Johannes, *Detailed Map of the Genome Is Now Ready*, WALL ST. J., Dec. 22, 1995, at B1.

cer,³⁸ and at least two children have undergone first attempts to replace a gene causing cystic fibrosis with normal human DNA.³⁹ Precise mapping of most genetic diseases, not to mention the design and proven efficacy of gene therapies, remains in the future, however. Most diseases of known genetic origin involve a complex set of genes, not just one, and safe, efficient delivery systems of "normal" human DNA to human patients still elude researchers.⁴⁰ Moreover, while many diseases do not occur absent a genetic propensity, most genetic diseases still seem to require environmental catalysts of some kind to manifest themselves.⁴¹ Thus, not everyone who carries a gene making them susceptible to cancer of the colon will develop such cancer, for not every carrier will also suffer exposure to the unknown environmental triggers necessary for the development of the disease. In sum, while genetic research and understanding accumulate at an unprecedented pace, human genetics as a science and gene therapy as an applied technology remain mostly unknown and untested.⁴²

In particular, the old debate about whether the influence of "nature" or "nurture" predominates in people remains unresolved. Indeed, the best educated guess informs us only that human organisms are complicated and that the various influences of nature and nurture vary unquantifiably in the most significant of human characteristics.⁴³ In this context of profound ignorance, most geneticists report their incremental work with little popular fanfare or publicized discussion of the social, ethical, and legal implications of human DNA research.⁴⁴ Some have attracted a mass audience, however, with speculation regarding the genetic origins of obesity, alcoholism, sexual orientation, and even the propensity for "risk-taking" and "shyness."⁴⁵ Moreover, some social scientists have re-popularized long

38. See, e.g., Francis S. Collins, *Identification of Disease Genes: Recent Successes*, HOSP. PRAC., Oct. 15, 1991, at 93; Mary-Claire King, *Localization of the Early-Onset Breast Cancer Gene*, HOSP. PRAC., Oct. 15, 1991, at 12.

39. See Johannes, *supra* note 37.

40. See *id.*

41. See *id.*

42. See NELKEN & LINDEE, *supra* note 35, at 2-18.

43. See *id.* at 5-11, 195-97.

44. Note that funding for the international Human Genome Project includes academicians examining the "Ethical, Legal, and Social Implications" or "ELSI" of human DNA research, but their work seldom receives notice beyond scientific and medical specialty publications. See, e.g., Nancy S. Wexler, *Disease Gene Identification: Ethical Considerations*, HOSP. PRAC., Oct. 15, 1991, at 145.

45. See NELKEN & LINDEE, *supra* note 35, at 93, 145 (regarding obesity); *id.* at 91-94, 100, 161-62 (regarding alcoholism); *id.* at 159-168 (regarding risk-taking); *id.* at 140-141 (regarding shyness).

discredited claims of the alleged genetic origin of such human behavior or attributes as criminality and intelligence.⁴⁶

Western culture and politics, in turn, have seized on genetic determinism, eager to understand a host of social ills as “naturally” dictated and hence beyond any palliative of “nurture.”⁴⁷ As Dorothy Nelkin and M. Susan Lindee have observed, this recent popular refocus on the supposed genetic causes of individual and social problems arises less from any scientific research itself than from the popular *desire* to explain such problems genetically.⁴⁸ Culturally, we attribute many more human problems and characteristics to genetics than verified research warrants because we crave these simple, clear, objective-seeming explanations of frustrating complex behavior and issues.⁴⁹

I see the recent rise of genetic determinism, indeed the renaissance of social Darwinism, as a political phenomenon, absolving the privileged of responsibility or guilt for social evils such as poverty, racism, and neglect.⁵⁰ Genetic determinism sanctions the consignment of an underclass—economic, racial, and mostly urban—to its “naturally” or biologically “inferior” fate, while the privileged withdraw to private “gated communities,” indoor shopping centers, and elite schools.⁵¹ At the same time, as Professors Nelkin and Lindee observe, genetic determinism “medicalizes” society, prompting us to ascribe human behaviors once seen as moral choices to diseased DNA instead.⁵² Diseased or abnormal DNA is subject to no moral

46. See, generally RICHARD J. HERRNSTEIN & CHARLES MURRAY, *THE BELL CURVE: INTELLIGENCE AND CLASS STRUCTURE IN AMERICAN LIFE* (1994); JAMES Q. WILSON & RICHARD J. HERRNSTEIN, *CRIME AND HUMAN NATURE* (1985).

47. See NELKEN & LINDEE, *supra* note 35, at 41-49, 68, 101-126, 143-144, 149-168, 193-199 (tracing the rise of genetic determinism or “essentialism,” as they call it, in contemporary popular culture).

48. See *id.*

49. See *id.*

50. Popular social critics have recently published book-length studies concluding that American poverty itself is genetic, resulting from an inferior genetic endowment for intelligence and success in African-Americans, and not from racism or other social disadvantage. See e.g., HERRNSTEIN & MURRAY, *supra* note 46; see generally DINISH D’SOUZA, *THE END OF RACISM: PRINCIPLES FOR A MULTICULTURAL SOCIETY* (1995). These authors therefore oppose programs such as public assistance and affirmative action for perpetuating, they claim, genetic inferiority.

51. Escalating white, middle-class fear of crime, for example, prompts “flight” to secure, exclusive, private domains inhabited by a largely white, economically privileged class, even though white, middle-class fear of crime arises from race and class stereotypes, and not from a realistic threat. See, e.g., JOE R. FEAGIN & HERNAN VERA, *WHITE RACISM: THE BASICS* 7, 114-24, 153 (1995); Fitzgerald, *Stories of Child Outlaws: On Child Heroism and Adult Power in Juvenile Justice*, *supra* note 17, at 499 (describing and substantiating white, middle-class fear of crime victimization by impoverished children of color disproportionate to crime victimization statistics).

