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**THE STATE OF AFFAIRS REGARDING COUNSELING FOR
EXPECTANT PARENTS OF A CHILD WITH A DISABILITY: DO
ACOG'S NEW PRACTICE GUIDELINES SIGNIFY THE ARRIVAL
OF A BRAVE NEW WORLD?**

INTRODUCTION

*Whether 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.*¹

In 1990, Congress enacted the Americans with Disabilities Act² (ADA), inspiring the “genuine hope that people with disabilities could participate equally and be welcomed in all aspects of American life.”³ Passage of the ADA was brought about by significant contributions from the disabled community.⁴ The ADA was particularly significant because “[d]emands for true integration and acceptance replaced those for mere tolerance, and the goal looked to be achievable.”⁵

To what degree has this integration and acceptance taken place? The tort actions of wrongful birth and wrongful life indicate that there is much work left to be done in the realm of promoting equality for, and eliminating discrimination towards, persons with disabilities. Wrongful birth and wrongful life suits are a “unique subset of medical malpractice claims arising from a defendant’s negligent failure to inform potential parents of the risk that their offspring may suffer from a congenital defect.”⁶ In both wrongful birth and wrongful life tort actions, the parents bringing suit are necessarily required to avow that they would have aborted their fetus had they known of their now-

1. *Becker v. Schwartz*, 386 N.E.2d 807, 812 (N.Y. 1978).

2. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. 12101–12213 (2006)).

3. Wendy F. Hensel, *The Disabling Impact of Wrongful Birth and Wrongful Life Actions*, 40 HARV. C.R.-C.L. L. REV. 141 (2005).

4. *Id.*

5. *Id.*

6. Darpana N. Sheth, *Better Off Unborn? An Analysis of Wrongful Birth and Wrongful Life Claims Under the Americans with Disabilities Act*, 73 TENN. L. REV. 641, 644 (2006).

living⁷ child's congenital condition.⁸ The actionable injury in parents'⁹ wrongful birth lawsuits is their lost choice of whether or not to carry their unborn child to term, given their hypothetical knowledge that the child would be impaired.¹⁰ The legal theory in a wrongful life suit, similar to that of a wrongful birth suit, is that the child, often via his guardian, asserts that he would not have been born but for the health care provider's negligent failure to inform his parents of his potential congenital condition.¹¹ The "operable injury" in a wrongful life tort action is the *life of the child itself*.¹² Both wrongful birth and wrongful life suits can hardly be reconciled with the goals and promises of the ADA.¹³

The American College of Obstetricians and Gynecologists (ACOG) recently issued a Practice Bulletin regarding guidelines (Practice Guidelines) for screening for fetal chromosomal abnormalities such as Down syndrome.¹⁴ The essence of the Practice Guidelines is that women of *all ages* should now be offered both first trimester aneuploidy screening and amniocentesis

7. It seems theoretically possible to sustain such a claim if the child has deceased. It is necessary, however, for the child to have been born.

8. There is some confusion surrounding the distinction between "wrongful conception" and "wrongful birth" claims. Some scholars define wrongful birth claims as only applicable to claims that require parents to avow that they would have had an abortion had they known of their fetus' congenital condition. *See, e.g.,* Michelle McEntire, Comment, *Compensating Post-Conception Prenatal Medical Malpractice While Respecting Life: A Recommendation to North Carolina Legislators*, 29 CAMPBELL L. REV. 761, 764 (2007) (noting that the injury in a claim for wrongful birth is the plaintiff-parents' deprivation of "the right to choose whether to terminate the pregnancy"). Others include in the larger category of wrongful birth the claims mentioned above, but also claims against a geneticist who failed to advise parents of their risk of bearing a child with a disability before conception. *See, e.g.,* Sheth, *supra* note 6, at 645; Kathleen A. Mahoney, Note, *Malpractice Claims Resulting from Negligent Preconception Genetic Testing: Do These Claims Present a Strain of Wrongful Birth or Wrongful Conception, and Does the Categorization Even Matter?*, 39 SUFFOLK U. L. REV. 773, 775 (2006). For purposes of this Comment, the latter claims are defined as "wrongful conception" claims and, thus, largely outside the scope of this Comment. In this Comment, wrongful birth claims are defined much as they are by the Missouri legislature: "No person shall maintain a cause of action or receive an award of damages based on the claim that but for the negligent conduct of another, a child would have been aborted." MO. REV. STAT. § 188.130(b) (2000); *see also* Mahoney, *supra* (discussing Minnesota's similar statutory ban of wrongful birth claims).

