The Disabling Impact of Wrongful Birth and Wrongful Life Actions

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I. INTRODUCTION

Individuals with disabilities have made significant strides toward integration and acceptance in American society in the last fifty years. Passage of the Americans with Disabilities Act ("ADA") in 1990¹ and comparable state laws represented for many the first public acknowledgement that discrimination against people with disabilities is immoral and intolerable even when committed by private individuals. More than at any other time in American history, the enactment of the ADA inspired genuine hope that people with disabilities could participate equally and be welcomed in all aspects of American life.² Demands for true integration and acceptance replaced those for mere tolerance, and the goal looked to be achievable. Some scholars have concluded that the ADA and similar legislation was brought about in part by the transformation of the disabled community from a group of disparate individuals to a collective body insistent on civil rights for the whole.³

The excitement and optimism that existed in the wake of the ADA's passage has since diminished. Relatively few individuals with disabilities have met with success in the legal arena under the ADA,⁴ and societal atti-

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¹ Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101–12213 (2000)).

² See, e.g., Ann Hubbard, *The Major Life Activity of Belonging*, 39 WAKE FOREST L. REV. 217, 255–56 (2004) (describing the text and history of the ADA as "rich with proclamations of a national commitment to welcome persons with disabilities into all aspects of society"); Susan Stefan, *Delusions of Rights: Americans with Psychiatric Disabilities, Employment Discrimination and the Americans with Disabilities Act*, 52 ALA. L. REV. 271, 271 (2000) ("When President Bush signed the Americans with Disabilities Act in the Rose Garden among hundreds of people with disabilities, the mood was one of tremendous hope and triumph.").

³ See, e.g., Deborah Kaplan, *The Definition of Disability: Perspective of the Disability Community*, 3 J. HEALTH CARE L. & POL'Y 352, 352 (2000) (noting that the disability rights movement "can claim primary political responsibility for the ADA"); Laura L. Rovner, *Disability, Equality, and Identity*, 55 ALA. L. REV. 1043, 1059–63 (2004) (describing how disability advocates' attempts to frame their struggle as one for civil rights were responsible for and reflected in the ADA).

⁴ For example, one study reflects that employers win 95.7% of ADA cases at the federal appellate level. John W. Parry, 1999 Employment Decisions Under the ADA Title I-

tudes toward disability have been challenged by prenatal genetic testing and the corresponding torts of wrongful birth and wrongful life. For some time, tests have existed that, when used properly, could advise a pregnant woman of certain birth defects that her unborn child possessed or was likely to possess, like Down syndrome, anencephaly, or Tay-Sachs disease. With the completion of the Human Genome Project, scientific knowledge of genetic markers is exploding.⁵ Hundreds of tests now exist that give pregnant women the ability to detect human conditions ranging from the severely disabling to those that "many people dismiss as insignificant afflictions."⁶

Such scientific advancement has not come without cost. As the number of tests has expanded, so too has the number of lawsuits alleging negligence against the medical profession.⁷ When genetic impairments are detected upon the birth of a child, some parents have chosen to sue under the tort of wrongful birth, claiming that they would have avoided conception or aborted their unborn child had the impairment been properly diagnosed.⁸ The injury identified in these cases is the parents' lost choice

Survey Update, 24 MENTAL & PHYSICAL DISABILITY L. REP. 348 (2000). See also Samuel R. Bagenstos, *The Americans with Disabilities Act as Welfare Reform*, 44 WM. & MARY L. REV. 921, 923 (2003) (arguing that the success rate of plaintiffs in employment litigation brought under the ADA "is second in futility only to that of prisoner plaintiffs").

⁵ See, e.g., Edward J. Larson, *The Meaning of Human Gene Testing for Disability Rights*, 70 U. CIN. L. REV. 913, 913 (2002) ("During the 1990s . . . triumphant researchers claimed to isolate the genes that contribute to some forms of Alzheimer's disease, breast cancer, cystic fibrosis, depression, eating disorders, fragile X syndrome, Gaucher disease, Huntington's disease—and the list goes on through the alphabetical registry of human conditions, traits, and behaviors.").

⁶ Id. at 921; see also Erik Parens & Adrienne Asch, The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations, in PRENATAL TESTING AND DISABILITY RIGHTS 3 (Erik Parens & Adrienne Asch eds., 2000) (noting that testing is available for minor conditions "such as polydactyl (a trait involving an extra little finger)"); Cynthia M. Powell, The Current State of Prenatal Genetic Testing in the United States, in PRENATAL TESTING AND DISABILITY RIGHTS, supra, at 4, 50 (noting that "[a]ny genetic condition for which the gene has been localized or mutation identified can be tested for prenatally... includ[ing] not only disease-causing genes but also those affecting complex traits, such as obesity, intelligence, and sexual orientation").

⁷ Cf. Atlanta Obstetrics & Gynecology Group v. Abelson, 398 S.E.2d 557, 563 (Ga. 1990) ("[W]ith the continued advances in medical science which are occurring daily, the problems presented by the concept of 'wrongful birth' actions can only become increasingly more numerous and more complex."); Mark F. Grady, *Better Medicine Causes More Lawsuits, and New Administrative Courts Will Not Solve the Problem*, 86 Nw. U. L. REV. 1068, 1070–71 (1992) (noting a "seventeen-fold increase" in malpractice claims in recent decades which has "resulted from improvements in the technology"). The plaintiffs' bar has not ignored this trend. One New Jersey firm, for example, notes its expertise in securing wrongful birth judgments on its website, stating that "the frequency of these types of cases will continue to increase as prenatal testing becomes even more accurate in detecting serious birth defects." *See* Blume, Goldfaden, *Firm News: Focus on Wrongful Birth Defects, at* http://www.newjerseytrialattorneys.com/whatsnew/wrongbirth.html (last visited Nov. 28, 2004).

⁸ Cases can arise in a number of contexts, including a physician's failure to provide adequate genetic counseling, to interpret test results correctly, or to warn that a child will be born with a defect. *See* Canesi v. Wilson, 730 A.2d 805, 810–11 (N.J. 1999) (detailing

over whether or not to carry an impaired child to term.⁹ Alternatively or in addition to such claims, wrongful life actions have been initiated in the impaired child's name. Because the alleged negligence did not actually cause the child's impairment, but instead enabled the child to come into being, the operable injury is the child's life itself, with non-existence identified as the preferred alternative.¹⁰

The controversy surrounding wrongful birth and wrongful life litigation has existed for many years and is well documented.¹¹ The courts faced with these issues have overwhelmingly rejected wrongful life actions while at the same time approving those for wrongful birth.¹² In part, this has occurred because courts have found it more palatable to identify lost parental choice as the injury than to answer the metaphysical question of whether non-existence is ever preferable to life, however burdened.¹³ In contrast, many tort scholars who have addressed this issue have concluded that both wrongful birth and wrongful life actions should be permitted to go forward. They reason that both torts correspond well, if not perfectly, with traditional negligence principles.¹⁴

¹¹ See, e.g., Alan B. Handler, *Individual Worth*, 17 HOFSTRA L. REV. 493, 500 (1989) (noting that all jurisdictions faced with wrongful birth and/or wrongful life claims "have struggled mightily with its perplexing legal and moral issues").

the contexts in which such cases arise). In some circumstances, cases are also brought against laboratories that have negligently performed the testing itself. *See, e.g.*, Curlender v. Bio-Science Labs., 165 Cal. Rptr. 477 (Cal. Ct. App. 1980).

⁹ See discussion infra Part IV.B.

¹⁰ See, e.g., Kassama v. Magat, 792 A.2d 1102, 1116 (Md. 2002) (noting that injury in wrongful life is "the fact that [the plaintiff] was born; she bears the disability and will bear the expenses only because, but for the negligence of [the defendant], her mother was unable to terminate the pregnancy and avert her birth"); Procanik v. Cillo, 478 A.2d 755, 760 (N.J. 1984) (noting that plaintiff's wrongful life action did "not allege that the negligence of the defendant doctors" caused the defect in question or that the plaintiff "ever had a chance to be a normal child").

¹² See infra Part III.B.

¹³ See id.

¹⁴ See, e.g., Alan J. Belsky, Injury as a Matter of Law: Is This the Answer to the Wrongful Life Dilemma?, 22 U. BALT. L. REV. 185, 188, 268 (1993) (analyzing wrongful life under a traditional negligence framework and concluding that recognition of the tort is necessary to encourage "the pace of technology to achieve the maximally attainable state of medical care"); Anthony Jackson, Action for Wrongful Life, Wrongful Pregnancy, and Wrongful Birth in the United States and England, 17 LOY. L.A. INT'L & COMP. L. REV. 535, 543-44 (1995) (arguing that wrongful life actions satisfy "each of the requirements for a traditional tort action," and that "substantial injustice" results when courts refuse to recognize them); Michael B. Kelly, The Rightful Position in "Wrongful Life" Actions, 42 HASTINGS L.J. 505, 507-08, 589 (1991) (arguing that the theories underlying traditional tort principles support recovery for wrongful life, and that "[s]traightforward application of traditional tort remedial approaches, complete with the benefits rule, leaves plaintiffs ample room to prove their damages"); Michael B. Laudor, In Defense of Wrongful Life: Bringing Political Theory to the Defense of a Tort, 62 FORDHAM L. REV. 1675, 1704 (1994) (defending wrongful life as "a testament to the ability of our courts to pursue . . . the timehonored principle of a remedy for every wrong"); Deana A. Pollard, Wrongful Analysis in Wrongful Life Jurisprudence, 55 ALA. L. REV. 327, 371 (2004) ("Wrongful life cases should be analyzed under basic negligence principles."); Horace B. Robertson, Jr., Toward Rational Boundaries of Tort Liability for Injury to the Unborn: Prenatal Injuries, Precon-

In the midst of this robust public debate, there is one point of view that has received less attention—that of individuals with disabilities.¹⁵ Although much has been written about the impact of genetic testing as a general matter, surprisingly little legal scholarship has focused on the impact that wrongful birth and wrongful life actions might have on the community of people with disabilities. Often, the consideration tort scholars give to this viewpoint is confined to a discussion about the benefits of providing needed compensation to disabled individuals and their caregivers.¹⁶ Particularly in the wrongful life context, scholars have argued that the theoretical difficulty in identifying "life" as an injury does not outweigh the practical reality of an injured party who needs assistance.¹⁷

The problematic aspects of wrongful birth and wrongful life actions, however, far exceed the conceptual difficulties that attach to these torts. Wrongful birth and wrongful life suits may exact a heavy price not only on the psychological well-being of individuals with disabilities, but also on the public image and acceptance of disability in society. Rather than focusing on a defendant's conduct, as in a traditional tort action, both wrongful birth and wrongful life suits ultimately focus on the plaintiff's disability, a status that is at least partially a societal construction. Juries in such actions are required to evaluate whether a particular disability is so horrible, from the nondisabled perspective, as to make plausible the choice of abortion or contraconception by the parent, or non-existence by the disabled child. Since only the child's diagnosis is ascertainable at this critical point in time, the centrality of impairment in defining personhood is reinforced and inescapable. Any benefits secured by individual litigants in court are thus taxed to the community of people with disabilities as a whole, placing at risk, in the drive for individual compensation, the gains secured by collective action and identity.

This Article argues that the costs of recognizing wrongful life and birth actions are too high. Part II begins by detailing the theoretical models of disability and the role they play in shaping public attitudes and

ception Injuries, and Wrongful Life, 1978 DUKE L. J. 1401, 1456 (1978) (concluding that wrongful birth "is consistent with traditional tort theories of recovery and damages").

¹⁵ This is not to suggest that all individuals with disabilities speak with one voice. *See infra* Part IV.A. Few tort scholars, however, have devoted substantial consideration to the impact of such litigation on people with disabilities.

¹⁶ See, e.g., Belsky, *supra* note 14, at 245 (concluding, after acknowledging the potential negative impact of wrongful life actions on people with disabilities, that "[i]mprovements in genetic technology must advance, even at the expense of social stigma. Tort law is not responsible for the stigma associated with being born with a given handicap; it serves only to encourage prudent behavior though pecuniary penalty."); Pollard, *supra* note 14, at 367–69 (arguing that wrongful life actions are appropriate because the impaired child is in need of financial assistance).

¹⁷ See infra note 166. Some courts have also taken this position. See, e.g., Curlender v. Bio-Science Labs., 165 Cal. Rptr. 477, 488 (Cal. Ct. App. 1980) ("[A] reverent appreciation of life compels recognition that plaintiff, however impaired she may be, has come into existence as a living person with certain rights.").

legal remedies. Although race and gender theories have infused into mainstream legal discourse in the past several decades, disability theory has been a relative latecomer to the table.¹⁸ Because wrongful birth and life cases lie at the intersection of tort law and disability law, these theoretical models of disability provide an essential interdisciplinary foundation for evaluating the negative imagery of disability reinforced by these torts. Part III then describes the evolution of wrongful birth and life actions in the United States. This Part pays particular attention to the disparate approaches courts take when dealing with the birth of healthy but unwanted children and the birth of children with genetic defects. Part IV deconstructs the disabling message of the case law by using the combined tools of therapeutic jurisprudence and social disability theory. Social disability theory unravels the images of disability reinforced by legal rules, and therapeutic jurisprudence identifies and evaluates the psychological and social impact of such imagery. This combined analysis provides a fresh and unique approach for assessing the true coercive influence of these torts on individuals with disabilities, their families, and greater society. It also reveals that, just as in wrongful life actions, the implicit underlying injury in wrongful birth actions is the impaired child rather than the mother's lost reproductive choice. Even though the courts have treated the two torts differently, they are analytically similar and lead to equally problematic anti-therapeutic consequences. The next two Parts respond to common arguments advanced by advocates of wrongful birth and wrongful life actions. Part V addresses the belief that lines can be drawn between actionable and non-actionable disabilities by consensus and explores the inherently subjective decisions that these actions require juries to make. Part VI then addresses the problem of deterrence and the concern that the absence of a cause of action will permit negligence in genetic testing to flourish. Finally, Part VII argues that the collective identity of disability inspired by the minority group model must prevail over the medical model of disability in this expanding frontier of liability. Absent a focus on the civil rights and collective well-being of people with disabilities as a group, disability will retain its position as an inherently limiting concept that controls one's identity in society. Tort law should not serve as a tool of injustice under the guise of benevolent intervention on behalf of individuals with disabilities. Because relief to individual litigants in wrongful birth and wrongful life actions is purchased at a cost to society as a whole, neither action should be recognized by state legislatures or the courts.

¹⁸ See Harlan Hahn, Feminist Perspectives, Disability, Sexuality and Law: New Issues and Agendas, 4 S. CAL. REV. L. & WOMEN'S STUD. 97, 99 (1994) ("Once a relatively obscure and unacclaimed field in medicine or rehabilitation, the study of disability is emerging as an endeavor that could eventually complement the valuable multi-disciplinary contributions inspired by feminist concerns.").

II. CONCEPTUAL MODELS OF DISABILITY: FROM DISPARATE INDIVIDUALS TO SOCIAL FORCE FOR CHANGE

The infusion of interdisciplinary thinking into the consideration of legal issues has gained considerable momentum over the past few decades. Only recently, however, have legal scholars begun to incorporate theories of disability espoused by social science, philosophy, and like disciplines into related legal discourse.¹⁹ Consequently, any evaluation of wrongful life and birth claims must begin with an exploration of the historical models of disability enshrined both in the law and in public opinion. These models in turn provide the foundation for deconstructing the images and conceptions of disability that motivate the case law on wrongful birth and wrongful life.

A. The Medical Model of Disability

Historically, the medical model has dominated public thinking about impairment and disability.²⁰ In this model, disability is a personal trait that results from the internal functional limitations of an individual.²¹ These limitations are "typically linked to incapacity and dependence, which, in turn, may lead to social and economic isolation."22 Physicians serve as the gatekeepers of disability with respect to both the identification and the remediation of disorders.²³ It is an unstated assumption that the medical community can precisely identify impairments and accurately assess functionality.²⁴ Because disability is viewed as originating from internal rather than external sources, the subjective experiences of impaired individuals are simply disregarded.²⁵ Biology is, in effect, destiny. Since society did not cause the social disadvantages that flow naturally from biology, it is under no obligation, moral or otherwise, to alleviate them.²⁶ Thus,

¹⁹ See, e.g., Mary Crossley, The Disability Kaleidoscope, 74 Notre DAME L. Rev. 621, 627 (1999) (noting that "[u]nlike its race and gender counterparts . . . disability theory by and large has not filtered into the legal literature on disability"). Professor Crossley's groundbreaking article posits that looking at issues through "a disability studies lens may bring into focus how some legal decisionmakers continue to act on the assumption that biology *is* destiny when it comes to disability." *Id.*; *cf.* Elizabeth A. Pendo, *Disability, Doc*tors and Dollars: Distinguishing the Three Faces of Reasonable Accommodation, 35 U.C. DAVIS L. REV. 1175, 1191 (2002) (concluding that "the failure to develop a coherent and consistent theory of disability" has resulted in inconsistency in disability-related legisla-²⁰ Crossley, *supra* note 19, at 649.

²¹ Id.; see also Paula E. Berg, Ill/legal: Interrogating the Meaning and Function of the Category of Disability in Antidiscrimination Law, 18 YALE L. & POL'Y REV. 1, 4-5 (1999).

²² Richard K. Scotch, Models of Disability and the Americans with Disabilities Act, 21 Berkeley J. Emp. & Lab. L. 213, 219 (2000).

²³ Crossley, *supra* note 19, at 650; Pendo, *supra* note 19, at 1192–93.

²⁴ Crossley, *supra* note 19, at 651.

²⁵ *Id.* at 650.

²⁶ Id. at 650-51; Kaplan, supra note 3, at 353 ("Society has no underlying responsibil-

any remediation society chooses to undertake falls under the heading of charitable intervention rather than entitlement.²⁷

In light of the medical model's focus on biology, the model's solution to disability is likewise biological. Social policy centers on "eliminat[ing] as much disability as possible, by using medical technology to cure existing disability or prevent future disability, and ... us[ing] rehabilitative techniques to help disabled individuals approximate dominant physical standards as closely as possible."28 The government facilitates this policy by providing financial support to secure medical assistance for those able to overcome their limitations and to meet the needs of those who cannot.²⁹ Despite significant advances, both legally and socially, the medical model continues to form the basis of much of American and international thinking on disability.³⁰

B. The Social Model of Disability

The late 1960s saw the beginning of a shift in American thinking about disability that radically challenged the medical model.³¹ Often referred to as the social model, this approach contends that disability is a "social construction shaped by environmental factors, including physical characteristics built into the environment, cultural attitudes and social behaviors, and the institutionalized rules, procedures, and practices of private entities and public organizations."³² Rather than focusing on the inherent physiological limitations of individuals, this model emphasizes social forces in constructing the experience of disability.³³ Because physical

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ity to make a 'place' for persons with disabilities, since they live in an outsider role waiting to be cured.").

²⁷ Crossley, supra note 19, at 651-52 ("Because disability is not socially caused, the disabled individual has no claim of right to social remediation, and any benefits or assistance that society chooses to bestow on persons with disabilities can be viewed as a charitable response of 'doing special things.'").

²⁸ *Id*. at 652.

²⁹ Id. at 650; Scotch, supra note 22, at 219.

³⁰ See Rovner, supra note 3, at 1086-87 (evaluating the current entrenchment of the medical model of disability in American jurisprudence); see also Crossley, supra note 19, at 652 ("This medical model of disability, while it has been increasingly challenged by disability theorists and disability-rights activists, persists in the popular understanding of disability, as well as in the legal commentary on disability.").

³¹ See, e.g., Lisa Eichhorn, Major Litigation Activities Regarding Major Life Activities: The Failure of the "Disability" Definition in the Americans with Disabilities Act of 1990, 77 N.C. L. REV. 1405, 1414-16 (1999); Miranda Oshige McGowan, Reconsidering the Americans with Disabilities Act, 35 GA. L. REV. 27, 46 (2000).

³² Scotch, *supra* note 22, at 214.