52. NELKEN & LINDEE, *supra* note 35, at 194-95.

force or social policy, of course. If ameliorable at all, diseased DNA is subject only to medical or scientific therapies.⁵³

Likewise, genetic determinism now permeates our popular and legal views of conception, childbirth, and childrearing, medicalizing this realm of human accomplishment and failure as well.⁵⁴ Parenthood has become for many a quest for genetic perfection, with the availability of pre-conception genetic screening, "genius" sperm banks, prenatal testing, intrauterine therapies, and life or death decisions for "defective" newborn children.⁵⁵ Elizabeth Bartholet has written that medical technologies and a narcissistic obsession with perpetuating a particular genetic heritage undermine our cultural and legal approval of adoptive and other nongenetic family forms.⁵⁶ I would add that our cultural embrace of genetic determinism devalues all children and parenting by turning our focus to children's genetic make-up and away from children as people profoundly influenced, as we all are, by relationships with others.

The rhetoric of genetic defect and perfection, fueled by a medicalized culture convinced of genetic determinism, conceals a growing intolerance for human difference. Indeed, talk of genetic defect or perfection assumes a singular norm, a physical stereotype or ideal. Like the jurisprudential norm of individual autonomy, this genetic norm reflects only a particular, privileged perspective.⁵⁷ Culturally and legally, however, we accept this perspective as objective and real because it seems to arise from empirical science and not powerful bias.⁵⁸ We can therefore confidently, if mistakenly, define difference from the norm as inferiority, and now as genetic inferiority. From an adult perspective, all children are different (not autonomous), and hence legally inferior. Likewise, from the perspective of human genetic normalcy, all difference is diseased or defective and thus is subject only to therapeutic correction if subject to correction at all.

Even if we all agreed, though, on the benefit of correcting such genetic conditions as Down's syndrome or cystic fibrosis—and we have no such consensus now—could we also agree on the value or not of perpetuating other genetic manifestations such as near-sightedness, obesity, or even, as speculated, "risk-taking" and "shyness"? Of course, only speculation now posits such human behaviors as criminality or attributes as intelligence to

53. *See id.*

54. *See id.* at 174-192.

55. *Id.*; *see also* Lund, *supra* note 4, at 19-21.

56. *See* ELIZABETH BARTHOLET, *FAMILY BONDS: ADOPTION AND THE POLITICS OF PARENTING* (1993); *see also* NELKEN & LINDEE, *supra* note 35, at 58-78.

57. *See* MINOW, *supra* note 13, at 10, 13-18.

58. *See* NELKEN & LINDEE, *supra* note 35, at 41-49, 57, 198-199.

genetic determinism, and these speculations will likely be discredited.⁵⁹ In the meantime, however, our political rhetoric and jurisprudence reflect both this genetic determinism and the unstated assumption that deviance from the genetic norm is not celebrated human diversity, but rather malignant defect and disease. Since all children deviate from the accepted legal norm of autonomous adulthood, I draw the analogy that dependent childhood is a defect we "cure" as a society through nurture, education, and the passage of time. Upon completing the cure and reaching adulthood, children attain full legal recognition. Children who will not survive childhood, however, never complete the cure and attain the autonomy entitling them to legal personhood. If the analogy of childhood to defect or disease were inapt, then our jurisprudence and legal culture would not countenance medical decision making for seriously ill or disabled children only from the perspective of what these children might achieve in adulthood. When we conclude as a society, however, that children unable to survive childhood are not worth saving or their lives worth living, we devalue childhood itself, and all children with it.

III. Human Difference and Interdependency: Conjoined Twins

Every year in the United States, some forty pairs of conjoined twins are born, and most die, still joined, in early infancy.⁶⁰ All conjoined twins are "identical," sharing identical genetic compositions.⁶¹ Conventional medical protocol dictates surgically separating conjoined twins if their bodies can sustain each of them independently.⁶² Many twins share limbs or vital organs, however, requiring that surgeons choose just one twin to receive the single heart or shared limb.⁶³ Separation surgery thus often results in the death of one or both of the twins. In many cases, no medical prognosis can reliably guide parents as to whether surgery will prolong one or both twins' lives. While most conjoined twins die young, some survive to adulthood, whether conjoined or surgically separated. Three celebrated sets of conjoined twins lived in the first half of this century, for example, all three of whom led long, full lives.⁶⁴ Two of the pairs eventually married other people.⁶⁵

59. *See id.* at 2-18, 194-95.

60. *See* Claudia Wallis, *The Most Intimate Bond*, TIME, Mar. 25, 1996, at 60.

61. *See id.*

62. *See id.*; *see also infra* note 63.

63. Consider, for example, the case of the Lakeberg conjoined twins who shared a single heart. *See* Josh Plaut, *A Painful Separation: Moral Aspects of Surgery on Siamese Twins*, 50 SCI. WORLD, Nov. 5, 1993, at 7.

64. *See* Kenneth Miller, *Together Forever*, LIFE, Apr. 1996, at 44, 56.

65. *See id.*

Advances in surgical methods and medical technologies—enabling the reconstruction of organs, for example—now enhance the survival rates of surgically separated twins. The majority of surviving twins do so separated.⁶⁶ Indeed, most parents and physicians assume that separation enabling independent lives greatly benefits children born conjoined. Conjoined twins are objects of public pity, and sometimes disgust.⁶⁷ Few can imagine spending a lifetime utterly dependent on another person, unable even to move without that person's consent, and deprived constantly and forever of privacy. Dr. W. Hardy Honduran, an innovator in the surgical separation of conjoined twins, remarked, for example, "I've seen twins that have been left together. They can't walk. They can't even sit up. And because they're always stuck face-to-face, they fight constantly."⁶⁸

On the other hand, conjoined twins, like other identical twins, may enjoy paranormal communication and other special psychological and emotional bonds.⁶⁹ Studies confirm the phenomena of idiosyncratic languages between identical twins, consonance of emotions, and a preference for each other's company.⁷⁰ Identical twins appear able to experience such intimate interdependencies despite their development, as is usual, of disparate personalities.⁷¹ Nonetheless, or perhaps because of identical twins' unusual bonds, conventional psychological and educational wisdom dictates separating identical twins as well as conjoined twins. Parents are advised to dress identical twins differently, enroll them in different school classes and activities, and otherwise encourage their individualism.⁷²

I discern in these attitudes toward both conjoined and identical twins cultural hostility toward their interdependence and their connectedness, both physical and otherwise. Intimately attached twins defy the cultural and social norm of adult independence and self-sufficiency. If not independent and self-sufficient, twins appear lacking and perhaps inferior compared with the norm. Conjoined and identical twins seem permanently impaired from achieving the individual autonomy we understand as the hallmark of legal personhood.⁷³

66. See TWINS MAGAZINE, THE TWINSHIP SOURCEBOOK: YOUR GUIDE TO UNDERSTANDING MULTIPLES 74-75 (Nancy L. Segal et al. eds., 1992) [hereinafter THE TWINSHIP SOURCEBOOK].