9. A wrongful birth lawsuit may be brought by either or both parents. 23 CAUSES OF ACTION SECOND § 4, at 55 (Dana Campbell & Clark Kimball eds., 2003).

10. *Kassama v. Magat*, 792 A.2d 1102, 1103-04, 1115 (Md. 2002); *see also* Hensel, *supra* note 3, at 142 (discussing the development of wrongful birth claims).

11. *Kassama*, 792 A.2d at 1115; *see* Hensel, *supra* note 3, at 143.

12. Hensel, *supra* note 3, at 143; *see* *Kassama*, 792 A.2d at 1116.

13. *See e.g.,* Hensel, *supra* note 2, at 141 (noting that the "excitement and optimism" that ensued the passage of the ADA "has since diminished").

14. *ACOG Practice Bulletin No. 77: Screening for Fetal Chromosomal Abnormalities*, 109 OBSTETRICS & GYNECOLOGY 217 (2007) [hereinafter *ACOG 77*].

examinations.¹⁵ These Practice Guidelines form the basis for the clinical recommendations given by obstetricians and gynecologists across the country. The abortion rate for fetuses with Down syndrome, among women who have chosen to have such testing, is estimated to be between eighty and ninety percent.¹⁶ The increased number of fetal chromosomal abnormalities being diagnosed due to the promulgation of these Practice Guidelines teamed with the current abortion rate for fetuses with such a diagnosis inevitably results in a drastically increased number of abortions of fetuses diagnosed with a disability, and has led to an eight percent decrease in the Down syndrome population in the last two decades.¹⁷ Increased testing and, more arguably, increased termination of fetuses with congenital conditions, may be in part due to increased liability—or perceived liability—resulting from the availability of wrongful birth and wrongful life suits.¹⁸

With an increased focus on identifying congenital conditions in the womb and a staggering abortion rate of fetuses with such conditions, one would expect that—at the very least—expectant parents would be getting the proper information regarding the life aspirations and achievements of individuals with disabilities. Unfortunately, all too often this is not the case.¹⁹ State and federal legislators have responded to this “Brave New World” where fetuses are aborted by parents who have not been given information and counseling that may have been valuable in their difficult decision-making process. The Missouri legislature recently passed Missouri House Bill 818, or Section 191.923 of the Missouri Code, mandating informed genetic counseling for expectant parents of a child with a disability.²⁰ In 2007, Senator Brownback introduced legislation, co-sponsored by Senator Kennedy, called the Prenatally and Postnatally Diagnosed Conditions Awareness Act, containing many of the same recommendations.²¹ Congressman Sensenbrenner of Wisconsin

15. *Id.* at 219.

16. Nancy Cambria, *Laws Mandate Data on Down*, ST. LOUIS POST-DISPATCH, Nov. 9, 2008, at A1.

17. *Id.*

18. See Hensel, *supra* note 3, at 142 & n.7; see also 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) (book review) (arguing that improvements in technology generally increase negligent behavior).

19. See *infra* Part III.

20. H.B. 818, 94th Gen. Assem., 1st Reg. Sess. (Mo. 2008) (codified at MO. REV. STAT. § 191.923 (Supp. 2008)).

21. Prenatally and Postnatally Diagnosed Conditions Awareness Act, S. 1810, 110th Cong. (2007) (as introduced in the Senate, July 18, 2007).

introduced the companion version of the bill in the House of Representatives.²² Congress recently passed this federal legislation (the Prenatally and Postnatally Diagnosed Conditions Awareness Act) on September 25, 2008, by a voice vote,²³ and the bill was signed into law by President Bush on October 8, 2008.²⁴

This author believes that legislation similar to Section 191.923 of the Missouri Code and the Prenatally and Postnatally Diagnosed Conditions Awareness Act is necessary both to eliminate the legal threat of wrongful birth and wrongful life actions and to facilitate adequate and accurate genetic counseling for expectant parents of children with disabilities.