³³ See id. at 215 (citing MICHAEL OLIVER, THE POLITICS OF DISABLEMENT: A SOCIO-LOGICAL APPROACH xiv (1990) ("All disabled people experience disability as social restriction, whether those restrictions occur as a consequence of inaccessibly built environments, questionable notions of intelligence and social competence, the inability of the general population to use sign language, the lack of reading material in braille [sic] or hostile public attitudes to people with non-visible disabilities.")); see also Eichhorn, supra note 31, at 1414-16; McGowan, supra note 31, at 46.

environments and social structures are created by the nondisabled with faulty assumptions as to the normal range of functioning, they involuntarily and inevitably transform people with functional impairments into people with disabilities.³⁴ A typical (if somewhat simplistic) example cited by scholars is the individual in a wheelchair who is unable to enter a building constructed with stairs. The individual is disabled vis-à-vis the building not because of any physiological limitation, but because of a design flaw that did not contemplate the non-ambulatory.³⁵ As a result of such thinking, "assumptions of the inability to participate become self-fulfilling prophecies."³⁶ The message that people with impairments are considered to be somehow "other" than the rest of society is reinforced and pervasive.³⁷

Despite the powerful message of the social model of disability, even some advocates acknowledge it is sometimes overly restrictive in its view. In concentrating on the social causes of disability, the model largely ignores the potential impact of the impairments themselves. The unquestionable reality is that some individuals suffer from severe functional limitations that exist independently of any social construction of disability, such as profound mental retardation or Tay-Sachs disease.³⁸ In such cases, the limitations and suffering experienced by the individual are likely to overshadow the consequences of discrimination felt from society.³⁹ This recognition, however, does not undermine the significance of the social model. Regardless of the role played by specific impairments, external social and physical barriers remain as powerful forces barring the integration of people with disabilities into all aspects of American society.⁴⁰

Moreover, the remedies proposed by the social model apply with equal force whether or not some emphasis is given to the nature of impairment. Because the social model perceives the origin of disability as primarily social in nature, its remedy follows suit. Public policy centers not on curing the internal defects of the individual, but rather on curing the attitudes held by others and eradicating physical barriers that preclude full accessibility in society.⁴¹ This remedy is not passive in nature, and in-

³⁴ Rovner, *supra* note 3, at 1051–52; *see also* Crossley, *supra* note 19, at 653–54 ("Because members of society historically have not viewed persons with disabilities as part of the societal norm, no attempts have been made to avoid the creation of physical and attitudinal barriers built into the very framework of society—barriers that prevent persons with disabilities from fully participating in society.").

³⁵ See, e.g., Crossley, supra note 19, at 654; McGowan, supra note 31, at 45-46.

³⁶ Scotch, *supra* note 22, at 215.

³⁷ See Crossley, supra note 19, at 655.

³⁸ *Id*. at 657.

³⁹ Id.

⁴⁰ *Id.* at 658 ("[T]he social model need not deny that some limitations flow directly from impairment in order to argue that externally imposed disadvantages should be remedied.").

⁴¹ Id. As Professor Crossley explains, "rehabilitation" in the social model can take the

stead may, in many circumstances, require affirmative action to enhance accessibility.⁴²

C. The Civil Rights/Minority Group Model of Disability

The most recent theory articulated by scholars is the minority group model of disability, which begins, as does the social model, with the premise that disability is primarily a function of social relationships and discrimination rather than any inherent functional limitations.⁴³ It moves beyond the social model, however, by using this recognition as the foundation of group identity for people with disabilities. Historically, the divergence in the kind and degree of functional limitations dominated over any shared experience among impaired individuals. As Harlan Hahn has stated, "[t]he notion that a disability is unique and personal . . . implies that it is an essentially private problem to be resolved, conquered or overcome by individual effort rather than by public policies or social services."44 Once the problems associated with disability are acknowledged to be externally generated, however, individual impairments take a back seat to the universal experience of discrimination and stigmatization. Individuals with disabilities are encouraged to see themselves as members of a discrete minority group, similar to others in society. This group conception transforms relatively powerless individuals into a unified political body insistent on the "eradication of exclusionary social practices and structures as a matter of civil rights "45

The minority model, like its medical and social counterparts, is not without its critics. More so than in other minority groups in society, there are very real differences in the physical limitations and life-experiences

form of "altering the physical environment (for example, by building ramps and cutting curbs), or it may involve modifying social systems or policies to enable persons with disabilities to participate in, and benefit from, opportunities commonly enjoyed by nondisabled members of our society. This approach sees socially created barriers as generating an 'accommodation imperative,' which requires affirmative efforts to make all aspects of social and economic life accessible." *Id.* at 658–59.

⁴² *Id.* at 659.

⁴³ See, e.g., Hahn, supra note 18, at 98; Pendo, supra note 19, at 1193–94.

⁴⁴ Hahn, *supra* note 18, at 105. As Professor Hahn explains, one side effect of this perception of disability is the reluctance of people with disabilities to join disability-related organizations, because "the concept of 'misfortune' tends to reinforce the 'badge' of inferiority that is frequently affixed to physical differences." *Id.* at 105–06.

⁴⁵ Crossley, *supra* note 19, at 659 (noting that the minority group model gives individuals with disabilities the "civil right to be considered part of [the] norm and to be allowed to participate meaningfully"); *see also* Berg, *supra* note 21, at 43–44; Linda Hamilton Krieger, *Afterword: Socio-Legal Backlash*, 21 BERKELEY J. EMP. & LAB. L. 476, 476 (2000). In her article, Professor Krieger describes the perspective of disability advocates at a symposium at the University of California-Berkeley in March 1999, who maintained that "the right to assert a legal claim to access had transformed their individual and collective self-conceptions and their relationship to society. Law, in this view, had brought the movement a long, long way." *Id.*

of this group's members.⁴⁶ For example, many individuals with disabilities are not exposed to other group members during childhood, which may impair their ability to form a coherent group consciousness and culture.⁴⁷ Nevertheless, some scholars have credited the political awareness engendered by the minority model for the passage of the Americans with Disabilities Act and comparable civil rights legislation.⁴⁸

III. THE EVOLUTION OF WRONGFUL BIRTH AND WRONGFUL LIFE LITIGATION

As public thinking on the rights and roles of individuals with disabilities has shifted over time, tort law has struggled to keep pace, particularly when dealing with issues arising out of emergent technology. In some areas, the common law has clearly lagged behind modern conceptions of disability, moral culpability, and deterrence.⁴⁹ The rapid pace of technological innovation in the area of genetic testing, however, has forced courts, willingly or otherwise, to respond to cutting-edge issues striking at the core of the disability rights movement. Even a casual reading of the case law addressing wrongful birth and wrongful life reflects the uncertainty and discomfort courts feel when they must confront issues that implicate the fundamental, and sometimes divergent, goals of tort law and the meaning of life itself.

⁴⁶ Crossley, *supra* note 19, at 664.

⁴⁷ *Id.* at 663–64.

⁴⁸ See, e.g., Adrienne Asch, Disability Equality and Prenatal Testing: Contradictory or Compatible?, 30 FLA. ST. U. L. REV. 315, 327–28 (2003) (noting that "[t]he richness of [the social and minority rights] models of disability is the legislation they helped to create, embodying a national commitment to equal opportunity in education, public services, employment, transportation, and places of public accommodation" (citations omitted)); Kaplan, *supra* note 3, at 352, 358 (arguing that adoption of the social construction of disability urged by disability rights advocates was a primary impetus behind the enactment of the ADA); Rovner, *supra* note 3, at 1044 (explaining that the ADA "was viewed as a watershed in the disability community" in part because "it reflected ... an adoption of the movement's socio-political model of disability"); Scotch, *supra* note 22, at 214 (describing the ADA as the "culmination of a two-decade shift in federal disability policy" from a medical model of disability to a "socio-political or minority group model" (citations omitted)).

⁴⁹ For example, although negligence analysis takes into account a person's physical disabilities in establishing the requisite standard of care, the common law makes no such adjustment for mental infirmities despite modern understanding that such impairments are often biologically based and beyond the control of the individual in question. *See, e.g.,* Daniel W. Shuman, *The Psychology of Deterrence in Tort Law,* 42 U. KAN. L. REV. 115, 134 (1993) (describing how "various tort rules reflect the coolness of the developing tort law to psychiatry and psychology").

A. Cases Involving Healthy Children

1. The Early Cases

The early cases implicating wrongful birth and wrongful life did not involve genetic testing but, instead, resulted from the birth of healthy children who were, for a variety of reasons, either unexpected or unwanted by their parents. The reasoning courts employed in evaluating whether an "injury" had occurred in such circumstances provides unique insight into the subsequent cases focusing on children with disabilities.

The earliest claims in this category, often labeled "wrongful conception" or "wrongful pregnancy," were brought by parents against either physicians who had performed negligent sterilization procedures or abortions, or manufacturers who had developed faulty contraceptive products.⁵⁰ In both sets of circumstances, the defendants' negligence resulted in the birth of a healthy child despite the parents' clearly expressed desire to avoid conception. To some extent, such actions are consistent with traditional medical malpractice and product liability actions because the plaintiffs can easily establish that, but for the defendant's negligence, the child in question would not have been conceived. As a result, most jurisdictions have readily recognized this type of tort action.⁵¹ In virtually all cases, courts have awarded the plaintiff mothers their medical expenses and emotional distress damages associated with pregnancy and childbirth. However, most courts have rejected the expansion of such damages to the costs of raising the unexpected child to adulthood.⁵² Uncomfortable with the notion of labeling the child's life, rather than the mother's experience, as a legally compensable "injury," the majority of courts have refused to award additional child-rearing expenses.⁵³ Even those courts that

⁵³ See, e.g., Boone v. Mullendore, 416 So. 2d 718 (Ala. 1982); M.A. v. United States, 951 P.2d 851 (Alaska 1998); Wilbur v. Kerr, 628 S.W.2d 568 (Ark. 1982); Flowers v. Dis-

⁵⁰ See, e.g., Custodio v. Bauer, 59 Cal. Rptr. 463 (Cal. Ct. App. 1967); Coleman v. Garrison, 327 A.2d 757 (Del. Super. Ct. 1974).

⁵¹ See, e.g., Simmerer v. Dabbas, 733 N.E.2d 1169, 1171 (Ohio 2000) (noting that "[m]ost United States jurisdictions recognize this cause of action"); Emerson v. Magendantz, 689 A.2d 409, 411 (R.I. 1997) (reviewing cases). In more recent years, these cases have become increasingly common among parents seeking damages for the birth of a child with defects following a failed sterilization. *See, e.g.*, Williams v. Univ. of Chicago Hosps., 688 N.E.2d 130 (Ill. 1997); *Simmerer*, 733 N.E.2d at 1169.

⁵² See, e.g., Jackson, *supra* note 14, at 589 (noting that "of the thirty-six jurisdictions that allow wrongful pregnancy claims, twenty-eight deny damages for child-rearing as a matter of law" (citation omitted)); Catherine Palo, *Cause of Action for Wrongful Birth or Wrongful Life*, 23 CAUSES OF ACTION 2D 55 § 20 (2003) (noting that "the view in the vast majority of jurisdictions" is that the "parents of healthy children born after an unsuccessful sterilization procedure involving medical negligence are entitled to pregnancy and childbearing expenses, but not child-rearing expenses"). Some courts have created exceptions to this rule in cases where the plaintiff underwent sterilization for financial reasons associated with child rearing. *See, e.g.*, Burke v. Rivo, 551 N.E.2d 1, 6 (Mass. 1990) (permitting recovery for costs of rearing child where parents' desire for sterilization "was founded on economic or financial considerations").

award such damages have acknowledged public policy concerns, including the "hope that future parents and attorneys would give serious reflection to the silent interests of the child and, in particular, the parent-child relationships that must be sustained long after legal controversies have been laid to rest."⁵⁴

Courts have treated tort actions seeking compensation for the birth of healthy children in cases where neither parent attempted to prevent conception with significantly more skepticism. Most common among such claims are cases brought by children alleging injury because of birth to an unwed mother.⁵⁵ Equating the social stigma of illegitimacy to an affliction with a "permanent disability,"⁵⁶ these litigants argued that their very lives were wrongful, and that they were thus entitled to compensation. Courts, however, have disagreed.⁵⁷ Although these courts acknowledged the hard-

⁵⁴ Sherlock v. Stillwater Clinic, 260 N.W.2d 169, 177 (Minn. 1977); *see also* Robertson, *supra* note 14, at 1449 (noting court concerns about "the psychic and emotional harm that might be inflicted upon a child by the mere litigation of a failed-contraception case" because "[w]in or lose, [parents and attorneys] have branded the child an 'emotional bastard").

⁵⁵See, e.g., Zepeda v. Zepeda, 190 N.E.2d 849 (III. App. Ct. 1963); cf. Williams v. New York, 223 N.E.2d 343 (N.Y. 1966) (seeking recovery for wrongful life where child was born illegitimately to institutionalized mother who had been raped by another patient).

⁵⁶ Zepeda, 190 N.E.2d at 857 (involving plaintiff who argued that his "adulterine birth ha[d] placed him under a permanent disability").

⁵⁷See, e.g., Vance v. T.R.C., 494 S.E.2d 714, 719 (Ga. Ct. App. 1997) ("An action brought by a child against the ... physician on the theory that because of his illegitimacy ... he would have been better not born has found almost no support in the law.") (quoting Fulton-DeKalb Hosp. Auth. v. Graves, 314 S.E.2d 653, 654 (Ga. 1984)); *Zepeda*, 190 N.E.2d at 858–59 (declining to find liability on a wrongful life theory in case brought by illegitimate child, discussing implications of such a suit as reproductive science advances, and recognizing that advances of law are better left to General Assembly and legislative study).

trict of Columbia, 478 A.2d 1073 (D.C. 1984); Fassoulas v. Ramey, 450 So. 2d 822 (Fla. 1984); Cockrum v. Baumgartner, 447 N.E.2d 385 (Ill. 1983); Chaffee v. Seslar, 786 N.E.2d 705 (Ind. 2003); Nanke v. Napier, 346 N.W.2d 520 (Iowa 1984); Johnston v. Elkins, 736 P.2d 935 (Kan. 1987); Schork v. Huber, 648 S.W.2d 861 (Ky. 1983); Pitre v. Opelousas General Hosp., 530 So. 2d 1151 (La. 1988); Macomber v. Dillman, 505 A.2d 810 (Me. 1986); Rouse v. Wesley, 494 N.W.2d 7 (Mich. Ct. App. 1992); Girdley v. Coats, 825 S.W.2d 295 (Mo. 1992); Hitzemann v. Adam, 518 N.W.2d 102 (Neb. 1994); Szekeres v. Robinson, 715 P.2d 1076 (Nev. 1986); Kingsbury v. Smith, 442 A.2d 1003 (N.H. 1982); O'Toole v. Greenberg, 477 N.E.2d 445 (N.Y. 1985); Jackson v. Bumgardner, 347 S.E.2d 743 (N.C. 1986); Johnson v. Univ. Hosp. of Cleveland, 540 N.E.2d 1370 (Ohio 1989); Wofford v. Davis, 764 P.2d 161 (Okla. 1988); Butler v. Rolling Hill Hosp., 582 A.2d 1384 (Pa. Super. Ct. 1990); Emerson v. Magendantz, 689 A.2d 409 (R.I. 1997); Smith v. Gore, 728 S.W.2d 738 (Tenn. 1987); Terrell v. Garcia, 496 S.W.2d 124 (Tex. Civ. App. 1973); C.S. v. Nielson, 767 P.2d 504 (Utah 1988); Miller v. Johnson, 343 S.E.2d 301 (Va. 1986); McKernan v. Aasheim, 687 P.2d 850 (Wash. 1984); James G. v. Caserta, 332 S.E.2d 872 (W. Va. 1985); Beardsley v. Wierdsma, 650 P.2d 288 (Wyo. 1982). This approach, however, has not been universal. Courts in California, New Mexico, Oregon and Wisconsin generally permit recovery of the costs of rearing the child without offset. A few jurisdictions, moreover, permit recovery for the expenses of rearing the child offset by the benefits secured by the parents. See Simmerer, 733 N.E.2d at 1172 (detailing the varying approaches to assessing damages in wrongful pregnancy cases); Palo, supra note 52, at § 20 (discussing the primary schemes of recovery in wrongful pregnancy actions).

ship and stigma experienced by children of unwed parents,⁵⁸ they were more concerned with the "vast" legal and social impact that could ultimately result if any person "born into the world under conditions they might regard as adverse" could sue, particularly in light of "man's . . . ever greater control over the functions of nature."⁵⁹ As a result, courts have concluded that the legislative branch, rather than the judiciary, is the proper place for resolving such disputes.⁶⁰

2. Contemporary Cases

Today, thirty-one states and the District of Columbia recognize a cause of action against a medical professional for the unwanted birth of a healthy child.⁶¹ In addition to these suits, some parents in the last fifteen years have attempted to impose liability for unwanted children under the torts of false representation and fraud. In these cases, a healthy child was born

⁵⁸ See, e.g., Zepeda, 190 N.E.2d at 856 ("It would be pure fiction to say that the plaintiff suffers no injury. The lot of a child born out of wedlock, who is not adopted or legitimatized, is a hard one."); Slawek v. Stroh, 215 N.W.2d 9, 22 (Wis. 1974) (citing Zepeda). Although the stigma of illegitimacy has changed dramatically in public opinion and legislation in the last several decades, traditional common law afforded such children "no rights in law." Zepeda, 190 N.E.2d at 856. In Zepeda, the court noted that "[the plaintiff's] parents had no right to his custody and no subsequent act of theirs could make him legitimate He could not compel his parents to support him, he could not inherit and he could have no heirs except his widow and the issue of his own body." *Id*.

⁵⁹ Zepeda, 190 N.E.2d at 858–59; *see also* Stills v. Gratton, 127 Cal. Rptr. 652 (Cal. Ct. App. 1976) (rejecting wrongful life action based on illegitimacy because of the inability to measure damages, but approving mother's wrongful birth action where birth followed botched abortion).

⁶⁰ See, e.g., Zepeda, 190 N.E.2d at 859.

⁶¹ E.g., Boone v. Mullendore, 416 So. 2d 718 (Ala. 1982); Univ. of Ariz. Health Sci. Ctr. v. Superior Ct. of Maricopa, 667 P.2d 1294 (Ariz. 1983); Wilbur v. Kerr, 628 S.W.2d 568 (Ark. 1982); Foy v. Greenblott, 191 Cal. Rptr. 84 (Cal. Ct. App. 1983); Ochs v. Borrelli, 445 A.2d 883 (Conn. 1982); Coleman v. Garrison, 327 A.2d 757 (Del. Super. Ct. 1974); Flowers v. District of Columbia, 478 A.2d 1073 (D.C. 1984); Ramey v. Fassoulas, 414 So. 2d 198 (Fla. Dis. Ct. App. 1982); Fulton-DeKalb Hosp. Auth. v. Graves, 314 S.E.2d 653 (Ga. 1984); Cockrum v. Baumgartner, 447 N.E.2d 385 (Ill. 1983); Garrison v. Foy, 486 N.E.2d 5 (Ind. Ct. App. 1985); Johnston v. Elkins, 736 P.2d 935 (Kan. 1987); Maggard v. McKelvey, 627 S.W.2d 44 (Ky. Ct. App. 1981); Macomber v. Dillman, 505 A.2d 810 (Me. 1986); Jones v. Malinowski, 473 A.2d 429 (Md. 1984); Clevenger v. Haling, 394 N.E.2d 1119 (Mass. 1979); Clapham v. Yanga, 300 N.W.2d 727 (Mich. Ct. App. 1981); Sherlock v. Stillwater Clinic, 260 N.W.2d 169 (Minn. 1977); Miller v. Duhart, 637 S.W.2d 183 (Mo. Ct. App. 1982); Kingsbury v. Smith, 442 A.2d 1003 (N.H. 1982); P. v. Portadin, 432 A.2d 556 (N.J. Super. Ct. App. Div. 1981); Hardin v. Farris, 530 P.2d 407 (N.M. Ct. App. 1974); Mears v. Alhadeff, 451 N.Y.S. 2d 133 (N.Y. App. Div. 1982); Pierce v. Piver, 262 S.E.2d 320 (N.C. Ct. App. 1980); Bowman v. Davis, 356 N.E.2d 496 (Ohio 1976); Mason v. W. Pa. Hosp., 453 A.2d 974 (Pa. 1982); Smith v. Gore, 728 S.W.2d 738 (Tenn. 1987); Garwood v. Locke, 552 S.W.2d 892 (Tex. App. 1977); McKernan v. Aasheim, 687 P.2d 850 (Wash. 1984); James G. v. Caserta, 332 S.E.2d 872 (W. Va. 1985); Marciniak v. Lundborg, 450 N.W.2d 243 (Wis. 1990); Beardsley v. Wierdsma, 650 P.2d 288 (Wyo. 1982); see also Don C. Smith, Jr., Cause of Action Against Physicians for Wrongful Conception or Wrongful Pregnancy, in 3 CAUSES OF ACTION 83 § 4 (Wesley H. Winborne ed., 1984 & Supp. 2004) (surveying state wrongful conception actions).

after one parent represented to the other that he or she was infertile.⁶² The courts' rationale in refusing to entertain such claims is predictably similar to that voiced in other cases dealing with healthy children. Most frequently cited is the unwillingness to recognize the child's life as an item of compensable damage.⁶³ Courts have reasoned that reaching a contrary conclusion would result in the "unseemly spectacle" of parents disparaging their child in open court and denying their affections in order to maximize the damage award.⁶⁴ Courts have also expressed concern that such assertions would irreparably harm the emotional well-being of the child to the point of "brand[ing] [him] an 'emotional bastard."⁶⁵ As a result, courts have concluded that they should reject the plaintiffs' claims on public policy grounds.⁶⁶

B. Cases Involving Children with Disabilities

The rationales courts use both to award and to deny recovery for "normal" children stand in contrast to those articulated by jurisdictions recognizing wrongful birth or wrongful life in the context of a child born with a genetic defect. While courts give heavy emphasis to the inherent benefits of rearing a child in the former, many courts ignore these benefits in the latter.⁶⁷ The divergent treatment in the case law highlights the continued ambiguity and bias attached to concepts of disability in modern society.