67. See *id.* at 75-76, 77-78 (reciting accounts of several conjoined twins, some surgically separated finally, and some not).

68. Plaut, *supra* note 63, at 7.

69. See Miller, *supra* note 64, at 55-56.

70. See, e.g., THE TWINSHIP SOURCEBOOK, *supra*, note 66, at 181-82, 240-41; see also *id.* at 96-99 (regarding reports and studies of twin extrasensory perception).

71. See *id.* at 73-74.

72. See *id.* at 240-41, 243-46, 246-48, 252-57, 259-62.

73. See *supra* note 6 and accompanying text.

Because our legal understanding of personhood as autonomous now excludes conjoined and most identical twins, their lives may illuminate a path for expanding our jurisprudence the better to embrace human differences. In particular, such twins seem to personify human attributes of connectedness and interdependence, of fluidity in identity, and of the value of co-operation, identified by many feminist and other legal critics as now excluded from our legal understanding of personhood.⁷⁴ Three recent cases of conjoined twins who received international media attention help illustrate, I believe, this observation.

In December 1992, a prenatal ultrasound test revealed that Reitha Lakeberg was carrying conjoined twins, two girls joined at the chest and abdomen.⁷⁵ Ms. Lakeberg's obstetrician and husband advocated aborting the twins, but Ms. Lakeberg insisted on continuing the pregnancy to term.⁷⁶ When in June of 1993 the twins were delivered at Chicago's Loyola Hospital, neonatologists determined that they shared a liver and a single misshapen heart.⁷⁷ Only a mechanical ventilator sustained the twins, named Angela and Amy.⁷⁸ Dr. Jonathan Muraskas, the twins' attending physician at Loyola, advised the Lakeberg parents against attempting surgical separation of Angela and Amy.⁷⁹ Only the twin receiving the once-shared heart would survive surgery, and, in his experience, only for a few months.⁸⁰ Moreover, Dr. Muraskas predicted that both twins would die sooner rather than later so long as they shared the heart.⁸¹ Dr. Muraskas and his colleagues at Loyola Hospital therefore urged the Lakeberg parents to provide comfort care only and to permit Angela and Amy to die a "natural" and imminent death.⁸² "We sort of pleaded with" the Lakeberg parents, Dr. Muraskas said, "to take the babies off the ventilator" and let them die.⁸³

The Lakebergs determined to attempt surgical separation, however, in order to give at least one of the girls a chance of longer survival.⁸⁴ In August, the Lakebergs and their baby daughters traveled to Philadelphia's

74. Leading feminist critiques include, for example, Sylvia Law, *Rethinking Sex and the Constitution*, 132 U. PA. L. REV. 955 (1984); Matsuda, *supra* note 21; Martha L. Fineman, *Challenging Law, Establishing Difference: the Future of Feminist Legal Scholarship*, 42 FLA. L. REV. 25 (1990).

75. *See* Plaut, *supra* note 63, at 7.

76. *See id.*

77. *See id.*

78. *See id.*

79. *See id.*

80. *See id.*

81. *See id.*

82. *See id.*

83. *Id.*

84. *See* Anastasia Toufexis, *The Ultimate Choice*, TIME, Aug. 30, 1993 at 43, 44 [hereinafter *Ultimate Choice*].

Children's Hospital where a team of surgeons experienced in separation of conjoined twins had agreed to attempt the procedure.⁸⁵ The surgeons chose Angela, the physically stronger of the two, to receive the one heart, and permitted Amy to die in surgery.⁸⁶ Amy did die immediately, of course, but Angela survived the procedure.⁸⁷

Indeed, Angela survived ten months after the surgery and died unexpectedly only a few days shy of her first birthday.⁸⁸ Residing in Children's Hospital's Intensive Care Unit, Angela had steadily improved physically post-surgery, learning gradually to breathe and eat without mechanical aid, and requiring little pain medication as she improved.⁸⁹ She was an affectionate child who delighted her caregivers by blowing kisses to people, laughing, and cuddling.⁹⁰ She enjoyed splashing in the bath, watching the "Aladdin" video, and sucking lollipops.⁹¹ Angela also learned to attract attention from her nurses by pulling electronic monitors off her body.⁹² Angela's full recovery seemed sufficiently likely for her doctors to predict her discharge from the hospital during the summer of 1994.⁹³ Without warning, however, Angela developed respiratory illness, followed by a blood vessel malfunction, causing her sudden, acute, and rapidly fatal illness.⁹⁴ Angela died in June of 1994.⁹⁵

The public debate over the Lakeberg case centered on cost-benefit analyses.⁹⁶ In July of 1993, for example, Chicago's Loyola Hospital refused Ms. Lakeberg's request to perform the surgical separation.⁹⁷ The cost of the twins' surgical care would top a million dollars, the Hospital said, while Dr. Muraskas estimated the chances of one twin surviving at just one percent.⁹⁸ Accounts variously reported that the Lakebergs either had no medical insurance at all or that their insurance was inadequate.⁹⁹ Ultimately, Loyola Hospital refused to perform the separation. Philadel-

85. See *id.*; Stephen E. Lammers, *Tragedies and Medical Choices*, 110 CHRISTIAN CENTURY 845, 845 (1993); Karen Pallarito, *\$1 Million Treatment for Siamese Twin Reignites Cost Debate*, MODERN HEALTHCARE, Aug. 30, 1994, at 44.