Although a woman's right to procreative choice, including access to an abortion in certain circumstances, as affirmed in *Roe v. Wade*²⁵ and subsequent decisions, is indelibly woven into the fabric of wrongful birth or wrongful life claims,²⁶ this Comment is not meant to be a wide-ranging indictment of abortion.²⁷ Nor is the Comment intended to focus solely on Down syndrome. Down syndrome, also known as trisomy 21, is one of many genetic disorders that can be diagnosed *in utero* but cannot be "cured" in any clinical sense.²⁸ The specific mention of Down syndrome in the recent ACOG Practice

22. Prenatally Diagnosed Condition Awareness Act of 2007, H.R. 3112, 110th Cong. (2007) (as introduced in House, July 19, 2007).

23. 154 CONG. REC. H9918–20 (daily ed. Sept. 25, 2008).

24. Prenatally and Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110-374, 122 Stat. 4051 (2008) (to be codified at 42 U.S.C. § 280g-8).

25. 410 U.S. 113 (1973).

26. See *Hummel v. Reiss*, 608 A.2d 1341, 1346 (N.J. 1992). In fact, wrongful birth and wrongful life claims were brought before *Roe*. See *id.* at 1343 (citing *Gleitman v. Cosgrove*, 227 A.2d 689 (N.J. 1967)); see generally Alan J. Belsky, *Injury as a Matter of Law: Is This the Answer to the Wrongful Life Dilemma?*, 22 U. BALT. L. REV. 185, 191–96, 191 n.15 (1993) (providing a history of pre-*Roe* wrongful life and wrongful birth claims). The number and success of such claims, however, has drastically increased since *Roe* was decided. See generally Belsky, *supra*, at 191 (supporting the argument that judicial decisions concerning wrongful life and wrongful birth actions "have followed a clear course paralleling the progression of the constitutional right to practice birth control and procure abortions").

27. For a discussion of the moral and social implications of the legal right to abortion as opposed to actions for wrongful birth and wrongful life, see for example, Hensel, *supra* note 3, at 171–81 (arguing that although "[a] woman's right to reproductive freedom includes the right to make unpopular choices regarding the future of her pregnancy," selective termination and wrongful birth and wrongful life actions have distinct moral and social implications); Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315, 340 (2003); John A. Robertson, *Procreative Liberty in the Era of Genomics*, 29 AM. J.L. & MED. 439, 457–58 (2003) (suggesting that allowing parents the choice to terminate a pregnancy if the fetus is found to have a congenital disability does not send the message to "persons with those conditions or disabilities that their lives are not valued or that it would be preferable that they had not been born," as some scholars have argued).

28. Down syndrome, or trisomy 21, is a condition that occurs from three copies of the twenty-first chromosome.

Guidelines,²⁹ its mention in Section 191.923 of the Missouri Code,³⁰ and in the Prenatally and Postnatally Diagnosed Conditions Awareness Act,³¹ and the staggering abortion rate for fetuses diagnosed with Down syndrome,³² place certain emphasis on this condition and make it particularly ripe for discussion in the arena of prenatal testing and disability rights.

Rather, this Comment seeks to honestly discuss the impact the tort actions of wrongful birth and wrongful life—both premised as they are on the assertion that a fetus would have been aborted had the parents known of the fetus' congenital condition—have on the disabled community and on society at large. Scholars have predicted the onset of defensive medicine as a result of wrongful birth and wrongful life actions.³³ Arguably, ACOG's recent Practice Guidelines represent such defensive medicine, insofar as it militates towards a standard of care without sufficient guarantees that expectant parents are receiving adequate information and counseling. This Comment attempts to explore the subsequent impact defensive medicine may have on informed consent and proposes some legislative solutions to eliminate the threat of legal action via wrongful birth and wrongful life actions and to further ensure accurate, non-directive genetic counseling.

Part I of this Comment evaluates some of the historical models of disability and their impacts on legal approaches to disability law. Part II discusses the flaws in the tort actions of wrongful birth and wrongful life and the equally flawed impact these actions have had on the current state of genetic counseling for expectant parents of a child with a disability. Part III discusses the new ACOG Practice Guidelines, the response of some disability groups to these Practice Guidelines, and some expected ramifications of the Practice Guidelines. Part IV will discuss several legislative solutions to the current legal climate, including some frameworks for barring wrongful birth and wrongful life actions as well as a discussion of both the recently passed Missouri legislation and the Prenatally and Postnatally Diagnosed Conditions Awareness Act. Part V will propose a more informed decision-making process for expectant parents of a child with a disability, one that is in accord with the goals and promises of the ADA, and that guarantees that all expectant parents of a child diagnosed with a disability have access to the necessary information and non-directive counseling.