 $^{^{62}}$ E.g., C.A.M. v. R.A.W., 568 A.2d 556 (N.J. Super. Ct. App. Div. 1990) (involving father who claimed that he had had a vasectomy); Moorman v. Walker, 773 P.2d 887, 888 (Wash. Ct. App. 1989) (involving mother who claimed that she was infertile).

⁶³ E.g., C.A.M., 568 A.2d at 563; *Moorman*, 773 P.2d at 889.

⁶⁴ *Moorman*, 773 P.2d at 889 (criticizing the tort by explaining that "[a]n unhandsome, colicky or otherwise 'undesirable' child would provide fewer offsetting benefits, and would therefore presumably be worth more monetarily in a 'wrongful birth' case"); *see also C.A.M.*, 568 A.2d at 563 (quoting McKernan v. Aasheim, 687 P.2d 850, 855 (Wash. 1984)).

⁶⁵ See Moorman, 773 P.2d at 889; see also C.A.M., 568 A.2d at 563–61 (agreeing with California courts that "it is not sound social policy to allow one parent to sue the other one over the wrongful birth of their child . . . [since] using the child as the damage element in a tortious claim of one parent against the other could seldom, if ever, result in benefit to the child").

⁶⁶ Moorman, 773 P.2d at 889; C.A.M., 568 A.2d at 563 ("The specter of the mother claiming as her damages the wrongful existence of her normal, healthy child . . . and the father potentially arguing that the mother should have mitigated her damages by aborting their child, clearly support the conclusion . . . that we should not embark upon the resolution of such a dispute.").

⁶⁷ See, e.g., Rouse v. Wesley, 494 N.W.2d 7, 10 (Mich. Ct. App. 1992) ("[I]n the context of a wrongful pregnancy action, we hold as a matter of law that the value of the life of a child will always outweigh the customary cost of raising that child to majority."); Taylor v. Kurapati, 600 N.W.2d 670, 679 (Mich. Ct. App. 1999) ("We consider the best reason [for not allowing recovery of expenses related to rearing a healthy child] to be that the costs of raising such a child are outweighed by the value of that child's life."); Terrell v. Garcia, 496 S.W.2d 124, 128 (Tex. Civ. App. 1973) ("[T]he satisfaction, joy and companionship which normal parents have in rearing a child make [the] economic loss [associated with child rearing] worthwhile."); see also Jackson, supra note 14, at 591–93 (discussing the tendency of courts to award child-rearing and emotional distress damages in cases involving the birth of children with disabilities).

1. The Early Cases

Wrongful birth and life claims arising out of the birth of children with disabilities was first addressed in *Gleitman v. Cosgrove*,⁶⁸ decided by the New Jersey Supreme Court in 1967. In that case, the mother contracted rubella⁶⁹ in the early stages of her pregnancy and, concerned that the virus had affected her developing child, consulted her physician for information. The physician assured her that there would be no undue effect on the fetus despite the fact that it was commonly known in the medical community that rubella in early pregnancy could result in birth defects.⁷⁰ When the child was subsequently born suffering from mental retardation and "substantial defects . . . in sight, hearing and speech,"⁷¹ the parents sued for wrongful birth and the child sued for wrongful life on the ground that had the mother received the correct information, she would have considered having an abortion.⁷²

Evaluating the child's wrongful life claim first, the court was troubled by the fact that, unlike the traditional medical malpractice case in which negligence directly affected the fetal condition, the child never had a chance of being born "normal" or "healthy" regardless of the physician's actions.⁷³ Instead, the child alleged that the "injury" caused by the physician's negligence was "be[ing] born to suffer with an impaired body," since his mother would have aborted him had she been fully apprised of his impairments.⁷⁴ Concluding that it was "logically impossible" to "measure the difference between his life with defects against the utter void of nonexistence," the court rejected the claim as not cognizable at law.⁷⁵

It found the wrongful birth claim of the parents, on the other hand, more difficult to resolve. Unlike the problematic injury element above, the court recognized that the physician's failure to accurately inform them of the potential for defects clearly did cause the mother's anguish and the father's attendant financial responsibilities, which would not have arisen had the mother elected to have an abortion.⁷⁶ Nevertheless, the court rea-

^{68 227} A.2d 689 (N.J. 1967).

⁶⁹ Rubella is also known as German measles.

⁷⁰ Gleitman, 227 A.2d at 690. Plaintiff's expert testified that "women who have German measles in the first trimester of their pregnancy will produce infants with birth defects in 20 to 50 per cent of the cases." Id.

⁷¹ Id.

⁷² Id. at 691. Specifically, the child plaintiff sued "for his birth defects," the mother sued "for the effects on her emotional state caused by her son's condition," and the child's father sued "for the costs incurred in caring for [the child]." Id. at 690.

⁷³ *Id.* at 692. 74 Id. at 693–94.

⁷⁵ Id.

⁷⁶ Id. at 692–93 (noting that the mother "can say that an abortion would have freed her of the emotional problems caused by raising of a child with birth defects; and [the father] can assert that it would have been less expensive for him to abort rather than raise the child").

soned that providing compensatory damages on this basis would still require it to weigh these injuries against the "complex human benefits of motherhood and fatherhood," a task it considered "impossible."⁷⁷ Even if it could accomplish such a task, moreover, the court refused on public policy grounds to allow "tort damages for the denial of the opportunity to take an embryonic life."⁷⁸ Stating that "[i]t is basic to the human condition to seek life and hold on to it however heavily burdened," the court, basing its opinion in part on a pre-*Roe* statute criminalizing abortions without lawful justification, concluded that

[a] court cannot say what defects should prevent an embryo from being allowed life such that denial of the opportunity to terminate the existence of a defective child in embryo can support a cause for action. Examples of famous persons who have had great achievement despite physical defects come readily to mind, and many of us can think of examples close to home. A child need not be perfect to have a worthwhile life. . . . The sanctity of a single human life is the decisive factor in this suit in tort. Eugenic considerations are not controlling. We are not talking here about the breeding of prize cattle.⁷⁹

More than ten years later, the issues of wrongful birth and wrongful life resurfaced in the New York Court of Appeals case of *Becker v. Swartz*.⁸⁰ The plaintiff mother in *Becker* alleged that her physician neither advised her of the increased risk of birth defects in women over thirty-five years of age nor recommended that she have an amniocentesis.⁸¹ She subsequently gave birth to a child with Down syndrome,⁸² who is described in the opinion as "retarded and brain-damaged."⁸³ The mother and father

Id. at 808 n.1 (internal citations omitted).

83 Id. at 808.

⁷⁷ Id. at 693.

⁷⁸ Id.

⁷⁹ Id. at 693–94.

⁸⁰ 386 N.E.2d 807 (N.Y. 1978).

⁸¹ As described by the court, "[a]mniocentesis is the '[transabdominal] * * * [sic] aspiration of fluid from the amniotic sac.' (Stedman's Medical Dictionary [23d ed].)" Biochemical tests are performed on the sample of amniotic fluid withdrawn, often times allowing the detection of chromosomal abnormality." *Id.* at 808 n.2.

⁸² The court describes Down syndrome as

a syndrome of mental retardation associated with a variable constellation of physical abnormalities caused by a chromosomal anomaly. While a normal fetus has 23 pairs of chromosomes, mongoloid children commonly have an additional chromosome in what is classified as chromosome pair 21, giving rise to the descriptive term "trisomy 21." It is this chromosomal anomaly—a critical portion of chromosome 21 being represented in most cells three times instead of twice—which is thought to precipitate this syndrome of mental retardation.

brought suit for wrongful birth and filed for wrongful life on behalf of their infant.⁸⁴ Like the *Gleitman* court before it, the *Becker* court acknowledged the complexity of the wrongful life action, reasoning that it "casts an almost Orwellian shadow, premised as it is upon concepts of genetic predictability once foreign to the evolutionary process[;] . . . [a]ny such resolution, whatever it may be, must invariably be colored by notions of public policy, the validity of which remains, as always, a matter upon which reasonable men may disagree."⁸⁵ The court concluded that the action was fundamentally flawed, primarily because the infant plaintiff could not be shown to have suffered a legally cognizable injury in the absence of a corresponding right to "be born as a whole, functional human being."⁸⁶ In a passage that has since been extensively quoted by courts rejecting a wrongful life cause of action, the court postulated that

[w]hether it is better never to have been born at all than to have been born with even gross deficiencies is a mystery more properly to be left to the philosophers and the theologians. Surely the law can assert no competence to resolve the issue, particularly in view of the very nearly uniform high value which the law and mankind has placed on human life, rather than its absence.⁸⁷

The court found it equally problematic that wrongful life "demands a calculation of damages dependent upon a comparison between the Hobson's choice of life in an impaired state and nonexistence. This comparison the law is not equipped to make."⁸⁸ Accordingly, the court concluded that the legislature, rather than the judiciary, was the appropriate place to measure the infant's damages.⁸⁹

The *Becker* court took a different approach when it turned to the parental claims for wrongful birth. It concluded that such an action was cognizable, in part because "nothing extraordinary" was required to ascertain compensatory damages in the form of expenses related to the care

⁸⁴ The opinion also evaluates the companion case of *Park v. Chessin*, 400 N.Y.S.2d 110 (N.Y. App. Div. 1977). In *Park*, the plaintiffs' first child suffered from polycystic kidney disease and died after five hours of birth. *Gleitman*, 227 A.2d at 809. The plaintiffs consulted their obstetrician about the possibility that subsequent children would be afflicted with the disease and were incorrectly informed that it was not hereditary. *Id*. As a result, the plaintiffs conceived and gave birth to a second child who likewise suffered from polycystic disease, but who lived two and one half years. Alleging that they would have chosen not to conceive a child had they received the correct advice, the plaintiffs commenced suit against the physicians for wrongful birth on their own behalf and wrongful life on behalf of their infant child. *Id*.

⁸⁵ Id. at 810.

⁸⁶ Id. at 812 (quoting Park v. Chessin, 400 N.Y.S.2d 110, 114 (N.Y. App. Div. 1977).

⁸⁷ Id.

⁸⁸ Id.

⁸⁹ Id.

and treatment of the child.⁹⁰ Psychic or emotional harm, however, was another matter. Although it recognized that "parents of a deformed infant will suffer the anguish that only parents can experience upon the birth of a child in an impaired state," the court reasoned that "parents may yet experience a love that even an abnormality cannot fully dampen."⁹¹ Since fairness would require the court to offset any emotional damages by these benefits, calculation of emotional damages was too speculative and best left to the legislative realm.⁹²

After the Becker decision, many courts endorsed a cause of action for wrongful birth for reasons similar to those articulated by the New York Court of Appeals.93 Judicial acceptance of a wrongful life action, however, continued to be elusive until the 1980 decision by the California Appellate Court in Curlender v. Bio-Science Laboratories.94 The plaintiff in Curlender, a child born with Tay-Sachs disease,⁹⁵ sued for wrongful life on the ground that the defendant laboratory negligently performed tests and thus failed to detect that her parents were both carriers of the genes known to cause the disorder.⁹⁶ The court began its opinion by distinguishing the rejection of wrongful life in the context of illegitimacy, reasoning that "[s]urely there is a world of difference between an unwanted healthy child who is illegitimate ... and the severely deformed infant plaintiff "⁹⁷ While prior courts had correctly concluded that the illegitimate or unwanted child suffered no injury by being born, the severely impaired child presented a "palpable injury, involving not only pecuniary loss but untold anguish on the part of all concerned"98 Acknowledging that public policy and "a deeply held belief in the sanctity of life" had led many courts to reject this cause of action, the Curlender court nevertheless concluded that there was no "universal accep-

Id. at 816. Plaintiff's estimated life expectancy was four years. Id.

⁹⁶ Id. at 815.

97 Id. at 825.

98 Id. at 826.

⁹⁰ Id. at 813.

⁹¹ *Id.* at 814.

⁹² Id.

⁹³ See, e.g., Goldberg v. Ruskin, 471 N.E.2d 530, 532–33, 535–38 (Ill. App. Ct. 1984); Speck v. Finegold, 408 A.2d 496, 508–09 (Pa. Super. Ct. 1979), *aff'd in part and rev'd on other grounds*, Speck v. Finegold, 439 A.2d 110 (Pa. 1981).

^{94 165} Cal. Rptr. 477 (Cal. Ct. App. 1980).

⁹⁵ Id. at 815–16. The court, citing SCHMIDT'S ATTORNEYS' DICTIONARY OF MEDICINE, defined the fatal disorder as "[a] familial [hereditary] disease affecting children . . . characterized by partial or complete loss of vision, mental underdevelopment, softness of the muscles, convulsions, etc." Id. at 815 n.4. The court described the plaintiff specifically as

suffer[ing] from "mental retardation, susceptibility to other diseases, convulsions, sluggishness, apathy, failure to fix objects with her eyes, inability to take an interest in her surroundings, loss of motor reactions, inability to sit up or hold her head up, loss of weight, muscle atrophy, blindness, pseudobulper palsy, inability to feed orally, decerebrate rigidity and gross physical deformity."

tance of the notion that 'metaphysics' or 'religious beliefs,' rather than law, should govern the situation \dots "99

According to the court, countervailing public policy in the form of "regard for social welfare" and the need to safeguard careful genetic testing were significant concerns that warranted careful consideration.¹⁰⁰ The court reasoned that eugenic abortion in the wake of *Roe v. Wade*¹⁰¹ was now both available and legal.¹⁰² It further intimated that in some circumstances, eugenic abortions are actually desirable as a means to limit the "increasingly large part of the overall health care burden" represented by genetically defective children.¹⁰³ Concluding that tort law should reflect the "basic changes in the way society views such matters" and was "needed to avoid genetic disaster," the court endorsed a wrongful life cause of action.¹⁰⁴ It was not troubled, as other courts were, by the seeming difficulty of labeling life as injury, reasoning that

[t]he reality of the "wrongful life" concept is that such a plaintiff both *exists* and *suffers*, due to the negligence of others. It is neither necessary nor just to retreat into meditation on the mysteries of life. We need not be concerned with the fact that had defendants not been negligent, the plaintiff might not have come into existence at all. The certainty of genetic impairment is no longer a mystery. In addition, a reverent appreciation of life compels recognition that plaintiff, however impaired she may be, has come into existence as a living person with certain rights.¹⁰⁵

In one of the most controversial portions of the decision, the court acknowledged in dicta that its reasoning would support a cause of action by an impaired child against his parents for inflicting an "injury" by choosing to give birth.¹⁰⁶ In the court's view, if parents made a conscious and informed choice to carry a seriously impaired child to term, nothing should "protect [them] from being answerable for the pain, suffering and misery which they have wrought on their offspring."¹⁰⁷ The court concluded that the "defective child" was entitled to recover damages for pain and suffering experienced during her lifetime, as well as special pecuniary damages incurred as a result of her impaired condition.¹⁰⁸

⁹⁹ Id. at 826.

¹⁰⁰ Id.

¹⁰¹ 410 U.S. 113 (1973).

¹⁰² Curlender, 165 Cal. Rptr. at 487.

¹⁰³ Id. (quoting Father and Mother Know Best: Defining the Liability of Physicians for Inadequate Genetic Counseling, 87 YALE L.J. 1488, 1496, 1499 (1978)).

¹⁰⁴ *Curlender*, 165 Cal. Rptr. at 487.

¹⁰⁵ Id. at 829.

 $^{^{106}}$ *Id*.

 $^{^{107}}$ Id.

¹⁰⁸ Id. at 831.

In the wake of the controversial Curlender decision, the state legislature acted immediately to insulate parents from the liability envisioned in the opinion.¹⁰⁹ The viability of the wrongful life cause of action itself, however, was affirmed by the California Supreme Court two years later in the case of Turpin v. Sortini.¹¹⁰ In that case, the court confirmed its agreement that the sanctity of life did not preclude recognition of a wrongful life action, reasoning that "it is hard to see how an award of damages to a severely handicapped or suffering child would 'disavow' the value of life or in any way suggest that the child is not entitled to the full measure of legal and nonlegal rights and privileges accorded to all members of society."111 The court did concede, however, that a jury was unlikely to conclude that the plaintiff's "affliction," deafness, rendered life "worse than not being born at all."¹¹² Although the court awarded special damages because of the "significant medical and financial burden" the child's existence placed on the entire family, the court denied recovery of general damages because the plaintiff never had a chance of being born without her affliction, and it would be impossible to ascertain the extent of an injury in this context.¹¹³

2. Contemporary Cases

Given the progressive extension of abortion rights and the expansion of prenatal genetic testing, the novelty of wrongful birth and wrongful life cases has since worn off. At the time of publication, more than half of all jurisdictions have endorsed a wrongful birth cause of action.¹¹⁴ Those courts consistently cite rationales comparable to those of the early courts, such as deterring negligence in genetic testing, preserving parental autonomy, and compensating parents for the medical expenses associated with dis-

¹⁰⁹ CAL. CIV. CODE § 43.6 (West 2003).

¹¹⁰ 643 P.2d 954 (Cal. 1982).

¹¹¹ Id. at 961–62.

¹¹² *Id.* at 962.

¹¹³ *Id.* at 965.

¹¹⁴ See, e.g., Robak v. United States, 658 F.2d 471 (7th Cir. 1981) (interpreting Alabama law); Daniels v. Delaware, 120 F. Supp. 2d 411 (D. Del. 2000) (interpreting Pennsylvania law); Phillips v. United States, 508 F. Supp. 544 (D.S.C. 1981) (interpreting South Carolina law); Gildiner v. Thomas Jefferson Univ. Hosp., 451 F. Supp. 692 (E.D. Pa. 1978); Moores v. Lucas, 405 So. 2d 1022 (Fla. Dist. Ct. App. 1981) (disapproved of by Kush v. Lloyd, 616 So. 2d 415 (Fla. 1992)); Blake v. Cruz, 698 P.2d 315 (Idaho 1984); Goldberg v. Ruskin, 499 N.E.2d 406 (III. 1986); Arche v. U.S. Dep't of Army, 798 P.2d 477 (Kan. 1990); Reed v. Campagnolo, 630 A.2d 1145 (Md. 1993); Viccaro v. Milunsky, 551 N.E.2d 8 (Mass. 1990); Shelton v. St. Anthony's Med. Ctr., 781 S.W.2d 48 (Mo. 1989); Smith v. Cote, 513 A.2d 341 (N.H. 1986); Berman v. Allan, 404 A.2d 8 (N.J. 1979); Becker v. Schwartz, 386 N.E.2d 807 (N.Y. 1978); Nelson v. Krusen, 678 S.W.2d 918 (Tex. 1984); Naccash v. Burger, 290 S.E.2d 825 (Va. 1982); Harbeson v. Parke-Davis, Inc., 656 P.2d 483 (Wash. 1983); James G. v. Caserta, 332 S.E.2d 872 (W. Va. 1985); *see also* Palo, *supra* note 52, at § 4 (listing jurisdictions that have recognized wrongful birth).

ability.¹¹⁵ Those few jurisdictions that have rejected wrongful birth actions have done so on a variety of grounds, including the belief that the true injury under consideration in these cases is the defective child's life and the determination that deference to the legislative branch is warranted.¹¹⁶

With only three exceptions,¹¹⁷ however, courts have consistently rejected wrongful life actions.¹¹⁸ Many courts, echoing the early cases, have reasoned that life burdened with defects is better than no life at all, and thus that the plaintiff child suffered no legally cognizable injury in being born.¹¹⁹ The conclusion that damages are incalculable under such circumstances continues to be widespread,¹²⁰ and many courts also articulate a variety of public policy reasons that warrant rejection of the tort.¹²¹ In contrast, the three jurisdictions that recognize wrongful life actions—California, New

¹¹⁷ Only California, New Jersey and Washington currently recognize a cause of action for wrongful life. *See, e.g.*, Curlender v. Bio-Science Labs., 165 Cal. Rptr. 477, 489–90 (Cal. Ct. App. 1980); Procanik v. Cillo, 478 A.2d 755, 764 (N.J. 1984); Harbeson v. Parke-Davis, Inc., 656 P.2d 483, 496 (Wash. 1983).