86. See *Ultimate Choice*, *supra* note 84, at 44.

87. See *id.*

88. See Anatasia Toufexis, *The Brief Life of Angela Lakerg*, TIME, June 27, 1994 at 61, 61 [hereinafter *Brief Life*].

89. See *id.*

90. See *Brief Life*, *supra* note 88, at 62.

91. See *id.*

92. See *id.*

93. See *id.* at 61.

94. See *id.* at 62.

95. See *id.* at 61.

96. See *Ultimate Choice*, *supra* note 84, at 44; Pallarito, *supra* note 85, at 4.

97. See Plaut, *supra* note 63.

98. See *Ultimate Choice*, *supra* note 84, at 43; Pallarito, *supra* note 85, at 4.

99. See *Ultimate Choice*, *supra* note 84, at 44; Pallarito, *supra* note 85, at 4.

phia's Children's Hospital agreed to perform the surgery, and to cover the costs with funds earmarked for charitable cases, asserting that the twin chosen to receive the heart stood a good chance of recovery.¹⁰⁰

Physicians, health care policy makers, and medical ethicists roundly criticized the Hospital's decision in the press. The comments of Erik Parens, an ethicist at a New York think tank, were typical. "This case screams out," he said, "for us to start thinking rationally about how we allocate resources."¹⁰¹ Not Children's Hospital, but all of society pays for such costly care as the Lakeberg twins required.¹⁰² We fear rationing health care resources, Mr. Parens observed, "when, in fact, we're rationing all the time."¹⁰³ Arthur Caplan, Director of the Center for Biomedical Ethics at the University of Minnesota, also decried the estimated million dollar expense.¹⁰⁴ "There are kids with no tetanus shots, moms that have never been to the doctor or who have just given birth and don't know *how* to feed their babies, and no resources are pointing in those directions," he said.¹⁰⁵ Moreover, the Lakeberg father seemed particularly undeserving of charity once press reports revealed Ken Lakeberg's violent criminal history and his squandering of funds donated for the twins on fancy meals and drugs.¹⁰⁶ Seizing upon Dr. Muraskas' original estimate that, at best, one Lakeberg child had no better than a one percent chance of survival, commentators concluded the cost was too high for so little benefit.¹⁰⁷

To me, however, the Lakeberg case illustrated more the inherent inequities and contradictions of the United States health care "system" than any genuine concern about resource allocation. Had the Lakebergs enjoyed secure private insurance sufficient for paying for the twins' care, or were the Lakebergs independently wealthy, I doubt so many authorities would have brazened the opinion that such private funds were misspent. Moreover, foregoing surgical separation would not, as a practical matter, have assured any other American children tetanus shots, adequate nutrition, or prenatal care. In fact, the Lakeberg case was not even unusual, for neonatology units in American hospitals routinely administer million-dollar care to critically sick infants born with congenital defects.¹⁰⁸ In the cost-benefit analysis of the Lakeberg case, then, commentators took greatest issue with the

100. See Pallarito, *supra* note 85, at 4.

101. *Id.*

102. See *id.*

103. *Id.*

104. See *Ultimate Choice*, *supra* note 84, at 44.

105. *Id.*

106. See *Sequels: Dad's Dues*, PEOPLE, Dec. 27, 1993, at 123, 123.

107. See *id.*; see also Lammers, *supra* note 85, at 845.

108. See *Brief Life*, *supra* note 88, at 62.

benefit, for they expected Angela to die.¹⁰⁹ A million dollars in charity should not have been spent, it seemed, to sustain the life of one child almost certain to die anyway in a matter of months.¹¹⁰

As it turns out, however, Angela's grim prospects were no medical certainty. Dr. Muraskas, the Loyola neonatologist who gave Angela only a one percent chance of survival admitted a year later, once Angela had died, that he had contrived those odds only "to try to make the family agree with us" to remove life support from the twins upon their birth.¹¹¹ Referring to Mr. Lakeberg's illegal drug problems and the family's situation, Dr. Muraskas stated, "You have to ask yourself if chain-smoking parents in a trailer park is the most conducive environment for a sick child."¹¹² Dr. Muraskas thus seemed to have anticipated that one of the twins would survive hospitalization for ultimate discharge home. Indeed, Angela's surgeons in Philadelphia concluded that she had better than a ninety-five percent chance of survival after surgery.¹¹³ It appears, then, that the cost issue raised so vehemently in the Lakeberg case was at least inappropriate. Those commentators inveighing against the million-dollar cost of Angela's care simply did not calculate a ninety-five percent chance of her leading a healthy, "normal" post-life surgery.¹¹⁴

The clamor over cost in the Lakeberg case obscured more fundamental issues. The first question, it seems to me, is whether the Lakeberg twins should have been separated at all, and, if so, why? Should the Lakeberg twins have been separated for their own sake? Surgery and Amy's death enabled Angela to survive long enough to learn to laugh.¹¹⁵ Does the year of life Angela gained justify the separation and Amy's death? Angela's parents and her Philadelphia surgeons believed it did.¹¹⁶ Under different circumstances, Angela could have survived to lead a "normal" life. Would

109. See *id.*; see also Pallarito, *supra* note 85, at 44.

110. See, e.g., Lammers, *supra* note 85, at 845.

111. *Brief Life*, *supra* note 88, at 62.

112. *Id.*

113. See *id.* at 61.

114. See *id.* Moreover, any system of socialized medicine would no doubt have cast the Lakeberg case in a different light entirely. While medical costs are controlled and health care effectively rationed in a socialized system, such a system would not likely have singled out the Lakebergs as a cause celebre in a debate over costs versus benefits. After all, the Lakeberg twins were just two of many thousands of critically ill newborn children challenging health care systems with astronomical costs for their care. See, e.g., David Orentlicher, *Destructing Disability: Rationing of Healthcare and Unfair Discrimination Against the Sick*, 31 HARV. C.R.-C.L. L. REV. 49, 49-50 (1996) (observing that every health care system rations health care because of relatively unaffordable costs, and that the American system has historically rationed care by patients' ability to pay the costs); *id.* 74 n. 111 (observing that socialized health care systems in Canada and Britain ration through waiting lists).

115. See *Brief Life*, *supra* note 88, at 62.

116. See *id.*

those results have better justified the twins' separation and Amy's death? If so, why? Are duration and normalcy the criteria for the value of human life? In other words, does childhood become more valuable, more entitled to legal regard, the closer it approximates independent or autonomous adulthood? Had we known for certain that Angela would survive just a year, would that year of childhood have justified the separation and Amy's death?

A formal legal response to those questions is simply that the Lakeberg parents had the right, indeed, a constitutional right, to decide whether to separate the twins.¹¹⁷ Absent medical certainty regarding the girls' life expectancy, the Lakebergs wielded the legal right to determine their children's medical treatment.¹¹⁸ That right was hollow, of course, so long as the Lakebergs could not afford the twins' medical treatment. Incapable of paying for the surgery themselves, the Lakebergs had no "right" to tap government assistance or private charity for aid,¹¹⁹ as the many commentators on their case emphasized.¹²⁰ Had no other hospital come forward to provide the surgery without cost to the Lakebergs, then, the girls would have died at Loyola Hospital as Dr. Muraskas predicted and urged.

Even had economic factors not undermined the Lakeberg parents' right, however, their formal legal right fails to account for the personhood of their twin baby girls. By distinguishing the parents' rights from the twins' own legal recognition, I do not mean to question the propriety of the Lakeberg parents' decision to separate the twins surgically. I have no doubt from the published accounts that parental love motivated at least Reitha Lakeberg's passionate fight to secure life-prolonging medical treatment for at least one of her daughters.¹²¹ Moreover, I recognize and affirm that parental decision making encompasses a necessarily subjective calculus of the effects of a child's medical care on the child, on other family members, and on the family as a whole. I seek, rather, to focus analytical attention on the *legal* status of the twins themselves, distinguishing their interests as people from those of their parents or of the state, however benevolent those adult interests may be. That analytical attention raises important questions, I believe, about the legal context in which the twins' lives were publicly debated. Was the prolonged life of Angela with a chance of surviving to adulthood more important, legally and morally, than

117. See generally ROBERT H. MNOOKIN & D. KELLY WEISBERG, CHILD, FAMILY AND STATE: PROBLEMS AND MATERIALS ON CHILDREN AND THE LAW 590-627 (3d. ed. 1995).

118. See *id.*

119. See *id.*

120. See, e.g., *Ultimate Choice*, *supra* note 84, at 44 (quoting medical ethicists Erik Parens and Arthur Caplan); Lammers, *supra* note 85, at 845.

121. See *Ultimate Choice*, *supra* note 84, at 44.

the life Angela and Amy shared, however briefly, conjoined? Are children legally cognizable only to the extent their lives approximate the norm of potential autonomous adulthood?

The case of Eilish and Katie Holton, a pair of Irish conjoined twins, brings these questions into sharper focus. Born in 1988 to a Dublin couple, Liam and Mary Holton, Eilish and Katie were joined at the chest and abdomen and shared just two legs between them.¹²² Unlike the Lakeberg twins, the Holton girls had separate hearts, but they shared other major organs. Nurtured in a loving home, the Holton twins grew to healthy, happy three-year-olds.¹²³ They struggled to learn to walk as they were "top heavy," but otherwise their development was in every way normal.¹²⁴ Eilish and Katie also developed different personalities, with Eilish more reserved and shy and Katie more outgoing and playful.¹²⁵ The two girls were obviously enamored of each other, sharing their responses and emotions as well as most of one body.¹²⁶

Still, the Holton parents began to explore the possibility of surgically separating Eilish and Katie. Numerous consultations with Irish and English physicians failed to quantify the benefits or risks the twins faced in surgery.¹²⁷ On the one hand, only one or neither twin might survive surgery.¹²⁸ Further, assuring the girls physical independence would necessitate successive operations debilitating their childhoods and would also require the permanent use of prosthetic devices to replace shared limbs.¹²⁹ On the other hand, Mary Holton worried over the girls' reception in public. People already stared rudely at the children during public outings, and Mary Holton longed for peoples' "acceptance" of the conjoined twins.¹³⁰ The Holton parents also worried about the twins' physical limitations so long as they were joined, hoping that separation would provide the girls greater mobility, independence, and normalcy.¹³¹

Shortly after the girls' third birthday, the Holton parents authorized their surgical separation.¹³² Prior to surgery, the Holtons tried to help prepare the interdependent girls for separation. They showed dolls joined with

122. See *20/20: Divided by Love—The Story of Conjoined Twins*, (ABC television broadcast, Feb. 5, 1993) [hereinafter *20/20: Divided by Love*].

123. See *id.*

124. *Id.*

125. See *id.*

126. See *id.*

127. See *id.*

128. See *id.*

129. See *id.*

130. See *id.*

131. See *id.*

132. See *id.*

velcro to the twins, and then pulled the dolls apart to demonstrate the girls' future.¹³³ Four days after the long operation, Katie died from a weak heart, as an autopsy later showed.¹³⁴ Doctors speculated that Eilish's stronger heart had sustained both children, and that Katie's was too weak to support a separated, independent twin. The Holtons comforted themselves with the belief that, without the surgery, the physical demands on the two hearts, one strong and one weak, might have eventually killed both girls.¹³⁵

Eilish, meanwhile, grieved for Katie.¹³⁶ For a long time whenever Eilish awoke, she immediately sadly searched her side where Katie once always lay beside her.¹³⁷ Eilish also kept up running conversations with the absent Katie all day long.¹³⁸ Her parents believe that Eilish's grief began to subside as she seemed to absorb more of Katie's missing personality.¹³⁹ Like Katie, Eilish became more outgoing and spirited.¹⁴⁰ When three years after Katie's death Eilish was fitted for a new prosthetic hip and leg, and understanding the prosthesis was to augment part of her body, Eilish promptly named the device "Katie."¹⁴¹

Hoping to attain a better life for both girls, the Holtons lost a daughter and Eilish seems to have lost a part of herself. Another, more autonomous individual might have thrilled to the liberty and independence of separation from a conjoined twin. Those who understand their identities as continuously informed by their relationships and experiences may feel more empathetic with Eilish's grief. While American jurisprudence posits an autonomous individual as the model for legal personhood, feminist legal scholars have criticized this model as narrowly exclusive, devaluing people who understand themselves in the context of their community, family, and other human connections.¹⁴² To the question of what course was "best" for Eilish and Katie or for the Lakeberg twins, we can answer only subjectively. We should apprehend, however, that the Holton parents' fears that an intolerant society would reject the conjoined twins prompted their separation. In a different, better society, people would "accept," as Mary Holton termed it,¹⁴³ the conjoined twins' congenital condition as another de-