¹¹⁸ See, e.g., Daniels v. Delaware, 120 F. Supp. 2d 411 (D. Del. 2000); Reed v. Campagnolo, 810 F. Supp. 167 (D. Md. 1993), certifying questions to 630 A.2d 1145 (Md. 1993); Gildiner v. Thomas Jefferson Univ. Hosp., 451 F. Supp. 692 (E.D. Pa. 1978) (interpreting Pennsylvania law); Phillips v. United States, 575 F. Supp. 1309 (D.S.C. 1983) (interpreting South Carolina law); DiNatale v. Lieberman, 409 So. 2d 512 (Fla. Dist. Ct. App. 1982); Atlanta Obstetrics & Gynecology Group v. Abelson, 398 S.E.2d 557 (Ga. 1990); Blake v. Cruz, 698 P.2d 315 (Idaho 1984); Goldberg v. Ruskin, 499 N.E.2d 406 (Ill. 1986); Cowe v. Forum Group, Inc., 575 N.E.2d 630 (Ind. 1991); Bruggeman v. Schimke, 718 P.2d 635 (Kan. 1986); Taylor v. Kurapati, 600 N.W.2d 670 (Mich. Ct. App. 1999); Wilson v. Kuenzi, 751 S.W.2d 741 (Mo. 1988); Greco v. United States, 893 P.2d 345 (Nev. 1995); Smith v. Cote, 513 A.2d 341 (N.H. 1986); Karlsons v. Guerinot, 57 A.D.2d 73 (N.Y. App. Div. 1977); Azzolino v. Dingfelder, 337 S.E.2d 528 (N.C. 1985); Ellis v. Sherman, 515 A.2d 1327 (Pa. 1986); Nelson v. Krusen, 678 S.W.2d 918 (Tex. 1984); James G. v. Caserta, 332 S.E.2d 872 (W. Va. 1985); Dumer v. St. Michael's Hosp., 233 N.W.2d 372 (Wis. 1975); see also Palo, supra note 52, at § 20 (listing jurisdictions that have rejected wrongful life cause of action).

¹¹⁹ See, e.g., Lininger v. Eisenbaum, 764 P.2d 1202, 1210 (Colo. 1988); Garrison v. Med. Ctr. of Del., Inc., 581 A.2d 288, 294 (Del. 1989); Blake v. Cruz, 698 P.2d 315, 322 (Idaho 1984); Siemieniec v. Lutheran Gen. Hosp., 512 N.E.2d 691, 702 (III. 1987); Bruggeman v. Schimke, 718 P.2d 635, 642 (Kan. 1986); Kassama v. Magat, 792 A.2d 1102, 1119 (Md. 2002) (listing court decisions in this area); Azzolino v. Dingfelder, 337 S.E.2d 528, 532–33 (N.C. 1985); Flanagan v. Williams, 623 N.E.2d 185, 191 (Ohio Ct. App. 1993); Ellis v. Sherman, 515 A.2d 1329, 1329 (Pa. 1986); Nelson v. Krusen, 678 S.W.2d 918, 925 (Tex. 1984).

¹²⁰ See, e.g., Azzolino, 337 S.E.2d at 533; Becker v. Schwartz, 386 N.E.2d 807, 812 (N.Y. 1978); Dumer v. St. Michael's Hosp., 233 N.W.2d 372, 375–76 (Wis. 1975).

¹²¹ See, e.g., Siemieniec, 512 N.E.2d at 702 (noting public policy of state "to protect and to preserve the sanctity of all human life"); Smith v. Cote, 513 A.2d 341, 352 (N.H. 1986) ("[T]he courts of this State should not become involved in deciding whether a given person's life is or is not worthwhile.").

¹¹⁵ See, e.g., Kassama v. Magat, 792 A.2d 1102 (Md. 2002); Canesi v. Wilson, 730 A.2d 805 (N.J. 1999).

¹¹⁶ See Atlanta Obstetrics & Gynecology Group v. Abelson, 398 S.E.2d 557, 561–63 (Ga. 1990); Azzolino v. Dingfelder, 337 S.E.2d 528, 532 (N.C. 1985) (noting that wrongful birth and wrongful life all "arise from the same alleged negligence and allege as injury the life of the same defective child. Only the impact of the alleged negligence and injury upon the individual plaintiffs differs.").

Jersey, and Washington—soundly reject these rationales. They have concluded instead that life is not always preferable to non-existence, that damages are readily ascertainable, and that principles of deterrence and compensation mandate recognition of the tort.¹²²

In some states, the issue is no longer subject to judicial determination because the legislature has stepped in to resolve the viability of these torts. The statutory result has overwhelmingly been to disavow both actions, at least in cases involving post-conception negligence.¹²³

IV. THERAPEUTIC JURISPRUDENCE: A NEW APPROACH

A. The Significance of Therapeutic Jurisprudence

As the discussion above reflects, United States courts and legislatures have almost universally refused to recognize wrongful life actions. As a result, one might expect to find approval for the status quo among tort scholars and commentators. Such support, however, has been somewhat scarce. Instead, many scholars have argued that actions for both wrongful birth and wrongful life fit comfortably within traditional tort paradigms, notwithstanding the courts' concerns to the contrary.¹²⁴ Why, then, do the legislative and judicial branches fail to take note of these arguments? One of the heralded benefits of the negligence standard is its ability to evolve according to society's ever-changing conceptions of fairness, compensation, and justice. To the extent that tort law reflects this evolution, one would expect the doctrinal trend to be toward broader recognition of wrongful birth and wrongful life actions as prenatal genetic testing becomes the

¹²² See, e.g., Curlender v. Bio-Science Lab., 165 Cal. Rptr. 477, 489–90 (Cal. Ct. App. 1980) (recognizing that compensation is warranted for the harm endured by a wrongful life plaintiff, rejecting the criticism that wrongful life actions attempt "evaluation of a claimed right not to be born," and permitting punitive damages); Procanik v. Cillo, 478 A.2d 755, 764 (N.J. 1984) (concluding that deterrence and compensation goals are better served by permitting recovery by both parents and child); Harbeson v. Parke-Davis, Inc., 656 P.2d 483, 496 (Wash. 1983) (noting that wrongful life actions "foster the societal objectives of genetic counseling and prenatal testing, and will discourage malpractice").

¹²³ See IDAHO CODE § 5-334 (Michie 2003) (precluding actions claiming "person would not have been permitted to have been born alive but would have been aborted"); IND. CODE ANN. § 34-12-1-1 (West 2004) (same); MICH. COMP. LAWS ANN. § 600-2971 (West 2004) (banning both wrongful birth and wrongful life actions); MINN. STAT. ANN. § 145.424 (West 2004) (banning wrongful birth and wrongful life claims alleging a child would have been aborted); MO. ANN. STAT. § 188.130 (West 2004) (same); N.D. CENT. CODE § 32-03-43 (2003) (precluding wrongful life actions); 42 PA. CONS. STAT. ANN. § 8305(B) (West 2004) (precluding wrongful life); UTAH CODE ANN. § 78-11-24 (2003) (banning claims alleging that a person would not have been permitted to have been born alive but would have been aborted). *But see* ME. REV. STAT. ANN. tit. 24, § 2931 (West 2000); Thibeault v. Larson, 666 A.2d 112 (Me. 1995) (interpreting § 2931 to authorize recovery of damages for wrongful birth).

¹²⁴ See supra note 14.

norm.¹²⁵ Instead, the fact that many courts and legislatures have persistently refused to recognize these actions suggests that there are lingering concerns about the impact of these torts on the community of people with disabilities.¹²⁶

Therapeutic jurisprudence provides fresh insight into the potential reasons for judicial and legislative reluctance to acknowledge these actions. In the past twenty-five years, scholars have increasingly embraced therapeutic jurisprudence as a way to look beyond a law's facade and into its actual impact on the mental and physical health of the governed.¹²⁷ Proponents of therapeutic jurisprudence begin with the proposition that the law acts as a social force that brings about both therapeutic and antitherapeutic consequences for individuals in society.¹²⁸ The approach is normative in that it posits that the law should encourage therapeutic effects while minimizing anti-therapeutic effects.¹²⁹ These outcomes are evaluated using the tools of behavioral science to explore the law's impact on individuals' perceptions of physical health and mental well-being.¹³⁰ Proponents acknowledge that the desirability of any law should be assessed according to many factors, but maintain that a law's therapeutic consequences are significant and should be fully analyzed and explored.¹³¹ To the extent that empirical evidence is not available to support or refute theorized consequences, scholars identify areas in need of further research and development in the future.¹³²

In the context of the wrongful birth and life debate, therapeutic jurisprudence is uniquely situated to examine the potential impact of these torts on the well-being of people with disabilities, their families, and society. It is a particularly effective tool when applied against the theoreti-

¹²⁵ See Pilar N. Ossorio, *Prenatal Genetic Testing and the Courts, in* PRENATAL TEST-ING AND DISABILITY RIGHTS, *supra* note 6, at 308, 318 ("The legal system both expresses and reflects social norms.").

¹²⁶ Other scholars have argued that courts' refusal to recognize these actions arises out of their policy judgments rather than adept legal analysis. *See, e.g.*, Kelly, *supra* note 14, at 527–28.

¹²⁷ BRUCE J. WINICK, THERAPEUTIC JURISPRUDENCE APPLIED: ESSAYS ON MENTAL HEALTH LAW 3 (1997). Professor Winick, along with Professor David B. Wexler, pioneered this interdisciplinary approach to legal scholarship in the mental health law field and ultimately coined the term "therapeutic jurisprudence" in the late 1980s. *Id.* at 10–11. Since that time, numerous scholars have adapted this scholarly perspective to far reaching issues in psychiatry, criminology, philosophy, and beyond. *Id.* at 12.

¹²⁸ *Id.* at 3.

¹²⁹ Id. at 4.

¹³⁰ Id. at 6; see also Daniel W. Shuman, Making the World a Better Place Through Tort Law?: Through the Therapeutic Looking Glass, 10 N.Y.L. SCH. J. HUM. RTS. 739, 744 (1993) (noting that therapeutic jurisprudence is particularly well suited to evaluating tort law issues because "[t]ort law's agenda for both deterrence and compensation are therapeutically driven—injury avoidance and restoration of the injured").

¹³¹ David B. Wexler & Bruce J. Winick, *Introduction* to Law in a Therapeutic Key: Developments in Therapeutic Jurisprudence xvii, xvii (David B. Wexler & Bruce J. Winick eds., 1996).

 $^{^{132}}$ Id.

cal backdrop of social disability theory, which deconstructs the meaning and message of disability. Both approaches strongly suggest that any benefits that wrongful birth and wrongful life actions secure for the individual plaintiff come at the cost of demeaning and demoralizing antitherapeutic messages delivered to the community of people with disabilities and to greater society. Consequently, this Article ultimately moves beyond therapeutic jurisprudence to argue that such consequences are not merely factors to be considered in evaluating these torts, but are themselves sufficient to warrant the rejection of these actions.

Problematic in this inquiry is the reality that few sources reflect what people with disabilities actually think about the legal actions of wrongful birth and wrongful life. Although researchers have conducted a few small-scale studies on attitudes of people with disabilities toward prenatal genetic testing generally,¹³³ there is little scholarship that explores attitudes toward the subsequent litigation. It is beyond question that a diversity of opinions exists within the disabled community, and this diversity ensures that not everyone will hear the same messages arising out of wrongful birth and wrongful life suits.¹³⁴ The arguments that follow, however, rely on social science research to the extent that it is available.

B. The False Dichotomy Between Wrongful Birth and Wrongful Life Actions

It is important to note at the outset that the following analysis makes few distinctions between the torts of wrongful birth and wrongful life. One might consider this a surprising approach given that many states recognize wrongful birth actions while simultaneously rejecting those for wrongful life. Such a dichotomy is based on the view that there are very real differences between the two causes of action, including two distinct, morally divergent interests to be protected. Wrongful life is controversial because it identifies the impaired child's life as the operable injury, a concept contrary to many deeply held beliefs in society. Wrongful birth, on the other hand, seems significantly more appealing because the injury identified is the parents' lost choice over the future of the pregnancy.¹³⁵ The

¹³³ See, e.g., Priscilla Alderson, *Down's Syndrome: Cost, Quality and Value of Life*, 53 Soc. Sci. & MED. 627 (2001) (interviewing forty adults with impairments about their opinions of prenatal genetic testing).

¹³⁴ See, e.g., Pamela Fadem et al., Attitudes of People with Disabilities Toward Physician-Assisted Suicide Legislation: Broadening the Dialogue, 28 J. HEALTH POL. POL'Y & L. 977 (2003) (discussing the diversity of opinion in this community on right-to-die issues).

sues). ¹³⁵ See, e.g., Canesi v. Wilson, 730 A.2d 805, 810 (N.J. 1999) (noting that wrongful birth action "is predicated on [the plaintiff's] right to determine for herself whether or not to continue or terminate her pregnancy"); Geler v. Akawie, 818 A.2d 402, 411–12 (N.J. Super. Ct. App. Div. 2003) (allowing recovery for wrongful birth in part because defendant's negligence deprived plaintiff of the option to accept or reject parental relationship with the child).

right of self-determination is among the most highly cherished in a democratic society, and choices relating to pregnancy and childbirth are considered "deeply personal."¹³⁶ A majority of the American public supports laws that exist to protect the exercise of these rights.¹³⁷ This apparent tension is one reason why wrongful life and wrongful birth actions can create such a quandary for disability scholars, many of whom are passionately committed to reproductive choice for all women.¹³⁸ Adrienne Asch, for example, a leading scholar in this field, has expressed at least limited support for wrongful birth on the grounds that "[c]ommitment to access and choice for women commits us to support those women who believe that they were denied testing or adequate counseling."¹³⁹ In contrast, she has expressed "unequivocal opposition to wrongful life suits" because of the life-as-injury rationale.¹⁴⁰ Thus, even some experts assert that the interests at stake in these two actions are significantly different and merit distinct consideration.¹⁴¹

There are meaningful distinctions between wrongful birth and wrongful life with respect to both their focus and the nature of compensation they provide.¹⁴² To label the injury in wrongful birth as lost choice in the abstract, however, is misleading and inaccurate. A close look at this tort makes clear that the impaired child, not the reproductive choice of the mother, is the true injury at stake. In every instance, the failure to diagnose an existing prenatal defect robs the mother of the opportunity to reflect

¹³⁶ Canesi, 730 A.2d at 818; see also Planned Parenthood v. Casey, 505 U.S. 833, 857 (1992) (affirming that constitutional protection extends to liberty interests "relating to intimate relationships, the family, and decisions about whether or not to beget or bear a child"); Provenzano v. Integrated Genetics, 22 F. Supp. 2d 406, 418 (D.N.J. 1998) ("No one can doubt that the decision to terminate a pregnancy is the single most personal and important moral decision that a woman can make during her lifetime.").

¹³⁷ See, e.g., Greg M. Shaw, *The Polls-Trends: Abortion*, 67 PUB. OPINION Q. 407, 409–10 (2003) (noting that between fifty-three to sixty-one percent of Americans consistently support abortion rights).

¹³⁸ See, e.g., Adrienne Asch, *Reproductive Technology and Disability, in* REPRODUC-TIVE LAWS FOR THE 1990s 69, 89 (Sherrill Cohen & Nadine Taub eds., 1989) (arguing that while ethical lines should be drawn for selective abortion following prenatal screening, "we still have to be prepared to respect the right of a particular pregnant woman in a particular situation to decide what she can accept for herself and for her child").

¹³⁹ *Id.* at 93.

¹⁴⁰ *Id.* at 94–95.

¹⁴¹ Many courts, in fact, rely on the language of self-determination in justifying wrongful birth decisions. *See, e.g.*, Haymon v. Wilkerson, 535 A.2d 880, 882 (D.C. 1987) (recognizing wrongful birth because of "the existence of the parental right of choice, and a correlative duty of the health care provider not to deprive the parents of an opportunity to make an informed decision"); Smith v. Cote, 513 A.2d 341, 348 (N.H. 1986) (noting that wrongful birth implicates important personal interests, including "preserving personal autonomy"); *Canesi*, 730 A.2d at 810 ("A wrongful birth cause of action is predicated on a woman's right to determine for herself whether or not to continue or terminate her pregnancy.").

nancy."). ¹⁴² For example, some courts have concluded that damages in wrongful birth extend only until the time that the child reaches adulthood rather than for the child's predicted lifespan. *See, e.g.*, Arche v. U.S. Dep't of Army, 798 P.2d 477, 486 (Kan. 1990) (limiting recovery in wrongful birth action to child's minority).

intelligently on her options and to decide deliberately whether to carry her impaired child to term. Those mothers who would choose to continue the pregnancy are deprived of the opportunity to prepare mentally and physically for the challenges attendant to raising a child with special needs. Instead, the parents first learn of the child's impairment at the time of birth, when their emotions and expectations are likely to be highest.¹⁴³ If lost choice is truly the injury, then this loss occurs at the moment that the door to an abortion has closed, regardless of which choice ultimately would have been exercised. Consequently, the mother who would have aborted and the mother who would have continued the pregnancy have suffered the identical negligence and the identical injury, although not identical damages.¹⁴⁴

According to the courts, however, the remedies of these mothers are not identical. In order to show causation in wrongful birth cases, courts require a mother to testify that she would have had an abortion or would have prevented conception if properly informed of her child's defect.¹⁴⁵ In

¹⁴³ See, e.g., Berman v. Allan, 404 A.2d 17 (N.J. 1979) (Handler, J., concurring in relevant part and dissenting in part) ("Without doubt, expectant parents, kept in ignorance of severe and permanent defects affecting their unborn child, suffer greatly when the awful truth dawns upon them with the birth of the child.").

¹⁴⁴ The extent of compensation would differ between these two categories. The mother who would have continued her pregnancy would be entitled to recover her emotional distress damages attendant to her lost choices. The mother who would have chosen to abort the child would also be entitled to the special medical expenses attendant to raising a child with disabilities to adulthood. *Cf.* Provenzano v. Integrated Genetics, 22 F. Supp. 2d 406, 419 (D.N.J. 1998) (concluding that plaintiff who offered no evidence as to whether she would have sought an abortion would likely be entitled only to emotional distress damages, and not medical expenses for the child).

¹⁴⁵ See, e.g., Keel v. Banach, 624 So. 2d 1022, 1027 (Ala. 1993) (causation requires a showing that "either the child would not have been conceived or the pregnancy would have been terminated"); *Haymon*, 535 A.2d at 882 (plaintiff satisfied cause of action in part because she testified she would have terminated fetus if properly informed of defect); Thornhill v. Midwest Phys. Ctr., 787 N.E.2d 247, 254 n.2 (III. App. Ct. 2003) (noting that "[o]ther jurisdictions also recognize that to establish proximate cause in a wrongful birth action, the parents must establish that but for the physician's negligence, they would have terminated the pregnancy or avoided conception"); *Smith*, 513 A.2d at 347; *Canesi*, 730 A.2d at 813 (holding that in a wrongful birth action, "proximate caus[e] is satisfied by showing that an undisclosed fetal risk was material to a woman in her position; the risk materialized, was reasonably foreseeable and not remote in relation to the doctor's negligence; and, had plaintiff known of that risk, *she would have terminated her pregnancy*" (emphasis added)); *see also* Pollard, *supra* note 14, at 344 ("Cause in fact is established by the mother's testimony that but for the failure to inform her of potential or actual birth defects, she would have avoided conception or would have had an abortion.").

One reported decision has specifically held that wrongful birth is actionable without such testimony. *See Provenzano*, 22 F. Supp. 2d at 416–18. However, this federal decision was issued prior to the New Jersey Supreme Court's decision in *Canesi* which stated that wrongful birth requires testimony that the mother would have sought an abortion or exercised preventative conception. *Canesi*, 730 A.2d at 813. Following *Canesi*, the *Provenzano* court revisited the issue and concluded that special damages could not be recovered. Apparently ignoring *Canesi*, it nevertheless maintained that emotional distress damages were compensable, a fact not disputed by the parties. Provenzano v. Integrated Genetics, 66 F. Supp. 2d 588, 593 (D.N.J. 1999); *cf.* Shelton v. St. Anthony's Med. Ctr., 781 S.W.2d 48, 49 (Mo. 1989) (concluding Missouri statute precluding actions alleging "that but for the negligent conduct of another, a child would have been aborted," did not preclude mother's

these cases, it is not lost choice in the abstract that is actionable, but the lost opportunity to abort the impaired child or to prevent conception. As in the wrongful life cases, the embodiment of the mother's injury is the child with defects who exists in the wake of the physician's negligence,¹⁴⁶ but here this message arises by implication rather than as a fundamental element of the cause of action. It is precisely because of this subtlety, however, that wrongful birth merits even more exacting scrutiny than wrongful life. The misleading rhetoric of choice and opportunity has allowed the tort of wrongful birth to garner widespread legal recognition, but has obscured its anti-therapeutic consequences.