133. *See id.*

134. *See id.*

135. *See id.*

136. *See 20/20: Divided by Love, supra note 122.*

137. *See id.*

138. *See id.*

139. *See id.*

140. *See id.*

141. *See id.*

142. *See, e.g., Law, supra note 74; Matsuda, supra note 21; Fineman, supra note 74; see also SANDEL, supra note 19, at 175-83.*

143. *20/20: Divided by Love, supra note 122.*

lightful human difference in a diverse human population. Societal acceptance, tolerance, and even celebration of human difference, in turn, would create a profoundly different context for parental decision making.

The Holton twins' pediatrician, Dr. Patrick Deasy, observed before the separation surgery, "I think the natural response when you see twins like [the Holtons] is to see if they can be like the rest of us and therefore lead separate existences."¹⁴⁴ Indeed, many people automatically assume that different characteristics in others manifest inferiority, and genetic engineering now looks to the day when therapies can right all abnormalities.¹⁴⁵ "But equally," Dr. Deasy said, "one would have to consider whether separating [the Holton twins] just for the sake of conforming to our ideas of normality would, in fact, help them or kill them."¹⁴⁶ Some parents may seek to engineer their children genetically, repair congenital abnormalities, or withhold life-prolonging treatment from a seriously ill or disabled child because those parents sincerely believe in the rightness and validity of the prevalent model of legal personhood, the autonomous individual. Other parents may make the same decisions regarding their children's treatment, not because they reject the child's abnormality, but because they fear for the child's future in a legal, cultural, and social environment which devalues and oppresses human difference. Whatever the motives, both sorts of parental decisions to separate conjoined twins or otherwise engineer conformity for their children may eventually result in the eradication of seriously ill and disabled children, the extinction of these forms of human difference.

Good riddance to human difference, we might reply, if it means the eradication of severe physical disabilities and concomitant suffering. Let us genetically engineer offspring and repair newborn children's abnormalities to every possible extent, the better to assure such children's quality of life. How do we distinguish, though, the disabled from the differently abled, the genetic or congenitally inferior from the diversity of the human species?

On a visit to the United States in 1995 for a replacement prosthesis, Eilish Holton visited the Hensel twins.¹⁴⁷ Brittany and Abby Hensel were born the same year as Eilish and Katie and, like them, were born joined at the chest and abdomen.¹⁴⁸ The Hensel parents, in consultation with their daughters, have refused so far to separate Abby and Brittany surgically.¹⁴⁹

144. *Id.*

145. See NELKEN & LINDEE, *supra* note 35, at 41-49, 68, 101-26, 143-44, 149-68, 193-99.

146. *Id.*

147. *20/20: Divided by Love*, *supra* note 122.

148. See *id.*

149. See *id.*

Their life together demonstrates, I think, that the distinction between disability and differently abled is often merely one of perspective.

At the time of Eilish Holton's visit the Hensel twins were six years old, healthy, and like most children their age, very active. They each controlled one arm and one leg, but had mastered co-ordinating so they could walk, run, and ride their bike.¹⁵⁰ To tie their shoes, count on their fingers, or accomplish all the other myriad daily tasks requiring two hands, they also co-ordinated and co-operated.¹⁵¹ Like other identical twins, Abby and Brittany had distinctly different personalities, one more aggressive and extroverted, the other more diffident and pensive.¹⁵² They fought occasionally, and Brittany once hit Abby in the head with a rock,¹⁵³ as other fighting siblings have done. When they disagreed, though, unlike other siblings, Abby and Brittany became completely stymied, sometimes actually unable to move.¹⁵⁴ Moreover, when the Hensel parents disciplined one twin with banishment to her room, the other twin was banished and punished too.¹⁵⁵ Perhaps as a consequence of this complete interdependence, Abby and Brittany exemplified between them exceptionally effective communication, unhesitating cooperation, and decision making by consensus.¹⁵⁶ At their preschool, the Hensel twins had spontaneously led a discussion about children fighting and how to avoid conflict.¹⁵⁷

Abby and Brittany Hensel are the antithesis of individual autonomy, then, and indeed exhibit the qualities of co-operation and connectedness often remarked upon in "female" culture.¹⁵⁸ They are seriously abnormal, and from some people's perspective, seriously disabled. They are undeniably human, however. Further, no objective or empirical test could discern that the Hensel twins are somehow inferior to normal children. For all the physical skills they may lack, they demonstrate keen relationship skills that most people never develop.¹⁵⁹ Had the Hensel parents repaired the twins'

150. See Miller, *supra* note 64, at 56.

151. See *id.*

152. See *id.*

153. See *id.*

154. See *id.*

155. See *id.*

156. See *id.*

157. See *id.*

158. For a discussion of "female culture" generally, see, for example, Law, *supra* note 74, Matsuda, *supra* note 21, and Fineman, *supra* note 74. See also SANDEL, *supra* note 19, at 175-83.

159. Daniel Goleman argues in his celebrated book EMOTIONAL INTELLIGENCE, for example, that impulse control, persistence, zeal, empathy, social graciousness, discipline, altruism, and compassion account more for success in both family relationships and in the work place than more traditional indices such as I.Q. See DANIEL GOLEMAN, EMOTIONAL INTELLIGENCE x-xiv (1995). I would suggest that, unlike many children Goleman cites in his work, *id.* at x-xi, 231-34,

congenital abnormality, neither the twins nor we could learn from, admire, and celebrate their very different and profoundly intimate sisterhood. In a more tolerant culture, one accepting of human difference and endowed with a jurisprudence reflecting an ethos of inclusiveness, Abby and Brittany could be appreciated as a wonderful variation on being human. Instead, in a culture which devalues difference and a jurisprudence premised on a narrow norm, the Hensel twins are disabled, inferior, and not quite human because they can never achieve autonomous individuality.¹⁶⁰

IV. What Do We Do Now?

It is not my purpose to judge morally the decisions of parents now coping with genetically or congenitally abnormal children. As other commentators have observed, in the United States, at least, many parents of such children are bereft of financial aid and sustaining social services.¹⁶¹ Moreover, ours is a culture and society carelessly neglectful or openly hostile to abnormal children and their families.¹⁶² The cases of the conjoined twins, for example, thus suggest no simple paradigm or prescription. Some will affirm parents' decisions to separate their twins, while others will laud parents' decisions to leave their twins conjoined. For my part, I am unwilling to second-guess the anguished decisions of parents confronted with critical and urgent choices profoundly shaping their children's and their own lives. The glare of public attention casts the strengths and weaknesses of each of these families into stark relief, prompting public approval or condemnation of each choice. The parents of conjoined twins appear heroic or contemptuous by turns, and thus isolated and ineluctably different from the rest of us. I would urge, however, that discussion of any genetically or congenitally abnormal children move beyond the moral judging of their parents. Who knows what you or I would have chosen for our children were we in the shoes of other, real parents?

Instead, I have proposed that we examine critically the *legal* culture constructing each of these parents' choices and work toward a jurisprudence which will embrace all of human difference, genetic and congenital included. American society lends itself, of course, to no facile analysis of how our law informs our culture and vice versa. As lawyers, we can work toward broadening our jurisprudence to include children, indeed all human

the Hensel twins have already learned through their interdependent relationship those attributes of "emotional intelligence" that he hopes schools and families will strive to instill in children.

160. See *supra* text accompanying note 6.

161. See, e.g., Crossley, *supra* note 8, at 1598-1605 (1993); Smith, *supra* note 2.

162. Recognizing pervasive discrimination against the disabled, the U.S. Congress enacted the Americans with Disabilities Act of 1990, 42 U.S.C.A. §§ 12101-213 (West Supp. 1997).

difference, in our legal understanding of personhood, hoping thus to help transform our culture to become more inclusive as well.

In the meantime, however, families urgently turn to us as lawyers for help. What, for example, should we advise the parents of a child with Down's syndrome when they are offered the option of plastic surgery transforming their son's features the better to approximate the norm?¹⁶³ I want to respond that, rather than changing the child, society must change to accept and value the child as he is. That response fails to recognize, though, the heartache the whole family suffers as the child bears daily cruel taunts and rejection. While I recognize that the law must prevent parents and physicians from discriminating against children who are seriously ill or disabled because of the illness or disability,¹⁶⁴ I affirm nonetheless the laws authorizing parents to make medical treatment decisions for their children because, unlike the state's or physicians', parents' decisions are more likely motivated by love for the children. Instead, I hope to focus the attention of our law and jurisprudence on fostering an economic, legal, and cultural environment which values children for themselves, regardless of how their abilities or disabilities may affect adulthood or adult society.

Another pressing example is the increasing psychiatric diagnosis and treatment of "Gender Identity Disorder" in young children.¹⁶⁵ Mental health professionals may diagnose this "disorder" when children's preferences for clothes, toys, and styles of play are "inappropriate" for their gender.¹⁶⁶ Professional and parental concern arises because of the social teasing and rejection young boys, for example, face when they play with girl dolls.¹⁶⁷ Hoping to spare children from social ostracizing, parents and professionals employ therapies to reorient young children in conformity with socially-accepted "gender identification."¹⁶⁸ Could we not instead reorient

163. Professor Barbara Bennett Woodhouse posed this question to me at the International Association of Family Law North American Conference on Parent-Child Relationships in Quebec City, Quebec, Canada, in June, 1996.

164. I agree, then, with the analyses of Mary Crossley, *Of Diagnoses and Discrimination: Discriminatory Nontreatment of Infants with HIV Infection*, 93 COLUMBIA L. REV. 1581 (1993), and Nelson Lund, *Infanticide, Physicians, and the Law: The "Baby Doe" Amendments to the Child Abuse Prevention and Treatment Act*, 11 AM. J. L. & MED. 1 (1985).

165. See KENNETH J. ZUCKER & SUSAN J. BRADLEY, GENDER IDENTITY AND PSYCHOSEXUAL PROBLEMS IN CHILDREN AND ADOLESCENTS 9, 11, 14 (1995) (diagnosis and treatment of the disorder can begin in preschool children).

166. See *id.* at 11, 15-16 (describing the disorder as manifested in children's choice of dress-up clothes); *id.* at 16-17 (describing the disorder as manifested in children's choice of toys); *id.* at 18-20 (describing the disorder as manifested in children's choice of play styles).

167. See *id.* at 19-20, 266 (describing teasing, rejection, and ostracism from their peers resulting in trauma to boy children who choose "girl" dress-up clothes, toys, and play styles and, to a lesser extent, to girl children who choose "boy" dress-up clothes, toys, and play styles).

168. In their book GENDER IDENTITY AND PSYCHOSEXUAL PROBLEMS IN CHILDREN AND ADOLESCENTS, Drs. Kenneth J. Zucker and Susan J. Bradley describe therapy for gender identity

society to accept and welcome children who defy gender stereotypes? It is more probable that researchers will pursue genetic therapies to "cure" socially unaccepted gender identification, as well as sexual orientation¹⁶⁹ and Down's syndrome.

Families and their lawyers who have fought on behalf of children diagnosed with Attention Deficit - Hyperactivity Disorder ("ADHD") may serve as a model for aiding children immediately in our current culture and for hastening the transformation of our legal culture as well. ADHD is a syndrome resulting in learning disabilities, including abnormal distractibility and impulsivity and, in some cases, hyperactivity as well.¹⁷⁰ Psychiatric professionals estimate that some three and a half million American children suffer from this disorder nationwide,¹⁷¹ and a comparable number of children receive therapy.¹⁷² Most children diagnosed with ADHD receive prescribed doses of Ritalin or other powerful therapeutic drugs which help most ADHD children concentrate better in school and better control impulsivity.¹⁷³ Because ADHD seems to run in families, some researchers anticipate one day identifying a genetic cause of the disorder, perhaps curable with other medical therapies.¹⁷⁴ For many parents and children, Ritalin and other drug therapies have seemed to work miracles, enabling ADHD children to meet the normal behavior and performance requirements of

disorder undertaken to reduce peer ostracism, *see id.* at 266, to treat "underlying psychopathologies," *id.* at 266-67, and to prevent adult transexuality, *see id.* at 267, as "obviously clinically valid and consistent with the ethics of our time," *id.* at 269. I would counter that the trauma for these children seems to result more from an intolerant environment than from some inherent flaw in them. The further observation of Drs. Zucker and Bradley that therapy undertaken to prevent adult homosexuality, *see id.* at 267-69, is "considerably more problematic," *id.* at 269-70, seems like an understatement, to say the least.