It might be argued that the dichotomy between wrongful birth and wrongful life actions is consistent with general tort law principles, as reflected in the required elements of an informed consent cause of action. Informed consent actions protect patients' rights to bodily integrity by requiring physicians to disclose certain information relating to proposed medical procedures.¹⁴⁷ Some courts have likened wrongful birth cases to these more traditional actions in medical malpractice because both torts implicate the right of self-determination.¹⁴⁸ To recover for the absence of informed consent, the plaintiff must show that the physician failed to communicate information regarding a proposed medical procedure that a reasonable patient would have considered material or, in other jurisdictions, that a reasonable physician would have disclosed.¹⁴⁹ In most jurisdictions, causation requires a showing that both a reasonable patient and the plaintiff patient would have chosen a different treatment or course of action if

medical malpractice action for emotional distress based on physician's failure to interpret ultrasound results correctly).

¹⁴⁶ See, e.g., Palo, *supra* note 52, at 55 ("Wrongful birth actions are brought by parents *to recover for the birth of an unhealthy child*. The parents' right to recover is based on the defendant's negligent deprivation of the parents' right not to conceive the child or to prevent the child's birth.") (emphasis added).

¹⁴⁷ DAN B. DOBBS, THE LAW OF TORTS § 250, at 653 (2000). Exceptions to disclosure exist in cases where the patient is incompetent or where the physician can demonstrate that the knowledge itself would harm the patient. *Id.* at 656. Subjects of disclosure include such matters as the risks of the procedure, the risks of foregoing the procedure, and the prognosis if treatment is accepted. *Id.* at § 251, at 658.

¹⁴⁸ See, e.g., Provenzano v. Integrated Genetics, 22 F. Supp. 2d 406, 415 (D.N.J. 1998) ("Wrongful birth is a distinct cause of action from that of informed consent, but both doctrines share notable similarities."); *Canesi*, 730 A.2d at 812 ("Like a cause of action for wrongful birth, a claim based on the doctrine of informed consent is predicated on the patient's right to self-determination."); Geler v. Akawie, 818 A.2d 402, 416 (N.J. Super. Ct. App. Div. 2003) (noting that "a wrongful birth case such as this closely resembles relevant elements of one based upon the doctrine of informed consent, since each is premised upon the patient's right of self-determination").

¹⁴⁹ See, e.g., Canterbury v. Spence, 464 F.2d 772, 791 (D.C. Cir. 1972). Notably, for those courts adopting the objective test in the wrongful birth context, "the scope of disclosure . . . is not coextensive with or measured by the woman's constitutional right to decide the fate of her pregnancy. . . . [Instead] [t]he physician's duty to warn is . . . limited by what risks a reasonably prudent patient in the plaintiff's position would consider material to her decision." *Canesi*, 730 A.2d at 815–16.

the information had been properly communicated.¹⁵⁰ If the plaintiff would have made the same treatment decision despite the desired disclosure, then the plaintiff has failed to demonstrate an injury, and there is no recovery.¹⁵¹ Thus, the patient who would have made a different choice and the patient who would have made the same choice are treated differently for purposes of recovery in informed consent cases, even though they were both victims of identical negligence and suffered an equal invasion of the right to bodily integrity. It may seem consistent to conclude that the plaintiff in a wrongful birth action who would have opted for a different result (i.e., an abortion or contraconception) should have a claim while she who would have chosen the same result (i.e., a live birth) should not.¹⁵²

However, the similarities of wrongful birth and informed consent actions should not overshadow the significant differences between them, including the divergent harms they involve and the disparate damages they award.¹⁵³ A typical informed consent action involves a physician's failure to disclose a risk of complications associated with surgery.¹⁵⁴ In this scenario, the undisclosed risk is one that affects only the plaintiff's personal health. Because the undisclosed risk in wrongful birth is the birth of a child with defects, however, wrongful birth presents unique public policy challenges and implications for people with disabilities and society generally. The requisite assertion that a mother would have aborted her child or prevented conception results in powerful anti-therapeutic consequences

If appropriate scans or tests are *not* offered, a woman's consent will not be in issue. If appropriate tests *are* offered, although she must consent for these not to constitute a battery (assuming touching is involved), the woman herself is not being treated. Further, the risks of which she may negligently not be advised are risks pertaining to the *fetus* discovered as a *result* of the testing; they are not risks inherent in the testing.

Rosamund K. Scott, Prenatal Screening, Autonomy and Reasons: The Relationship Between the Law of Abortion and Wrongful Birth, 11 MED. L. Rev. 265, 291 (2003).

¹⁵⁰ See DOBBS, supra note 147, at § 250, at 657; see also Canterbury, 464 F.2d at 790–91.

¹⁵¹ See Canesi, 730 A.2d at 813.

¹⁵² See id.

¹⁵³ See id. One of the difficulties in applying an informed consent analysis to wrongful birth is that the resultant "harm" does not necessarily "arise out of any affirmative violation of the mother's physical integrity." Karlsons v. Guerinot, 394 N.Y.S.2d 933, 939 (App. Div. 1977); see also Reed v. Campagnolo, 630 A.2d 1145, 1152–53 (Md. 1993) (recognizing wrongful birth while rejecting comparable action based on informed consent because no affirmative act was involved). Professor Rosamund Scott has noted these difficulties, writing:

¹⁵⁴ See, e.g., Canterbury, 464 F.2d at 776–78 (action for failure to reveal one percent chance of paralysis from disk surgery); William J. McNichols, *Informed Consent Liability in a "Material Information" Jurisdiction: What Does the Future Portend?*, 48 OKLA. L. REV. 711, 713 (1995) ("[M]ost informed consent cases involve situations where the patient claims that she was inadequately informed about the risks connected with treatment recommended by her physician, which would constitute a medical battery had she not consented.").

for society that are not present in a traditional informed consent action. Unlike wrongful birth actions, informed consent actions are largely personal matters with personal ramifications that do not implicate the civil rights of others in society.¹⁵⁵

Moreover, even if a wrongful birth action is equivalent to an informed consent action, the reality of wrongful birth's focus on the impaired child rather than on the mother's reproductive decision remains inescapable. As courts have articulated, a mother's right to prenatal information in a wrongful birth context is not coextensive with her right to an abortion.¹⁵⁶ A mother in the early stages of pregnancy may elect to have an abortion for any reason, including a severe defect, a minor defect, or no defect whatsoever in her fetus.¹⁵⁷ However, she may not pursue a wrongful birth action based on each of these reasons. Instead, as courts have repeatedly stated, the mother has a viable case for wrongful birth only when her child is born with severe defects.¹⁵⁸ Courts recognize no cause of action for the failure to identify or disclose impairments that courts consider less severe, but have not explicitly addressed where this distinction factors into the wrongful birth analysis.¹⁵⁹

In a wrongful birth action, the severity of the condition is implicitly considered in determining the scope of the physician's duty to disclose. In approximately half of all jurisdictions, this duty is measured by what a reasonable physician would disclose based on customary medical practice in the community, which itself considers the incidence and severity of the impairment for which testing is offered.¹⁶⁰ In the other half of jurisdictions, the duty is satisfied when a reasonable patient in the plain-tiff's position would find the risk material to her decision to consent.¹⁶¹ In

¹⁵⁵ Of course, informed consent actions do impact the community to the extent that they influence the cost of medical care for others and deter future incidents of negligence. Compensating the individual in such cases, however, does not come at a therapeutic cost to others. *See* discussion *infra* Part IV.C.

¹⁵⁶ See Canesi, 730 A.2d at 815.

¹⁵⁷ See Planned Parenthood v. Casey, 505 U.S. 833, 846 (1992); Roe v. Wade, 410 U.S. 113, 163–64 (1973).

¹⁵⁸ See, e.g., Arche v. U.S. Dep't of Army, 798 P.2d 477, 480–81 (Kan. 1990) (noting that Kansas only recognizes wrongful birth claims when the "child has such gross deformities, not medically correctable, that the child will never be able to function as a normal human being"); Smith v. Cote, 513 A.3d 341, 344 (N.H. 1986) (noting wrongful birth is "a claim brought by the parents of a child born with *severe* defects" (emphasis added)); *see also* Kelly, *supra* note 14, at 564–65 (noting that "[g]enetic counseling torts make sense in cases of severe genetic defects. The absence of a preferred trait does not cry out for judicial redress in the same way severe genetic defects do." (footnote omitted)); Scott, *supra* note 153, at 306–07 (describing how wrongful birth actions are tied to the significance of the disability in question).

¹⁵⁹ See Ossorio, supra note 125, at 316.

¹⁶⁰ See *id.* at 314; *see also* Scott, *supra* note 153, at 298 (noting that the incidence and significance of a disorder "are key factors" in setting the professional standard of disclosure).

¹⁶¹ See Ossorio, supra note 125, at 314; Scott, supra note 153, at 298–99; see also Canesi, 730 A.2d at 816 ("The physician's duty to warn is thus limited by what risks a

these jurisdictions, the severity or materiality of the risk will necessarily be assessed, at least in part, by looking to the functional limitations experienced by the child in question and the burdens the child places upon the mother. The more limiting the impairment is deemed to be, the more likely the law will mandate disclosure. As in wrongful life actions, the focus thus returns to the desirability of the impaired child rather than the reproductive choice of the mother.

Under a physician-centered standard, jurors will be bound by medical experts' testimony regarding the professional scope of disclosure.¹⁶² Under the patient-centered standard, however, jurors are given the power to determine which defects are considered so horrible that a reasonable person might choose to abort on that basis.¹⁶³ Given the fact that "a significant proportion" of people worldwide favor "allowing prenatal diagnosis and selective termination for conditions such as two missing fingers, short stature, obesity, or even limited musical talent," the outcome of the jury's analysis may be disturbingly biased.¹⁶⁴ Consequently, analogizing a wrongful birth action to a traditional informed consent action does not alter the fact that wrongful birth cases, like wrongful life cases, adopt a highly subjective and problematic focus on the impaired child.

Finally, it is worth noting that this Article's collective treatment of wrongful birth and wrongful life is consistent with the approach adopted by many scholars and courts that advocate the recognition of wrongful life actions. These authors reason that a regime that denies or grants relief to a disabled child based solely on the fortuitous circumstance of his parents' availability to sue makes little sense.¹⁶⁵ On the same logic, because wrongful birth and wrongful life actions result in equally anti-therapeutic consequences for people with disabilities, neither action should be recognized.

reasonably prudent patient in the plaintiff's position would consider material to her deci-

sion."). ¹⁶² See Dobbs, supra note 147, at § 250, at 655; see also George P. Smith, II, The Vagaries of Informed Consent, 1 IND. HEALTH L. REV. 109, 119 (2004) (noting that in determining the scope of professional disclosure, "a jury panel will seek to decide the issue in conflict by comparing the testimony of competing medical experts").

¹⁶³ Cf. Azzolino v. Dingfelder, 337 S.E.2d 528, 541 (N.C. 1985) (Martin, J., dissenting in relevant part) (noting that wrongful birth would not permit recovery for "fanciful reasons" because it is predicated on what a "reasonable person" would do).

¹⁶⁴ Wolfram Henn, Consumerism in Prenatal Diagnosis: A Challenge for Ethical Guidelines, 26 J. MED. ETHICS 444, 445 (2000).

¹⁶⁵ See, e.g., Turpin v. Sortini, 643 P.2d 954, 965 (Cal. 1982) ("[I]t would be illogical and anomalous to permit only parents, and not the child, to recover for the cost of the child's own medical care."). But see, Jackson, supra note 14, at 609 (arguing that courts should recognize wrongful life actions but not wrongful birth actions).

C. The Disabling Messages of Wrongful Birth and Wrongful Life Actions

At first impression, wrongful birth and life actions may seem therapeutically valuable to the community because they provide individuals with a consistent source of funding for the high cost of medical care that often accompanies severe impairments. Several courts and commentators have offered this rationale in support of both torts.¹⁶⁶ These authors argue that whatever the intangible effects of such actions on the psyche and wellbeing of individuals with disabilities, there is a tangible need for money to secure the services that the litigants may desperately need.¹⁶⁷ The families of disabled individuals will clearly suffer in the absence of compensation, because the stress, concern, and fear for each child's future are unlikely to abate in the absence of a consistent and secure source of funding. As a result, these authors maintain that the transfer of wealth effected by wrongful birth and life suits is both beneficial to the litigants and consistent with one of the fundamental goals of tort law—loss spreading.¹⁶⁸

Such logic is compelling at the individual level. There is unquestionably a serious need for additional resources and assistance to be directed toward individuals with disabilities, and society should carefully scrutinize any policy that forgoes a potential avenue of relief. However, providing desirable assistance via wrongful life and birth actions reflects the benevolent paternalism embedded in the medical model of disability, in which the nondisabled "assume the role of protectors, guides and spokespersons for disabled citizens" without ever challenging the "attitudinal discrimination" in society.¹⁶⁹ A close look at the precursors to relief in wrongful birth and wrongful life litigation makes clear that any benefits secured come at great expense both to the litigants involved and to the community of people with disabilities.

Wrongful birth and life actions do not offer compensation to all individuals who suffer as a result of a defendant's negligence, nor do they compensate all individuals with disabilities in need of relief. Instead, assistance is provided only to those willing to openly disavow their self-worth and dignity. Children must testify that they should have been aborted by their mothers. Mothers must testify that they would have aborted their children or prevented conception if only the defendant had presented

¹⁶⁶ See, e.g., Belsky, *supra* note 14, at 236 (noting that such compensation is "essential to alleviate the burden that would otherwise be imposed upon the child's parents and the state to support the child during her lifetime"); Kelly, *supra* note 14, at 567; Jackson, *supra* note 14, at 611 (noting that a cause of action for wrongful life is justified in part because it provides "justice, compassion and the necessary support" to children with disabilities).

¹⁶⁷ See, e.g., Procanik v. Cillo, 478 A.2d 755, 763 (N.J. 1984) (noting that courts should "seek only to respond to the call of the living for help in bearing the burden of their affliction").

¹⁶⁸ See Pollard, supra note 14, at 336.

¹⁶⁹ Hahn, *supra* note 18, at 106–07.

them the opportunity.¹⁷⁰ No matter how compelling the need, or how gross the negligence involved, no assistance will be extended to the family who would have chosen to embrace or simply accept the impaired child prior to his birth. Although the lost choice identified as the injury in wrongful birth claims is identical between the mother who would have aborted and the mother who would have decided to carry the impaired child to term, recovery is all or nothing. Against this background, the desperate parent is placed in an untenable position—either she must deny needed medical care for her child or disavow his very existence in open court in order to secure financial assistance.¹⁷¹ The "unseemly spectacle" that follows does much to explain the distaste with which many American and international courts view wrongful birth and life actions.¹⁷² Contrary to the rationale articulated in some cases, the existing approach to compensation is neither logical nor consistent with basic notions of human dignity or justice. Whatever the ultimate result of litigation, those involved are likely to feel abused and diminished rather than empowered and vindicated.

Significantly, this insidious message of disparagement is not whispered innuendo that only scholars and the particularly observant may overhear in the nuances of litigation. Instead, in both wrongful birth and life cases, it is a message openly voiced by the mother of a living child.¹⁷³ In some cases, parents have even sought to introduce their children as exhibits in litigation.¹⁷⁴ This fact exemplifies the problems posed by these legal actions that are not presented by the mere existence of prenatal genetic testing and open access to abortion. A woman's right to reproductive freedom includes the right to make unpopular choices regarding the

¹⁷² Moorman v. Walker, 773 P.2d 877, 889 (Wash. Ct. App. 1989).

¹⁷⁰ See, e.g., Rossi v. Somerset Ob-Gyn Assocs., 879 F. Supp. 411 (D.N.J. 1994) (granting judgment as a matter of law to defendants in wrongful life case where parents would not testify that they would have aborted if properly informed of their child's defect); Thornhill v. Midwest Phys. Ctr., 787 N.E.2d 247, 254 n.2 (III. App. Ct. 2003); Canesi v. Wilson, 730 A.2d 805, 813 (N.J. 1999) (noting that wrongful birth cases require testimony that parents would have chosen abortion); *see also* Palo, *supra* note 52, § 19 ("The most important element of proof in establishing a causal connection between the defendant's conduct and the birth of a child is the testimony of the child's parents . . . that [they] would have decided not to have the child had they known the child would be unhealthy; the parents' testimony carries the greatest weight.").

¹⁷¹ Some scholars have theorized that "healing entails empowerment," and that the tort system provides plaintiffs with such healing by "enlist[ing] the coercive power of the judicial system to reshape the power imbalance in their relationships" with defendants. Daniel W. Shuman, *The Psychology of Compensation in Tort Law, in* LAW IN A THERAPEUTIC KEY, *supra* note 131, at 433, 447–48 (detailing scholarship in this area). Because wrongful birth and wrongful life plaintiffs must actually denigrate themselves in order to secure recovery, the restoration of "balance" is unlikely. Instead, the most plausible outcome is further injury by the reinforcement of imbalances. *Cf. id.* (discussing the impact of feminist theory on perceptions of fault-based compensation in tort law).

¹⁷³ Not all children with disabilities are living at the time of litigation. Each case, however, involves the prerequisite of a live birth of a child with disabilities.

¹⁷⁴ See, e.g., *Thornhill*, 787 N.E.2d at 261 (noting that lower court did not abuse its discretion in refusing plaintiff's request to allow child to appear in courtroom as a "demonstrative exhibit").

future of her pregnancy.¹⁷⁵ To introduce burdensome government control over these choices, such as prohibiting eugenic abortion entirely, impermissibly injects community ethics into deeply private decision-making about the mother's best interests. In contrast, wrongful birth and wrongful life actions entail the opposite approach—a community pronouncement, via a government institution, that an individual's life with impairments is worse than nonexistence, or that a reasonable person would have aborted a now-living child. Although some scholars are skeptical of the ability of individual acts to communicate any consistent message to greater society,¹⁷⁶ this state-sanctioned message is an expression of public policy that implicates not only the immediate individuals involved, but the community of people with disabilities and other affected individuals.¹⁷⁷

The reverberating impact of such statements on the well-being of individuals with disabilities and society is potentially widespread. When a mother disavows the worthiness of her child's life in open court, those who lack first-hand knowledge of the child will naturally trust the mother's judgment. The anti-therapeutic consequences of the mother's pronouncement are correspondingly amplified, since the disparagement is voiced from within the community of people with disabilities and cannot be discounted by others as mere ignorance or prejudice.¹⁷⁸ Whereas the shared stigmatization of all people with disabilities serves as a uniting force under the civil rights model of disability, here it pits the community against itself in the drive for compensation.

It is undoubtedly true that the anti-therapeutic effect of this message on the child may be muted by his or her inability to comprehend the na-

¹⁷⁵ See, e.g., Planned Parenthood v. Casey, 505 U.S. 833, 916 (1992).

¹⁷⁶ See, e.g., Nancy Press, Assessing the Expressive Character of Prenatal Testing: The Choices Made or the Choices Made Available?, in PRENATAL TESTING AND DISABILITY RIGHTS, supra note 6, at 214 (describing several scholars' "well-argued objections" to the argument that prenatal genetic testing sends a message to society about people with disabilities).

¹⁷⁷ See, e.g., John A. Robertson, Genetic Selection of Offspring Characteristics, 76 B.U. L. REV. 421, 462 (1996). Professor Robertson discusses the distinction between actions that affect public spheres of life and actions that affect private spheres of life. He argues that although discrimination should not be tolerated in the public sphere, it may be "morally relevant in the private sphere" because it "involve[s] the intimate and the personal." *Id.* This dichotomy suggests that permitting widespread genetic testing and open access to abortion is not inconsistent with refusing to recognize wrongful life and wrongful birth actions. At the same time, it is problematic that wrongful birth and wrongful life actions force a mother to announce her decision publicly only because the defendant physician or laboratory deprived her of the opportunity to do so privately. Nevertheless, as the remainder of this Section demonstrates, announcing a thwarted desire to abort in a formally sanctioned legal action inevitably transforms personal pain into a community experience with community implications that must be taken into consideration.

¹⁷⁸ Cf. Adrienne Asch, Why I Haven't Changed My Mind about Prenatal Diagnosis, in PRENATAL TESTING AND DISABILITY RIGHTS, *supra* note 6, at 234, 251 ("Why should playmates' parents, the neighbors, or the schools change to incorporate existing children with disabilities if families and professionals, government, insurance companies, and science work as hard as they do to avoid the births of people who will have these conditions? Where do we first learn justice, sharing, and cooperation, but in the family?").

ture of the assertions in play, either because of extreme youth or the impairment in question.¹⁷⁹ But it is precisely when the most vulnerable members of society are unaware of potential danger that society should protect them most vigorously. Moreover, the anti-therapeutic messages of wrongful birth and wrongful life actions will be heard and comprehended by others in the court proceedings and beyond, thus imposing anti-therapeutic consequences on persons other than the individual litigants.¹⁸⁰ Testimony articulated in open court is ultimately enshrined by court reporters and revisited by the media and scholars thereafter.¹⁸¹ Whether or not the child involved is diminished by knowledge of this testimony, the anti-therapeutic consequences of its transmission to greater society are significant and represent an entrenchment of the medical model of disability.

This damage is not limited to the litigants in court. Wrongful birth and life actions transmit a potentially powerful message to all people with disabilities: as a matter of law, your impairment, standing alone, is a sufficient basis upon which to evaluate the quality of your life.¹⁸² Judicial recognition of such actions, particularly in the wrongful life context, is akin to a state-sanctioned acknowledgement that the community of one's peers may legitimately evaluate whether an individual with impairments has a rightful place in the community and whether his functional limitations are sufficiently disruptive to warrant the preference of nonexistence.¹⁸³ This

¹⁷⁹ This, however, will not always be the case. *See, e.g.*, Linda Ward et al., *Difference and Choice: Exploring Prenatal Genetic Testing and the Use of Genetic Information with People with Learning Difficulties*, 30 BRIT. J. LEARNING DISABILITIES 50 (2002) (describing a small study of people with learning disabilities, including one individual with Down syndrome and another with fragile X syndrome, discussing their opinions on issues including prenatal genetic testing and abortion).

¹⁸⁰ Cf. Shuman, supra note 130, at 739 (noting that tort law "shapes the way we relate to each other both in public and in private").

¹⁸¹ See, e.g., Edward A. Dauer, A Therapeutic Jurisprudence Perspective on Legal Responses to Medical Error, 24 J. LEGAL MED. 37, 38 (2003) (noting that malpractice litigation "is highly public, including linkages through federal and, in some instances, state laws to mandated disclosure of the facts of the error and the claim").

¹⁸² Concerns about this type of evaluation have been expressed by people with disabilities in comparable settings. In responding to a study about the attitudes of people with disabilities to physician-assisted suicide, for example, one person with a congenital disability stated:

I can't even think about physician-assisted suicide because it scares me—someone making a decision based on someone else's quality of life. In the past, when I was working [in] hospitals . . . I would hear other people ask [referring to people with disabilities], "What kind of life can they have?" That scares me.

Fadem et al., *supra* note 134, at 988; *cf.* Marsha Saxton, *Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion, in* **PRENATAL TESTING AND DISABILITY RIGHTS**, *supra* note 6, at 147, 161 (arguing, in the context of prenatal genetic testing generally, that "the diagnostic test reduces the entire set of human characteristics to one—the 'flawed, imperfect' part We in the disability community resist the notion that our humanness can be evaluated and then reduced to a flawed gene.").

¹⁸³ See Patrick J. Kelley, Wrongful Life, Wrongful Birth, and Justice in Tort Law, 1979 WASH. U. L.Q. 919, 939 (1979) (noting that the objective inquiry into whether nonexis-

anti-therapeutic message challenges fundamental ideals "basic to our constitutional order": that each living person in the United States is "equal under the law" and by right has a place in society.¹⁸⁴ The required elements of wrongful birth and wrongful life actions communicate that these basic ideals do not hold true for those with genetic defects. Instead, these torts broadcast the medical model's message of the biological inferiority and "otherness" of impaired individuals.¹⁸⁵ Disability is reinforced as an inherent personal trait, and biology, once again, becomes destiny.¹⁸⁶

Some may argue that the message of litigation here is no different than that of other torts, and thus no more damaging. Courts routinely assign value to people's lives in tort actions like wrongful death, where recovery varies according to the decedent's age, class, potential disability, and "other characteristics that seem morally irrelevant to a person's dignitary worth."¹⁸⁷ Although there is merit to this position, important qualitative differences distinguish the messages of wrongful birth and wrongful life actions from those of typical tort actions. One such difference is the nature of the testimony that the child and her mother are required to give. Another difference is that, in the quintessential negligence case, the defendant's act or failure to act caused a positive injury to the plaintiff. Awarding damages for that injury properly recognizes that the defendant deprived the plaintiff of something of value, whether his life, his emotional equanimity, or his freedom from bodily harm. Although admittedly the amount of damages will differ based on the characteristics of the plaintiff, all awards in some respect endorse the value of the plaintiff's life and his right to exist free from interference from others.¹⁸⁸

tence is preferable to life in a wrongful life case "contradicts the fundamental principle in our society that the life of each human being, whether handicapped or not, is valuable and deserves respect and protection"); *cf*. Smith v. Cote, 513 A.2d 341, 353 (1986) ("The necessary inquiry is objective, not subjective; the court cannot avoid assessing the 'worth' of the child's life.").

¹⁸⁴ Smith, 513 A.2d at 352; cf. Schloss v. Miriam Hospital, No. C.A. 98-2076, 1999 WL 41875, at *5 (R.I. Super. Jan. 11, 1999) ("The moral implications of allowing the child's claim are philosophically staggering: What moral obligation does one person (the physician) have to another (the child) to have prevented the child's suffering by preventing the child from living? Should any person knowingly or negligently shorten even the most miserable life by so much as a moment?").

¹⁸⁵ See Hahn, supra note 18, at 103 (noting that "[d]isabled persons probably comprise the only group that has not yet been successful in refuting accusations of biological inferiority"); cf. Arche v. U.S. Dep't of Army, 798 P.2d 477, 480–81 (Kan. 1990) (permitting recovery for wrongful birth where "the child has such gross deformities, not medically correctable, that the child will never be able to function as a normal human being" (emphasis added)).

¹⁸⁶ This problem also arises out of the increasing number of prenatal tests available. Professor Abby Lippman has written about the "geneticization" of health as a result of such tests, in "which differences between individuals are reduced to their DNA codes, with most disorders, behaviors and physiological variations defined, at least in part, as genetic in origin." Abby Lippman, *Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*, 17 AM. J.L. & MED. 15, 19 (1991).

¹⁸⁷ Ossorio, *supra* note 125, at 320.

¹⁸⁸ See, e.g., Leslie Bender, Feminist (Re)Torts: Thoughts on the Liability Crisis, Mass

Recovery in wrongful birth and wrongful life suits, on the other hand, does not affirm the value of the plaintiff's life—instead, it negates it. This effect is most apparent in the wrongful life context, where recovery turns on the jury's conclusion that life with impairments is objectively worse than non-existence.¹⁸⁹ Imagine, for example, a case involving a plain-tiff who is rendered a quadriplegic following a car accident caused by the defendant's negligence. In this case, an award of damages verifies the real loss that the plaintiff experienced as a result of the defendant's actions. No one is likely to conclude that this award is the functional equivalent of a jury determination that the plaintiff would be better off now if he were dead or had never existed. Accordingly, although negative messages may flow from traditional tort actions, these messages are not of the same magnitude as those created by wrongful birth and wrongful life actions.

The literature written by people with disabilities confirms that "[t]hese technologies make us feel devaluated as human beings," and that many do in fact receive the message that "[y]our birth was a mistake. Your family and the world would be better off without you alive."¹⁹⁰ It is difficult for "even a sophisticated, thoughtful person" to maintain a positive self-image in the face of such messages, especially when heard against the backdrop of a lifetime of stigmatization.¹⁹¹ Adrienne Asch has explained this struggle as follows:

For people with disabilities to work each day against the societally imposed hardships can be exhausting; learning that the world one lives in considers it better to "solve" problems of disability by prenatal detection and abortion, rather than by expending those resources in improving society so that everyone—including those people who have disabilities—could participate more easily, is demoralizing. It invalidates the effort to lead a life in an inhospitable world.¹⁹²

Although most of this literature discusses the consequences of prenatal genetic testing generally, the anti-therapeutic message is actually amplified in the context of wrongful birth and wrongful life litigation because most of these cases involve post-conception rather than pre-conception negli-

Torts, Power, and Responsibilities, 1990 DUKE L.J. 848, 875 (1990) ("Denying legal recognition of the harm [of intangible injuries caused by defendant's negligence] by failing to award money or devise alternative 'compensation' sends negative messages to plaintiffs about the importance or value of their lives, autonomy, and the range of their suffering.").

¹⁸⁹ Because this evaluation arises by implication in the wrongful birth context, it is equally true there.

¹⁹⁰ Saxton, *supra* note 182, at 160 (discussing the "remarkable congruence in the writing about this issue coming from people with disabilities around the world").

¹⁹¹ Id. at 152.

¹⁹² Asch, *supra* note 178, at 240.

gence.¹⁹³ The causal inquiry is thus not the prevention of a theoretical child with disabilities, but instead the active termination of a specific, identified fetus with impairments.¹⁹⁴ One could logically interpret legal recognition of such actions as akin to a public endorsement of eugenic abortion in lieu of the child's life with disabilities. Whether or not the distinction between post-conception and pre-conception negligence has any legal validity,¹⁹⁵ the distinction is likely to personalize the debate for individuals with disabilities and magnify the anti-therapeutic messages that arise out of litigation.¹⁹⁶

The disabling messages of wrongful birth and wrongful life torts also reverberate with the families of children with disabilities. Of particular concern is the moral blame and condemnation that may attach to the parents of all children with severe disabilities when courts choose to recognize wrongful birth and wrongful life suits. Once a court acknowledges that a child's existence can constitute a legal injury, parents who knowingly choose to carry a similarly afflicted child to term have "harmed" their child just as seriously as a negligent laboratory or doctor.¹⁹⁷ In fact, one could argue that these parents are more morally culpable than a negligent laboratory or physician because their choice to give birth to a disabled child was at some level intentional rather than the result of inadvertence or mistake.

Some may argue that it is more plausible that society will continue to view these parents with sympathy rather than condemnation even if wrongful birth and wrongful life actions gain increased recognition. Nonetheless, the court in *Curlender* did not merely hint at the culpability of

¹⁹³ Cf. Asch, supra note 138, at 82 ("What differentiates ending pregnancy after learning of impairment from striving to avoid impairment before life has begun is this: At the point one ends such a pregnancy, one is indicating that one cannot accept and welcome the opportunity to nurture a life that will have a potential set of characteristics—impairments perceived as deficits and problems.").

¹⁹⁴ See, e.g., Kelley, *supra* note 183, at 956 ("[T]he parents' revealed intention to abort is a more serious threat to the child's sense of worth and his relationship with his parents than the parents' revealed intention to avoid conception").

¹⁹⁵ One's position on this issue may hinge on one's belief as to when life begins, a debate that far exceeds the scope of this Article. Suffice it to say that the distinction between pre-conception and post-conception testing is, to some extent, parallel to society's appreciation of the distinction between birth control and abortion. Few in society deem the active use of birth control to be an aggressive act. Abortion, by definition, involves the active termination of a specific fetus.

¹⁹⁶ See Scott, supra note 153, at 320 ("The problem . . . is that while there is a conceptual distinction between the disvalue of the impairment on the one hand and the value of a life of someone with that impairment on the other, in the practice of prenatal screening and abortion the impairment and the actual life are both avoided *one and the same*.").

¹⁹⁷ See, e.g., Asch, supra note 138, at 88 (noting that in cases where a fetus is diagnosed as having impairments like Down syndrome, spina bifida, or cystic fibrosis, among others, most people would conclude that "failure to abort is cruel to the potential child, destructive to the family, socially irresponsible, and possibly immoral"). Such feelings of shame and guilt are similar to those historically experienced by the families of children with disabilities in the United States. See Kaplan, supra note 3, at 353.

parents who chose to forego abortion upon learning of a defect in utero. Instead, the court concluded in dicta that such parents should be directly "answerable for the pain, suffering and misery which they have wrought upon their offspring."¹⁹⁸ Although the California legislature acted quickly to remove the legal threat from such language, the sentiment itself remains, along with its potentially anti-therapeutic impact on parents.

Furthermore, the opinions expressed in Curlender do not stand in isolation. At least one scholar has indicated support for parental liability, arguing that "[t]he right [of the parents] to be free from interference in decisions on procreation ... does not necessarily affirm the righteousness of a decision to bring a child into the world. In some cases it might be possible to say that the parents have made a 'poor' decision and have wronged the child."¹⁹⁹ Other scholars have urged the adoption of widespread genetic testing as a means of reducing the burden on American healthcare.²⁰⁰ Advocates of state-wide screening programs, for example, have employed a cost-benefit analysis comparing the price of the testing to the societal burden of raising children with defects,²⁰¹ and the National Institute of Health has long stated that the birth of impaired children is avoidable with "good genetic counseling and risk assessment."²⁰² As is apparent, the desired result occurs only if the parents choose to have an abortion upon learning of the child's impairment post-conception.²⁰³ Thus, couched in the palatable rhetoric of preserving healthcare for all Americans is the menacing subtext of selective reduction of those deemed unworthy of its bounty. Some authors have argued that genetic testing will not inevitably lead to abortion as technology advances and permits physicians to correct defective genes in utero.²⁰⁴ Even assuming such proce-

²⁰³ See, e.g., Morris, *supra* note 200, at 304 (noting that "in the context of prenatal screening, prevention necessarily assumes termination of the pregnancy").

¹⁹⁸ Curlender v. Bio-Science Labs., 165 Cal. Rptr. 477, 488 (Cal. Ct. App. 1980).

¹⁹⁹ Belsky, *supra* note 14, at 241–42.

²⁰⁰ See, e.g., David T. Morris, Cost Containment and Reproductive Autonomy: Prenatal Genetic Screening and the American Health Security Act of 1993, 20 AM. J.L. & MED. 295, 301–03 (1994) (suggesting that "[c]ost reduction ... may ... justify furnishing prenatal genetic screening services to a greater segment of the population" and cataloguing the costs of raising a child with disabilities); cf. Fadem et al., supra note 134, at 989 (describing the distrust of people with disabilities toward government and the health care industry, including the response of one woman, disabled since birth, that "'I'm an expensive commodity' for HMOs concerned about 'the bottom line'" and "an able-bodied woman's worst nightmare"); Julia Walsh, Reproductive Rights and the Human Genome Project, 4 S. CAL. REV. L. & WOMEN'S STUD. 145, 171–72 (1994) (noting that the significant funding allocated by many state legislatures and the federal government "to providing genetic testing for diseases which have no known cure" may suggest "attempts to eliminate genetic disease as a means of managing health care costs").

²⁰¹ Gwen Anderson, NonDirectiveness in Prenatal Genetics: Patients Read Between the Lines, 6 NURSING ETHICS 126, 130 (1999).

²⁰² JOHN M. FREEMAN, PRENATAL AND PERINATAL FACTORS ASSOCIATED WITH BRAIN DISORDERS iii (Nat'l Inst. of Health, Publication No. 85-1149, 1985).

²⁰⁴ See, e.g., Pollard, supra note 14, at 357.

dures exist, however, the ease, limited expense, and certainty of abortion will continue to suggest this as the preferable alternative.²⁰⁵

Because wrongful birth and wrongful life actions extend compensation only to those parents who would have chosen to abort an impaired child, these torts strengthen and reinforce the message that abortion is the preferred means of "curing" disability in society. The potential impact of such messages is troubling. As one author explained, "[t]he belief that genetic conditions are 'defects' that can be avoided perpetuates a myth that leads to personal shame and family disgrace when such an event occurs."²⁰⁶ Against this background, abortion becomes both the preferred option and the morally correct choice upon a diagnosis of defect.²⁰⁷ Those unwilling to follow the prescribed route actively inflict a legal injury not only on their own child, but also on their already existing children as well as greater society.²⁰⁸

Worse still, if wrongful birth and life suits become commonplace, a parent's refusal to abort a disabled fetus may be considered a personal

Right now, abortion, unpleasant as it is, sounds to me a lot easier and more predictable.

Id. at 933.

²⁰⁶ Anderson, *supra* note 201, at 130.

²⁰⁷ See, e.g., Asch, supra note 138, at 88 ("To most people . . . at least partly because of the lack of accurate information about and contact with disabled individuals, failure to abort is cruel to the potential child, destructive to the family, socially irresponsible and possibly immoral."); Henriikka Clarkeburn, *Parental Duties and Untreatable Genetic Conditions*, 26 J. MED. ETHICS 400, 401 (2000) (arguing that where a condition exists for which nonexistence is preferred to life, and testing exists which can reveal such impairments, then the "parents' duty of beneficence" both requires them to acquire such information and to terminate the fetus upon diagnosis in order to further the child's best interests); Scott, supra note 153, at 302 (noting that "some might argue that abortion is morally required" following a prenatal diagnosis of Tay-Sachs disease).

²⁰⁸ See Asch, supra note 48, at 340. Professor Asch argues that in a society which endorses eugenic abortion for disabling conditions, "it will be very difficult for most families to consider bringing [such] children . . . into the world if they know that the society believes that their births should have been prevented." *Id.* at 341. All parents experience anxiety about their child's place in the world, and "those anxieties can only be heightened if parents know and love a child whose disabling characteristics meet with aversion, social embarrassment, discrimination, and exclusion." *Id.* It is worth noting, moreover, that some suits have been brought by the siblings of a disabled child on the grounds that the child's birth "forced them to endure family financial and emotional hardships." Azzolino v. Dingfelder, 337 S.E.2d 528, 530 (N.C. 1985). In this view, parents who choose to carry a disabled child to term are also actively inflicting injury on their existing children. *Cf.* Kelly, *supra* note 14, at 578 (proposing that nondisabled siblings be permitted to seek damages as part of the family unit where "the impaired child absorb[s] a disproportionate amount of their parents' time and resources").

²⁰⁵ See, e.g., Larson, *supra* note 5, at 932–33. Larson quotes James Watson as stating the following at a conference:

It seems to me the question we're going to have to face is, what is going to be the least unpleasant? Using abortion to get rid of nasty genes from families? Or developing germline procedures with which . . . you can go in and get rid of a bad gene.

assumption of the risk of all of the struggles and hardships that follow the child's birth. Disability correspondingly is transformed from a societal issue into an individual concern.²⁰⁹ Society is "spared collective responsibility" because the problem is now "the woman's own. She 'chooses,' and so we owe her nothing. Whatever the cost, she has chosen, and now it is her problem, not ours."²¹⁰ If such thinking becomes widespread, societal support for individuals with disabilities is likely to diminish considerably, especially since the level of compassion displayed toward any issue is often a function of its "involuntary" nature.²¹¹ For example, society views individuals who experience lung cancer following a life of healthy living with greater sympathy than those who smoked cigarettes despite knowing that cigarettes cause cancer. Similarly, society's compassion towards the mother of a child with disabilities will diminish if she "easily" could have prevented the hardships resulting from her child's condition. The freedom to choose becomes illusory when the choice to accept a child unconditionally, whatever his impairments, is no longer a viable social option.212

The compensation secured by individuals in litigation thus places at risk the ability of all individuals with disabilities to secure necessary support and assistance from society. The state's recognition of the disabled life as a potential legal injury may ultimately make the limited resources now available seem generous in the future.²¹³ The push for new technology and medical advances in treatment will diminish if the need for assistance arises only when mothers fail to take the preferred action upon being informed of the defect.²¹⁴ Private insurers may even conclude that a

²¹² See, e.g., ROTHMAN, supra note 209, at 11 (explaining that new choices provided by expanding technology come at the cost of other choices, such as "the choice not to control the quality [of our children], the choice of simply accepting them as they are").

²⁰⁹ See BARBARA ROTHMAN, TENTATIVE PREGNANCY: PRENATAL DIAGNOSIS AND THE FUTURE OF MOTHERHOOD 9 (1986). Rothman argues that the rise of prenatal genetic testing transforms disability from a social problem into individual problems, consistent "with the private property idea of children: the needs of *your* children are *your* problem." *Id.*

²¹⁰ *Id.* at 189.

²¹¹ See, e.g., Arthur L. Caplan, *Neutrality is Not Morality: The Ethics of Genetic Counseling, in* PRESCRIBING OUR FUTURE: ETHICAL CHALLENGES IN GENETIC COUNSELING 149, 155 (Dianne M. Bartels et al. eds., 1993), *quoted in* Larson, *supra* note 5, at 935 ("If it is possible to reduce the cost of care by preventing the birth . . . of those likely to have costly diseases and disorders . . . [then] [m]any will see the application of new knowledge concerning the genome as a legitimate and ethical way for society to decrease the burden of paying the costs associated with disease, disorder, and dysfunction.").