169. *See, e.g.,* NELKEN & LINDEE, *supra* note 35, at 119-20 (describing and discussing speculation that a genetic "cause" of male homosexuality has been discovered).

170. *See, e.g.,* Claudia Wallis, *Life in Overdrive*, TIME, July 18, 1994, at 59, 60. When hyperactivity is absent, the syndrome is referred to as "Attention Deficit Disorder" or "ADD." *Id.* For a comprehensive discussion of ADHD and ADD, the state of medical knowledge of these syndromes, their effects, and their treatments, authored by two Harvard Medical School psychiatrists diagnosed with adult ADD themselves, *see* EDWARD M. HALLOWELL & JOHN J. RATEY, *DRIVEN TO DISTRACTION: ATTENTION DEFICIT DISORDER IN CHILDREN AND ADULTS* (1994).

171. *See* Wallis, *Life in Overdrive*, *supra* note 170, at 43.

172. *See, e.g.,* Diane Granat, *The Young and the Restless*, WASHINGTONIAN, April 1995, at 60, 61 (noting that, because of difficulties in diagnosis, not all children receiving therapeutic medication have ADHD or ADD, and not all children with ADHD or ADD receive drug or any other therapy).

173. *See* Wallis, *supra* note 170, at 48-49 (describing Ritalin therapies and controversies surrounding Ritalin use); PAUL H. WENDER, *THE HYPERACTIVE CHILD, ADOLESCENT, AND ADULT: ATTENTION DEFICIT DISORDER THROUGH THE LIFESPAN* 59 (1987) (describing other drug therapies).

174. *See id.* *See also* Wallis, *supra* note 170, at 46-47.

school.¹⁷⁵ Families and their lawyers, however, have also succeeded in using the Americans with Disabilities Act¹⁷⁶ to compel public schools to accommodate the disabilities of ADHD children.¹⁷⁷

The diagnosis of ADHD, now the most frequent psychiatric diagnosis in children, is properly controversial.¹⁷⁸ ADHD behavioral symptoms seem common to all children in one degree or another.¹⁷⁹ All children (and even adults) struggle at times to concentrate in school. All children (and even adults) experience transports of excitement or anger triggering impulsive conduct. I do not doubt that ADHD children experience struggles and impulsivity more than the norm, with debilitating effects, and a genetic or biological agent may well be the cause. I would query, again, however, whether we ought to focus our efforts more on changing the child's environment than on changing the child with medication or other medicalized therapies. In response to families' insistence, often through lawsuits, public schools are increasingly altering teaching methods to help ADHD children.¹⁸⁰ Teachers employ more "hands-on" learning opportunities for ADHD children, for example, because ADHD children seem to learn more easily when they can use all five senses.¹⁸¹ Of course, most children learn more easily, educators generally agree, from "hands-on" learning experiences.¹⁸² Hence, school accommodations for ADHD children, legally compelled, may help reform public schools to more child-oriented teaching techniques of benefit to all children. Likewise, I suspect that curriculum designed to help "mainstream" children with Down's syndrome by educating their teachers and classmates in tolerance, respect, and acceptance benefits all the children and adults involved.

Perhaps educators and mental health professionals can better help children typed with "Gender Identity Disorder" also by educating these children's families, peers, and teachers to accept and welcome difference. As lawyers and policy makers, we should not attempt to substitute our judgment for that of the parents as they consider medicalized options for helping their children to conform more nearly to the norm. We should be-

175. See, e.g., Wallis, *supra* note 170, at 49; Anna M. Thompson, *Attention Deficit Hyperactivity Disorder: A Parent's Perspective*, PHI DELTA KAPPAN 433, 434-35, 437-38 (1996).

176. 42 U.S.C.A. § 12101-213 (West Supp. 1997).

177. See e.g., Wallis, *supra* note 170, at 49-50.

178. See Granat, *supra* note 172.

179. See *id.* (noting that skeptics about ADHD observe correctly that most people, including adults, experience behaviors used to diagnose ADHD in children).

180. See, e.g., Wallis, *supra* note 170, at 49-50.

181. See *id.*; Ruby L. Bailey, *More Parents Turn to Schools to Teach Their Learning-Disabled Children*, THE DETROIT NEWS, Sept. 10, 1996 at C1, C5 (describing both private school and public school programs for learning-disabled children, including ADHD children).

182. See, e.g., Bailey, *supra* note 181 at C5; Wallis, *supra* note 170 at 49-50.

come alert to opportunities, however, to use laws such as the Americans with Disabilities Act to help our public culture accept and welcome children with serious illnesses or disabilities.

V. Conclusion

We can only wonder what Eilish Holton thought of the Hensel twins. Eilish remained silent throughout her visit and merely stared.¹⁸³ Surgically re-engineered to better approximate the norm of individual autonomy, Eilish Holton may have glimpsed in the Hensel twins "what might have been." Our jurisprudence continues to struggle with treatment decisions for seriously ill and disabled children and faces the more recent challenge of regulating parents' attempts to engineer their offspring genetically. The medical and scientific technologies creating these treatment dilemmas offer the possibilities of eventually eliminating genetic and congenital abnormalities. Before we legally or morally support such treatment plans, however, we should consider what we lose when we eliminate the disabled or "differently abled." I hope we will not as a society wonder, as Eilish may have, what human interdependence might have been.

183. See 20/20: *Divided by Love*, *supra* note 122.