²¹³ See, e.g., Kelley, *supra* note 183, at 942 ("[W]hy should the state protect the child's life after it formally declares that the child would have been better off if he did not exist?").

ist?"). ²¹⁴ See Suzanne Tomlinson, Genetic Testing for Cystic Fibrosis: A Personal Perspective, 11 HARV. J.L. & TECH. 551, 563 (1998) (noting that one of the factors scientists consider in choosing which diseases to target for treatment is the number of people living with them); see also ROTHMAN, supra note 209, at 230–31 (noting that "two to three times as many people" were working on developing cures for Tay Sachs disease in the 1960s). Barbara Rothman concludes that public policy's shift towards screening programs and abortion "locks out the possibility of developing cures." *Id.* at 233.

mother's choice to bear an impaired child negates any responsibility to provide medical coverage for prenatally identified defects.²¹⁵ Moreover, society will no longer need to scrutinize whether the barriers faced by individuals with disabilities are externally created. Instead, disability will be reinforced as a status inherent in the individual, and society's assessment of the individual's worth will be limited to the capability of current medical techniques to identify and correct impairments.

V. THE PROBLEM OF LINE DRAWING

In an attempt to minimize or deny such consequences, some scholars have argued, with court approval, that however unpalatable the underlying message of wrongful birth and wrongful life actions may be, the reality is that there exist some disabilities that most honest people would agree render the child's existence an injury.²¹⁶ Such logic appears compelling and, as several courts have noted, seems to parallel the reasoning of case law and commentary advocating the right to die, which many Americans support.²¹⁷ Most commonly cited are those disorders in which the child is not consciously aware of his surroundings and has no hope of becoming so. When such a disorder also causes intense suffering, pain, and discomfort for the child, some scholars assert no reasonable person could conclude that life is always a gift to be preserved at any expense.²¹⁸ It seems plausible that society could identify a few such intolerably damaging disorders by consensus.

However, the wide range of disabilities for which individuals have sought compensation reflects the dangerous simplicity of this "consensus approach" to wrongful life and birth. Parents and children with disabilities have sought redress for injuries ranging from life with very severe disorders, such as Tay-Sachs disease,²¹⁹ to life with Down syndrome²²⁰ or con-

²¹⁵ Lippman, *supra* note 186, at 35 (describing reports of an HMO "planning to withdraw medical coverage for a woman who could have avoided the birth of a child with cystic fibrosis if she had 'chosen' to abort the pregnancy after the prenatal diagnosis was made").

²¹⁶ See, e.g., Belsky, supra note 14, at 231–32; Laudor, supra note 14, at 1694.

²¹⁷ See, e.g., Kelly, *supra* note 14, at 538 ("The law understands and accepts that, under some circumstances, it may be better to die than to go on living."); Pollard, *supra* note 14, at 359 (noting the "contemporary societal view that sometimes death is preferable to life").

²¹⁸ See, e.g., Pollard, *supra* note 14, at 353 ("At least in some cases, pain and suffering resulting from negligent genetic testing seems to far outweigh any benefits of life. For example, Tay-Sachs babies are born to experience extreme pain and suffering for up to four years, and then they inevitably die; thus, their pain and suffering from birth until death could have been avoided but for the malpractice."); *cf.* Asch, *supra* note 138, at 87 ("Even those most apprehensive about the anti-disability sentiment in prenatal diagnosis would probably tolerate or welcome abortions after diagnoses of Tay-Sachs disease and other degenerative conditions that cause extreme pain, loss of awareness of self and others, and death in early childhood.").

²¹⁹ See, e.g., Geler v. Akawie, 818 A.2d 402 (N.J. Super. Ct. App. Div. 2003).

²²⁰ See, e.g., Thornhill v. Midwest Physician Ctr., 787 N.E.2d 247 (Ill. App. Ct. 2003);

genital blindness.²²¹ As such diversity makes clear, whether or not consensus can be reached for any one disorder, a line will have to be drawn somewhere between actionable and non-actionable disabilities. Which disabilities will be judged so horrible that nonexistence is the preferred alternative?²²² And who will make that decision?²²³

The potential answers to these questions are troubling and track the medical model of disability. Inevitably, courts (or whichever societal institution is ultimately expected to draw the line between actionable and non-actionable disabilities) will evaluate an individual's functional limitations and the extent of his suffering in light of current medical knowledge and its ability to "cure" such ailments. If medicine can alleviate some of the symptoms of the defect, courts are not likely to deem the disability.²²⁴ Courts are unlikely to consider the impact of societal discrimination and external barriers to a "meaningful" life.²²⁵ Once again, disability will be reduced to the least common denominator of organistic functioning and focus exclusively on internally rather than externally imposed barriers. The difference this time is that judges and jurors, rather than physicians exclusively, hold the power to define disability and render judgment on its consequences for the individual.

The fact that wrongful birth and wrongful life torts entrench the medical model of disability is confirmed in the language of the line-drawing

Kassama v. Magat, 792 A.2d 1102 (Md. 2002).

²²¹ See, e.g., Lininger v. Eisenbaum, 764 P.2d 1202 (Colo. 1988) (wrongful birth).

²²² See, e.g., Kaplan, *supra* note 3, at 356–57 (arguing that "[m]ost people believe that they know what is and is not a disability. If you imagine 'the disabled' at one end of a spectrum and people who are extremely physically and mentally capable at the other, the distinction appears to be clear. However, there is a tremendous amount of middle ground in this construct, and it is in the middle that the scheme falls apart.").

²²³ At least one scholar, for example, has suggested that a cross-section of the community could develop a list of disabilities that parents should be permitted to test for prenatally. *See* THOMAS H. MURRAY, THE WORTH OF A CHILD 139–40 (1996). Adrienne Asch has criticized the creation of such a list as merely reinforcing a "message' about the badness of disability" that "tells people who currently have those conditions that it would be better if prospective parents went to considerable lengths to prevent the births of children with those conditions." Asch, *supra* note 48, at 339. Asch argues that permitting testing on a greater number of conditions is preferable because the reproductive decisions "will be those of the people ultimately raising children, and not society, in the form of its insurance carriers and clinicians as gatekeepers." *Id*.

²²⁴ *Cf.* Scott, *supra* note 153, at 309 (detailing a sliding scale of defects that might be considered "serious" under English abortion law, based in part on "the probability of effective treatment, either *in utero* or after birth" (citation omitted)); *see also* Mary Terrell White, *Making Responsible Decisions: An Interpretive Ethic for Genetic Decisionmaking*, HASTINGS CTR. REP., Jan.-Feb. 1999, at 15 (arguing that in constructing an ethical orientation to the use of genetic testing, scholars must recognize that "[a]dvances in the diagnosis and treatment of genetic disorders may rapidly change perceptions of what counts as a genetic disease or disability").

 $^{^{225}}$ Cf. Hahn, supra note 18, at 101 (describing the "common tendency to confuse disability with impairments . . . and to concentrate on clinical examinations that tend to exclude the analysis of problems outside the boundaries of the human organism").

inquiry and its causal focus on the impairment in isolation rather than in the context of family, community, and the individual as a whole person. The critical timeframe in both wrongful birth and wrongful life actions is the point at which the mother received or should have received the diagnosis of impairment relating to her developing fetus. At this point in time, the only information that can be communicated is the identification of the defect itself and its possible parameters, rather than its ultimate impact on the child.²²⁶ The unstated assumption is that the restriction flowing from the impairment can be precisely identified and accurately assessed.

Human experience has demonstrated, however, that the range of functioning among individuals with the same disabilities can vary dramatically. An individual with Down syndrome, for example, may be profoundly mentally retarded and severely restricted in motor functioning or may be capable of meaningful employment, relationships, and community engagement.²²⁷ A child with cystic fibrosis likewise "might die from it, survive with physical disability, or suffer no noticeable impairment."²²⁸ Because a child's placement on this continuum is mere conjecture at the time of diagnosis, courts ignore the individual litigant and the potential richness of his or her life in the causal determination.²²⁹ The individual is the impairment, and the value of existence is judged on that basis alone. Such circumstances cannot add to the physical or mental health of anyone other than those who are encouraged to feel lucky that they do not share the impairment. Alison Davis has eloquently written about how divergent real life can be from a diagnosis of defect:

I was born with severe spina bifida, and am confined to a wheelchair as a result. Despite my disability and the gloomy predictions made by doctors at my birth, I am now leading a very full, happy and satisfying life by any standards. I am most definitely glad to be alive. Yet, because handicapped people are now presumed by some doctors, philosophers and Society in general to have the capacity only for being miserable and an economic burden on the community most of those who would otherwise grow

²²⁶ See Scott, *supra* note 153, at 310 (noting that "in some cases there will be medical uncertainties about how severe a given condition might be in the born child; in others there will be uncertainties . . . about whether a given condition will ever manifest itself").

²²⁷ See, e.g., Alderson, supra note 133 (detailing descriptive interviews with people with Down syndrome about the quality of their lives). Priscilla Alderson's interviews reveal people who can read, attend universities, hold jobs, and live independently. *Id.* at 631–33; see also Kassama v. Magat, 792 A.2d 1102, 1123 (Md. 2002) (noting that "[e]very recent study shows that people afflicted with Down's Syndrome can lead useful, productive and meaningful lives—that they can be educated, that they are employable, that they can form friendships and relationships and can get along in society").

²²⁸ Larson, *supra* note 5, at 922; *see also* Tomlinson, *supra* note 214, at 552 (discussing life with cystic fibrosis).

²²⁹ Functional differences could, however, be highly relevant in determining the amount of damages ultimately secured in litigation.

up to be like me are now aborted or "allowed to die" (such a comfortable euphemism) at birth. 230

In addition, arguments in favor of line-drawing often presume the existence of a defect that will manifest itself in the child either at birth or relatively soon thereafter. As technology advances, however, science will increasingly be able to predict the existence of late-onset diseases, where a considerable period of health and well-being precedes the genetic problems to follow.²³¹ Huntington's Disease, for example, is a highly debilitating and fatal condition that begins in adulthood.²³² Scientists have identified the gene responsible for this condition, and mothers can test for it prenatally.²³³ Huntington's Disease stands as a key example of the problems associated with line-drawing. Does the great suffering this disease causes at the end of life outweigh the joy experienced before it manifests? Assessing the merits of existence versus nonexistence in cases involving lateonset diseases may be even more ambiguous and subject to bias than in traditional wrongful life cases.

Compounding the dangerousness of this inquiry is the fact that whether or not the disability renders life an injury will be evaluated from the nondisabled perspective. This starting point is not neutral, but instead is a highly biased and culturally influenced perspective²³⁴ that considers those with even moderately limiting disabilities as "things" to be despised, avoided, or, at best, pitied.²³⁵ As the social model recognizes, we are a "cul-

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²³⁰ Alison Davis, Yes, the Baby Should Live, 31 NEW SCIENTIST 54 (1985), quoted in Christopher Newell, The Social Nature of Disability, Disease and Genetics: A Response to Gillam, Persson, Holtug, Draper and Chadwick, 25 J. MED. ETHICS 172, 173 (1999).

²³¹ Sonia Mateu Suter, *The Routinization of Prenatal Testing*, 28 AM. J.L. & MED. 233, 237 (2002) (explaining that "[w]ith the rapid identification of numerous genes through the Human Genome Project, scientists began to isolate genes associated with late-onset conditions"). Professor Suter contends that the emotional and social costs associated with adult testing of late-onset diseases "will multiply as concerns of late-onset testing are added to those of prenatal testing." *Id.* at 240.

²³² See Robert Lentner, *Huntington's Disease*, 2002 L. REV. MICH. ST. U. DETROIT C.L. 921, 921 (2002) (describing Huntington's Disease as "an inherited progressively degenerative brain disorder that results in the loss of both mental faculties and physical control" and which usually begins to manifest in the individual "between thirty and fifty years of age").

²³³ Suter, *supra* note 231, at 240 n.47.

²³⁴ See Hahn, supra note 18, at 110 ("There is often a crucial discrepancy between the views of oppressed groups and of supposedly detached analysts regarding equal rights as well as other subjects."). This evaluation cannot be excused as strictly "scientific" because history is replete with incidences of "science" disguising cultural bias and discrimination. See, e.g., Larson, supra note 5, at 920 (noting that the historical eugenic movement "claimed the mantle of scientific objectivity but was rife with cultural subjectivism"); Susan M. Wolf, Beyond "Genetic Discrimination": Toward the Broader Harm of Geneticism, 23 J.L. MED. & ETHICS 345, 348 (1995) ("There is nothing neutral or scientifically 'real' about identifying a genetic norm ...").

²³⁵ See, e.g., Asch, supra note 138, at 75 (explaining that "'normals' view the stigmatized, including the disabled, as 'not quite human'"); Phyllis A. Gordon et al., Attitudes Regarding Interpersonal Relationships with Persons with Mental Illness and Retardation,

ture dominated by standards created by and for the nondisabled."²³⁶ This fact renders jury involvement in such litigation distinct from the typical tort action in which jurors can determine actionable conduct based on their common conceptions and experiences.²³⁷ It is unlikely that potential jurors would share the disability in question in the litigation and are likely to have encountered the disability, if at all, through an acquaintance in the community. This distance from the disabled perspective leaves the jurors' determinations subject to bias and prejudice.²³⁸ The power to define disability, therefore, will lie in the hands of the "expert" physician and jurors conditioned to the medical model's image of impairment. None are likely to have insight into the potential richness that life may hold for those with even the most severe of defects. As Harlan Hahn has stated,

disabled persons do not experience the external environment in the same way as the nondisabled. The focus of attention is different; the concentration of energy is different; the impressions formed in personal interactions are different; and the [nondisabled] analysis of political problems may reflect this differenced vantage point. . . . [There are] positive aspects of everyday life that the nondisabled tend to take for granted—the sensuous touch of a sheet on the skin, the exhilaration of simply moving from here to there, the joy of communicating with a world that once seemed dark or silent.²³⁹

²³⁹ Hahn, *supra* note 18, at 110; *see also* Asch, *supra* note 48, at 332 ("Life with nearly all disability potentially contains rewarding personal relationships, stimulation and discovery, self-development, and contributions to others.").

⁷⁰ J. REHABILITATION 50, 50 (2004) (explaining that "[a] persistent negative attitude and social rejection of people with disabilities is evident throughout history and across cultures" and that "efforts to reduce negative stereotypes . . . do not appear to have been substantially successful").

²³⁶ Hahn, *supra* note 18, at 112; *see also* Scotch, *supra* note 22, at 222 ("The stigma associated with disability is so embedded and reinforced within our culture and social structure that it will take tremendous efforts to root it out.").

²³⁷ It also distinguishes wrongful life and wrongful birth cases from the right-to-die cases, which potentially implicate every member of society. For a contrasting view, see Kelly, *supra* note 14, at 548 (concluding that "[p]olicy concerns raised by courts [in wrongful life cases] pose a barrier courts already have surmounted in the context of right-to-die cases").

²³⁸ Cf. Kassama v. Magat, 792 A.2d 1102, 1123 (Md. 2002) ("In our view, the crucial question [in wrongful life actions] . . . is too deeply immersed in each person's own individual philosophy or theology to be subject to a reasoned and consistent community response, in the form of a jury verdict."). Significantly, biased attitudes toward people with disabilities have been shown to be prevalent even among professionals who work in disability-related fields. One study, for example, concluded that graduate students in rehabilitation counseling, described as "gatekeepers of both information and services" for people with disabilities, "are as prone to having negative or potentially biased attitudes [towards disability] as the general population." Daniel W. Wong et al., *Rehabilitation Counseling Students' Attitudes Toward People with Disabilities in Three Social Contexts: A Conjoint Analysis*, 47 REHAB. COUNSELING BULL. 194, 202 (2004).

An analogy drawn from the more familiar contexts of race and gender may be instructive, although not a perfect fit. Today, it is widely understood that there are no meaningful differences between races that are not created by institutional discrimination. Imagine, however, a wrongful life action brought by a mixed-race child against his white father in the South shortly after the end of the Civil War. The child could perhaps claim that his mixed-race status was such an affliction that he would have been better off never having been born.²⁴⁰ Imagine a white juror considering whether a "reasonable" person would conclude that this was so. One need not be a student of history to guess at the answer, or the race of the "reasonable" person contemplated.²⁴¹

Similar feelings exist and continue to present challenges today when dealing with gender issues internationally. China, for example, generally limits reproduction to one child per family. There are very tangible benefits to having a son as opposed to a daughter, since sons traditionally care for parents in their old age and are considered significantly more valuable than daughters.²⁴² The corresponding parental preference for boys has lead to the widespread abortion of female fetuses, resulting in 117 male babies born for every 100 girls.²⁴³ The Chinese government has condemned this practice and banned sex-identifying ultrasounds.²⁴⁴ Consider, however, the potential international outcry if the Chinese government had instead provided legal redress to those parents who carried a female child to term after a physician incorrectly identified the fetus as male. Based on the tangible social advantages that boys have, such an action could be deemed fair compensation for the "loss" experienced by the girl's parents. Undoubtedly, such actions would be denounced in the Western world because they would be considered in the context of Western social structures that acknowledge the equal status and worth of women and girls.²⁴⁵ Why is

²⁴⁰ Note that since abortion was not readily available at the time of the Civil War, causation would be virtually impossible to establish. Nevertheless, the argument identified here is not significantly different from those raised in the illegitimacy cases brought before abortion was widely available and legal.

²⁴¹ It is interesting to note that in 1963, the *Zepeda* court rejected a wrongful life cause of action based on illegitimacy in part because it would encourage suit by "all others born into the world under conditions they might regard as adverse," including "being born of a certain color . . . [or] race." Zepeda v. Zepeda, 190 N.E.2d 849, 858 (Ill. App. Ct. 1963).

²⁴² See Stephanie Hoo, China Gets Tough to Save Girls, ATL. J. CONST., July 16, 2004, at B1.

²⁴³ Id.

²⁴⁴ *Id.*; see also Graciela Gomez, Comment, *China's Eugenics Law as Grounds for Granting Asylum*, 5 PAC. RIM L. & POL'Y J. 563, 571 (1996) (explaining that Chinese "law bans fetal sex identification to combat a deeply ingrained traditional preference for sons that prompt [sic] many families to abort female fetuses").

²⁴⁵ See, e.g., Robertson, *supra* note 177, at 446 ("Typically, using abortion as a tool for selecting a child's gender has been deemed inappropriate, and has been condemned."). At least one scholar has suggested, however, that if social norms evolve to the point that society accepts genetic testing and eugenic abortion for sophisticated traits like intelligence and eye color, courts should not "stand in the way of that social evolution with doctrines designed to preclude liability." Kelly, *supra* note 14, at 568–69.

awarding compensation on the basis of gender so much more obviously abhorrent than awarding compensation on the basis of disability? Although there are very real costs associated with medical impairments, they represent only the beginning of the inquiry into the answer.

Race, gender, and disability clearly diverge in significant aspects. In one regard, however, they are much the same—societal discrimination forms the unchallenged and often invisible foundation of widespread beliefs concerning the ability, value, and identity of group members. The functional limitations associated with disability are only the beginning of the restrictions experienced by individuals with impairments. As with race and gender, many of society's pervasive negative images of disability result from subconscious institutional and social infrastructures.²⁴⁶ Providing legal remedies for wrongful life and wrongful birth reinforces and strengthens discriminatory beliefs by extending to them the moral authority of the state. The law should not be used to legitimize the views of those who continue to "equate impaired physical or mental functioning with impaired personhood and view persons with disabilities as somehow less than fully human, an attitude that feeds the growth of prejudice."²⁴⁷

To some extent, it is also more difficult to identify and demystify the negative social origins of disability than those of other historical biases and prejudices. Some have argued, for example, that wrongful life actions are warranted because parents will make the decision whether to terminate fetal life based on that child's best interests.²⁴⁸ Upon learning of a prenatal diagnosis of disability, however, the first question in most parents' minds is not what joy the child will be capable of during his lifetime, but rather what burdens will be placed on the parents during theirs.²⁴⁹ Statesponsored recognition that the existence of disabled children can be a legal injury only reinforces this perspective. Unlike other minority groups, in which at least one parent shares with the child the characteristic from which discrimination originates, parents of children with disabilities are usually unfamiliar with the defect in question and have no independent

²⁴⁶ See, e.g., Crossley, supra note 19, at 662; Hahn, supra note 18, at 98–100.

²⁴⁷ Crossley, *supra* note 19, at 661–62.

²⁴⁸ See, e.g., Turpin v. Sortini, 643 P.2d 954, 962 (Cal. 1982) (noting that parents "presumptively" consider the best interests of their future child in making decisions); Pollard, *supra* note 14, at 360 ("It seems clear that parents are in the best position to choose between life and non-life on behalf of their defective potential child and will make the decision in the fetus's best interests.").

²⁴⁹ See, e.g., Asch, supra note 138, at 81 (noting that there is often little joy in the arrival of a child with disabilities because "the immediate question raised is how much the child with a disability will burden the woman, her mate if she has one, siblings, relatives, and society as a whole"); Scott, supra note 153, at 302–03 (describing how it can be difficult to determine "whose interests are really at stake" in wrongful birth actions: in cases where the fetus has a chance at a "good or reasonable quality of life," "parental and fetal interests [may] become opposed to one another, since it is surely in the fetus' interests to be born").

experience by which to filter out societal prejudices.²⁵⁰ The rapid pace of genetic testing has left laboratories and obstetricians in a position in which they can provide little, if any, information to parents other than the diagnosis itself.²⁵¹ The parents' resultant decisions are made in an information vacuum and are thus doubly likely to be informed by fear and prejudice. In light of parental difficulties with such issues, judges and juries will experience even greater difficulty in attempting to evaluate wrongful life and birth claims. Because the inquiry into life as an injury "necessarily hinges upon subjective and intensely personal notions as to the intangible value of life," recognition of such actions will result in "markedly disparate, and hence, unpredictable outcomes."²⁵²

In the small category of cases involving children who suffer short, painful lives as a result of genetic defects, the impact of societal discrimination is obviously of minimal consequence. These children's internal limitations are tangible to even the most casual observer. As noted previously, however, the disabilities recognized as sufficient to state a cause of action are greatly diverse. Many of the most significant challenges and obstacles faced by individuals with disabilities result from societal prejudice and refusal to adapt to such individuals. An individual with Down syndrome, for example, may be limited to a life of isolation and exclusion not because of any inherent limitation on his ability to love and be loved, but rather as a result of social stigma and others' refusal to engage in such interaction. One study found that nondisabled adolescents rated children with Down syndrome as having more intelligence after they had facial surgery to correct their most obvious signs of impairment.²⁵³ Whatever functional limitations such children possessed, those limitations did not change with the surgery-all that changed was society's perception of their abilities. Permitting such prejudice to play a role, consciously or unconsciously, in a legal forum that openly evaluates the intrinsic worth of a life with disabilities legitimizes society's biases and permits them to flourish unchallenged.254

²⁵⁰ See Asch, supra note 138, at 86. For an interesting discussion of the historical messages communicated to parents of disabled children in the early twentieth century, including the belief that parents must "save" their disabled children by allowing them to die "either by withholding treatment or by lethal medication," see Larson, supra note 5, at 918– 20.

²⁵¹ See Powell, supra note 6, at 48–49 (concluding that "most women who receive information about a specific chromosome abnormality, birth defect, or genetic impairment in their fetus receive this information from health care providers unfamiliar with the natural history and outcomes of the condition").

²⁵² Smith v. Cote, 513 A.2d 341, 353 (N.H. 1986); *see also* Kassama v. Magat, 792 A.2d 1102, 1120, 1123 (Md. 2002).

²⁵³ See Crossley, supra note 19, at 663 (discussing study).

²⁵⁴ *Cf. Smith*, 513 A.2d at 353 (noting that characterizing life as an injury denigrates the dignity of the disabled and advances made by recent legislation).

The analogy made by some scholars and courts between the wrongful life debate and the right-to-die cases ignores this reality.²⁵⁵ To the extent that a patient who asserts a right to die can speak for herself regarding her personal desire to forego medical treatment, judicial recognition of such testimony respects the patient's right to self-determination and bodily integrity.²⁵⁶ Wrongful life actions, in contrast, rarely involve a plaintiff who can speak for herself. As mentioned earlier, parents who must assert on their child's behalf that nonexistence is preferable to life are often illequipped to distinguish between the impact of the medical impairment and societal prejudice on their child's quality of life. Consequently, judicial respect for parents' testimony can serve as an endorsement of negative societal perceptions of disability rather than respect for individual autonomy.

The right-to-die cases in which courts permit a relative to refuse treatment on behalf of an incompetent patient are somewhat more problematic.²⁵⁷ These cases suggest that, in some circumstances, society is comfortable assessing whether death is objectively preferable to life. However, these cases pay little attention to the question of whether the interests of people with disabilities are harmed by such evaluations, which are likely to reflect the pervasive prejudice and fear associated with a life of disability.²⁵⁸ This perspective is reflected in the strong opposition expressed by some disability rights organizations to legislation authorizing physicianassisted suicide or "death with dignity."²⁵⁹

²⁵⁵ See, e.g., Turpin v. Sortini, 643 P.2d 954, 961–62 (Cal. 1982); Kelly, *supra* note 14, at 538 (arguing that the policy rationale given in wrongful life cases of respecting and preserving life is inconsistent with the recognition in right-to-die cases that "[t]he law understands and accepts that, under some circumstances, it may be better to die than to go on living"); Mark Strasser, *Wrongful Life, Wrongful Birth, Wrongful Death, and the Right to Refuse Treatment: Can Reasonable Jurisdictions Recognize All But One?*, 64 Mo. L. REV. 29, 75 (1999) (arguing that because end-of-life issues often consider the best interests of the patient, an objective standard, "it seems clear that society does not believe that life is always preferable to death," and that the sanctity of life is not undermined by recognition of wrongful life).

²⁵⁶ See, e.g., Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 271 (1990) ("[N]o right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.") (quoting Union Pac. Ry. v. Botsford, 141 U.S. 250, 251 (1891)). This is not to suggest, however, that patients' seemingly voluntary decisions are free from the influence of societal perceptions of illness and disability. When the patient himself speaks, however, the court need not guess at his opinion. *See, e.g., Smith*, 513 A.2d at 352.

²⁵⁷ See Kelly, *supra* note 14, at 540 (arguing that the inconsistency between the policy rationales articulated in wrongful life and right-to-die cases "emerges even more clearly" in those cases employing a "best interests of the patient" standard).

²⁵⁸ See Adam M. Milani, Better Off Dead Than Disabled? Should Courts Recognize a "Wrongful Living" Cause of Action when Doctors Fail to Honor Patients' Advance Directives?, 54 WASH. & LEE L. REV. 149, 198 (1997) (explaining that "both courts and commentators find that recognition of [the right to wrongful life and right-to-die actions] is based upon a societal prejudice that life with a disability is not worth living").

²⁵⁹ See Fadem et al., supra note 134, at 978 (describing the "strong stand" taken by

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Furthermore, to the extent that right-to-die cases involve terminally ill patients with short life expectancies, the future of such individuals is relatively certain. Although this is equally true for some individuals involved in wrongful birth and wrongful life actions, the quality of life over time for many of these litigants is not only highly uncertain, but also highly dependent on the effects of societal discrimination. Whereas right-to-die jurisprudence may reflect the inevitable outcome of a terminal illness, wrongful life litigation predicts the future against a backdrop of limitsetting prejudice. As a result, the reasoning expressed in right-to-die cases does not fully alleviate the problems caused by the highly subjective linedrawing required in wrongful birth and life actions.

VI. THE PROBLEM OF DETERRENCE

It is hard to ignore the serious potential that wrongful birth and life actions have for communicating messages of blame, unworthiness, and despair to individuals with disabilities and their families. Although these actions provide help to individual litigants, their impact on the community of individuals with disabilities is significant and disturbing. The power of this insight, however, does not necessarily warrant the elimination of these causes of action. As advocates of wrongful birth and wrongful life actions correctly point out, everyone can agree on one difficult fact—there is a great need to deter negligence in the area of prenatal genetic testing.²⁶⁰ Physician education and training has lagged behind innovation, and unregulated diagnostic laboratories, pressured to develop tests that predict new impairments earlier and more conclusively, often have unacceptable error rates in test interpretation.

It is beyond question that the failure of such testing causes significant hardship and suffering whether or not a set of parents would have chosen to carry an impaired child to term. The chance to determine one's future, as discussed earlier, is inherently valuable and a central tenet of Ameri-

[&]quot;[t]he organized disability rights community" against California's Death with Dignity Act and Oregon's Death with Dignity Act). The authors of the article explain such opposition as "based on recognition of the marginalized status of people with disabilities as a vulnerable population in American society due to well-documented historical and continuing stigmatization and discrimination." *Id.* at 978, 984–93. The "small nonrepresentative" study conducted by the authors, however, suggests that this is not a uniform position within the disability community, and that some individuals with disabilities may support such legislation. *Id.* at 978–80 (summarizing conclusions of study).

²⁶⁰ See, e.g., Schloss v. The Miriam Hosp., No. C.A. 98-2076, 1999 WL 41875, at *2 (R.I. Super. Ct. Jan. 11, 1999) ("The tiny minority of jurisdictions which deny relief for the claim avoid the point that, if no relief is granted for persons who sustain recognizable injury from the negligence of the genetic testers, the public can have no legal assurance of caution by the testers."); Asch, *supra* note 138, at 93 (arguing that "[f]or this reason [of deterrence] alone, feminists as well as advocates of disability rights can accept [wrongful birth] actions"); Kelly, *supra* note 14, at 519–20; Pollard, *supra* note 14, at 339 ("This factor alone—discouraging medical practitioners from carelessness in genetic testing and disclosure—warrants imposition of liability in wrongful life cases.").

can values. A real threat exists that, in the absence of external incentives, physicians who strongly oppose abortion will be more likely to forego genetic testing in order to preempt a potential abortion.²⁶¹ Physicians must not be permitted to overlay their personal value systems on those of their pregnant patients. The question arises, then, of whether there is a way to control the field of prenatal genetic testing while simultaneously minimizing the anti-therapeutic consequences associated with wrongful birth and wrongful life actions. If no alternative means of deterrence exist, it is certainly plausible that the well-being of society may be ultimately enhanced by recognizing wrongful birth and wrongful life actions and thereby reducing the number of improper diagnoses.

No research has been conducted to test whether there are fewer incidents of negligence in prenatal genetic testing in those jurisdictions that recognize both wrongful birth and wrongful life actions. Further study in this area is clearly necessary. In the absence of such information, it is impossible to draw meaningful conclusions on the deterrent effects of these torts. One may note as a first principle, however, that those who believe that a deterrent effect exists often ignore the inadequacies of the tort system itself. As Dean Edward Dauer has described,

The T[herapeutic] J[urisprudence] lens has brought to light the possibility that the law's present system for dealing with the aftermath of medical error has some significant flaws. Whatever the economics of the process may be, its psychological dynamics seem to have for patients a range of impacts, very often unsatisfying if not adverse; and for physicians the high probability of antitherapeutic consequences that as a practical matter may both inhibit the implicit psychology of classical deterrence theory, and in fact create rather than reduce additional risks of clinical error. With respect to both its restoration and its patient safety objectives, the present system therefore seems to be deeply flawed.²⁶²

²⁶¹ See, e.g., Scott, supra note 153, at 288 ("The true effect of rejecting wrongful birth liability is to immunise from liability doctors who—either negligently or deliberately—fail to advise a woman of the tests or test results appropriate to her pregnancy"). Some have used this possibility to argue that wrongful life statutes are an unconstitutional "substantial obstacle" to the exercise of abortion rights under *Casey. See, e.g.*, Julie F. Kowitz, *Not Your Garden Variety Tort Reform: Statutes Barring Claims for Wrongful Life and Wrongful Birth Are Unconstitutional Under the Purpose Prong of* Planned Parenthood v. Casey, 61 BROOK. L. REV. 235, 264–65 (1995). Courts have disagreed, however, concluding that this scenario is "too tenuous" a grounds on which to strike down the statutes. Wood v. Univ. of Utah Med. Ctr., 67 P.3d 436, 445 (Utah 2002).

²⁶² Dauer, *supra* note 181, at 44; *cf*. Michelle M. Mello & Troyen A. Brennan, *Deterrence of Medical Errors: Theory and Evidence for Malpractice Reform*, 80 TEX. L. REV. 1595, 1598 (2002) (concluding that while there is "some limited evidence" of the deterrent effect of malpractice litigation, "overall the evidence is thin"); Shuman, *supra* note 171, at

The "poor fit" between the incidence of medical negligence and the incidence of lawsuits blunts the deterrent effect of the tort system. Because only a few patients injured by medical malpractice ever actually sue, and because "many malpractice lawsuits are brought and won by patients even though expert reviewers can identify no evidence of negligent care," there is little evidence that such suits provide any real deterrence to future acts of negligence.263

Such problems are amplified in the context of wrongful birth and wrongful life actions. Given the myriad state rules currently in effect and the deeply subjective nature of the injury inquiry, exclusive reliance on the tort system is unlikely to result in the consistent results needed to establish proper standards of care.²⁶⁴ Laboratories that conduct genetic tests, for example, may cater to clients in a multitude of jurisdictions. Depending on the fortuity of the client's location, the identical negligent conduct may thus result in liability to the parents, immunity from liability for the child, liability for both, or liability for no one. Moreover, liability depends upon the severity of the undetected defect rather than the nature of the conduct in question, and similar conduct could result in disparate legal results.²⁶⁵ Absent the ability to predict liability accurately in advance, actors will not appropriately identify the optimal level of care.²⁶⁶

Comprehensive federal regulation may hold more promise in this area. Advocates are currently clamoring for additional intervention into the practices of all laboratories performing genetic testing, some of which are now "essentially immune to federal laboratory-quality assurances."267 Given the serious consequences and anti-therapeutic results of misinformation in this area, the need for coordinated federal attention is clear and pressing. It may be that a comprehensive system of regulation with corresponding public or private penalties would provide needed relief in this area.²⁶⁸ In this scheme, deterrence would be affected without endorsing

^{437 (&}quot;There is nothing in any mainstream theory of human behavior . . . to suggest that tort law sanctions, as the tort system is presently structured, have the desired deterrent effect."). ²⁶³ Mello & Brennan, *supra* note 262, at 1618–20.

²⁶⁴ See, e.g., Smith v. Cote, 513 A.2d 341, 353 (N.H. 1986) (noting the strong possibility of "disparate" and "unpredictable" outcomes in rejecting wrongful life actions).

²⁶⁵ For example, one court may deem Down syndrome an insufficiently severe defect to render nonexistence preferable in a wrongful life action, while another may view the situation entirely differently. Likewise, the laboratory which fails to test for rubella will be liable for significantly greater damages than one who fails to test for a hereditary hearing impairment.

²⁶⁶ Cf. Mello & Brennan, supra note 262, at 1624 (noting that "in order to strengthen deterrence, reforms must heighten certainty, severity, or both").

²⁶⁷ Michael J. Malinowski & Robin J. R. Blatt, Commercialization of Genetic Testing Services: The FDA, Market Forces, and Biological Tarot Cards, 71 TUL. L. REV. 1211, 1230-33 (1997) (discussing the "general lack of regulatory quality control on genetic tests, which raises questions about their fundamental reliability").

²⁶⁸ See id. at 1233 (noting that state regulation is insufficient because licensing and monitoring efforts vary from state to state).

the anti-therapeutic messages of wrongful life and birth actions. Whether such regulation would be sufficient to secure the optimal level of deterrence remains to be seen.

The problem of coordination is unlikely to arise with physicians, who generally practice within the province of one state. They are far more likely to be deterred by the existence of legal sanctions for negligence in genetic testing, as attested to by the virulent tort reform battles currently taking place. Stringent licensing requirements by both the state and the American Medical Association, however, should create significant extra-legal incentives to take the appropriate level of care. Mistakes made by physicians in the area of prenatal testing are due in large part to a lack of training and information rather than any nefarious motives.²⁶⁹ The fast pace of innovation in this area has simply not allowed many care providers, particularly non-specialists, to stay informed.²⁷⁰ Continuing educational requirements or mandatory certification to practice prenatal care would be a first step in alleviating potential malpractice in the field. Practicing physicians would likely subject themselves to such requirements voluntarily in order to avoid the specter of open-ended liability in litigation.²⁷¹ Because such regulatory alternatives do not impose the harsh anti-therapeutic consequences experienced by physicians in the wake of medical malpractice claims, some scholars have theorized that they are superior vehicles for optimizing deterrence and patient safety than tort law.²⁷²

²⁷¹ *Cf.* Mello & Brennan, *supra* note 262, at 1629 ("Physicians deeply resent the moral, economic and psychic implications of malpractice litigation, and they would respond positively to the opportunity to practice in an environment free of these concerns.").

²⁷² See Dauer, supra note 181, at 43–44 (canvassing the results of empirical work on the subject). Dean Dauer writes that that the body of evidence compiled by several authors on the topic now reflects that the "depressive symptom clusters" and other negative effects of malpractice actions on physicians result in behaviors that may place "future patients" at increased risk of malpractice. *Id.* at 43 (citing Sara C. Charles et al., *Physicians' Self*-

²⁶⁹ See Mark A. Rothstein & Sharona Hoffman, *Genetic Testing, Genetic Medicine, and Managed Care*, 34 WAKE FOREST L. REV. 849, 858 (1999) ("A major problem with the 'geneticization' of primary care is that many primary care physicians have an inadequate level of education and training in the fast-changing field of genetics."); cf. Shuman, supra note 49, at 127–28 ("Much of the behavior subject to the tort system—the slip of a surgeon's scalpel or the momentary inattentiveness of an automobile driver—is impulsive rather than deliberative.").

²⁷⁰ In fact, this is true for most genetic tests available on the market, and a recent study by the Centers for Disease Control suggests that this problem is likely to become even more widespread as manufacturers market tests directly to consumers in national advertising campaigns. Tests now exist, for example, which can discover gene mutations that mark a significant risk in a woman's likelihood of developing breast cancer. Although consumerdirected advertisement boosted testing by thirty percent in less than one year, the CDC found that approximately half of all physicians did not understand the basic underlying genetic information, and that number increased significantly among family medicine and internal medicine physicians. *See* David Wahlberg, *CDC: Doctors Unprepared for Inquiries on Ads*, ATL J. CONST., July 16, 2004, at A4 (discussing CDC study); *see also* Carol L. Freund et al., *Natural Settings Trials—Improving the Introduction of Clinical Genetic Tests*, 32 J.L. MED. & ETHICS 106, 106 (2004) (noting that "physicians frequently are deficient in their general understanding of genetics and their use and interpretation of specific tests").

The suggestions set forth here certainly do not represent a perfect solution. Nevertheless, as one commentator recently stated, "[1]egal policy analysts must recognize that the malpractice liability system is neither the only nor the most frequent venue for examining and responding to errors and accidents."273

VII. PROPOSAL: A CALL TO COMMUNITY

With some creative thinking, there is little doubt that wrongful birth and wrongful life actions can satisfy the traditional elements of tort law. That knowledge, however, does not answer the fundamental question posed in this Article-should the law recognize them? Do they cause more harm than good for society in general and individuals with disabilities in particular, the very class they purportedly protect?

However desirable an outcome, the law does not provide a solution for every harm and a redress for every wrong. Public policy drives the formation of the law and constitutes its enduring backbone. In the case of wrongful birth and wrongful life actions, the countervailing policy considerations and anti-therapeutic messages are significant and potentially farreaching. Each action requires an assessment of the desirability of life with disabilities, either explicitly or implicitly. Neither acknowledges, however, that the problem of disability extends far beyond the mere identification of defect to encompass the prejudices, fears, and discriminatory behavior of the able-bodied. In the absence of such understanding, wrongful birth and wrongful life actions inevitably reinforce the precarious position of individuals with disabilities in society, weakening family relationships and community bonds. Once the nondisabled are given authority to judge from a "reasonable person" perspective whether or not the disabled life is worse than no life, the power of individuals with disabilities over their own identity and self-worth is seriously diminished. When compensation is tied to maternal testimony that abortion or contraconception was preferred to an existing child, the price of assistance is simply too high.

The hard fought gains secured by the disability rights movement should not be placed at risk in the drive for individual compensation. Wrongful birth and wrongful life actions require courts to draw lines among different types of impairments, reinforcing the medical model of disability and creating deep divisions among individuals with disabilities.²⁷⁴ The objective of such litigation is not to highlight the potential richness of life with

Reports of Reactions to Malpractice Litigation, 141 AM. J. PSYCHOL. 563 (1984) and Theodore Passineau, Physician Litigation Stress (2000) (unpublished study) (on file with Dauer)). ²⁷³ Dauer, *supra* note 181, at 37.

²⁷⁴ Cf. Asch, supra note 178, at 253 ("I am convinced that professional limit setting based on a committee's list of 'acceptable' and 'unacceptable' disabilities or variations will erode what cooperation exists among people with disabilities.").

disabilities, but instead the severity of the functional impairment in order to maximize the damage award. If such actions are widely recognized, individual differences, as reflected in individual impairments, will again dominate over the shared experience of stigmatization. Although recovery is posited as a means to assist people with disabilities, the negative historical consequences of such "benevolence," however well intended, are legion.

In the final analysis, tort law should enhance, not undermine, the progressive message endorsed by the minority model of disability and ultimately enshrined in the ADA—that of the inherent worth of every individual with disabilities, and her right to a place in society.²⁷⁵ Only by viewing wrongful birth and life actions as a collective threat facing all individuals with disabilities can tort law avoid endorsing such disabling and disturbing messages.

²⁷⁵ See Asch, supra note 48, at 341 ("Only when policies, laws, medical professionals, schools and media communicate that it is respectable and legitimate to live with a disability, and only when day-to-day reality approximates the aspirations that gave rise to the Americans with Disabilities Act, will it be possible to imagine that the social problems of disability will not compound any biological limitation.").