29. ACOG 77, *supra* note 14, at 217.

30. MO. REV. STAT. § 191.923 (Supp. 2008).

31. Prenatally and Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110-374, 122 Stat. 4051 (2008) (to be codified at 42 U.S.C. § 280g-8).

32. Cambria, *supra* note 16.

33. *See generally* Sheth, *supra* note 6, at 665 (“[A]llowing tort claims like wrongful birth and wrongful life may encourage physicians to practice defensive medicine For example, . . . [ordering] all available diagnostic tests in an effort to avoid liability for potentially exorbitant compensatory damages, regardless of the cost or need for the diagnostic test.”).

I. HISTORICAL MODELS OF DISABILITY

The use of interdisciplinary materials to influence legal issues and outcomes is one of the great triumphs of the past few decades of legal history.³⁴ One need only look to cases such as *Brown v. Board of Education*³⁵ to affirm this statement. Only recently, however, have legal scholars begun to incorporate such interdisciplinary materials into a discussion of disability related discourse.³⁶ Because disability legal theory is a relative latecomer to embrace the value of such interdisciplinary discourse, a review of the historical models of disability is useful to evaluate the development of disability law. These models “provide the foundation for deconstructing the images and conceptions of disability that motivate the case law on wrongful birth and wrongful life.”³⁷

The medical model of disability has dominated and continues to dominate much of public thinking about impairment and disability.³⁸ The essence of this model is that disability is a trait that results from the internal functional limitations of an individual.³⁹ Because disability is viewed as mainly a medical issue, “[p]hysicians serve as the gatekeepers of disability” and “[i]t is an unstated assumption that the medical community can precisely identify impairments and accurately assess functionality.”⁴⁰ This model essentially echoes the familiar phrase that “biology is destiny.”⁴¹ Importantly, “[s]ince society did not cause the social disadvantages that flow naturally from biology, it is under no obligation . . . to alleviate them [and] any remediation society chooses to undertake falls under the heading of charitable intervention rather than entitlement.”⁴²

Not surprisingly, the medical model’s focus on disability as biology leads to the conclusion that the solution to disability is similarly biological.⁴³ Social policy focuses on “eliminat[ing] as much disability as possible, by using medical technology to cure existing disability or prevent future disability . . . ,

34. See Hensel, *supra* note 3, at 145.

35. 347 U.S. 483, 493, n.11 (1954) (relying, in part, on evidence from social science research to conclude that racial segregation in public schools is unconstitutional).

36. See Mary Crossley, *The Disability Kaleidoscope*, 74 NOTRE DAME L. REV. 621, 627 (1999).

37. Hensel, *supra* note 3, at 146.

38. *Id.*

39. Crossley, *supra* note 36, at 649.

40. Hensel, *supra* note 3, at 146.

41. *See id.*

42. *Id.* at 146–47.

43. *Id.* at 147.

and . . . us[ing] rehabilitative techniques to help disabled individuals approximate dominant physical standards as closely as possible.”⁴⁴

Genetic counseling that fails in its stated goal of being non-directive thus both reflects and reinforces the medical model of disability. Parents who are not presented with “timely and informative counseling,” which includes “current information about the conditions that were tested for, the accuracy of such tests, and resources for obtaining support services for such conditions”⁴⁵ are done a disservice at the hands of years of public thinking about disability that fails to recognize that disability is more than simply a medical condition to be either cured or prevented. Wrongful birth and wrongful life tort suits “broadcast the medical model’s message of the biological inferiority and ‘otherness’ of impaired individuals. Disability is reinforced as an inherent personal trait, and biology, once again, becomes destiny.”⁴⁶

By contrast, the social model of disability contends that disability is, at least in part, “a social construction shaped by environmental factors.”⁴⁷ As opposed to the medical model, which focuses on the inherent physical limitations of individuals, the social model “asserts that ‘disability’ is not caused by impairment but by the social barriers . . . that people with impairments . . . come up against in every arena.”⁴⁸ A classic example would be an individual in a wheelchair who cannot enter a building constructed with stairs. Such an 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.”⁴⁹ The important consequence of such thinking is that

44. Crossley, *supra* note 36, at 652 (footnotes omitted); see Hensel *supra* note 3, at 147. While it is certainly not the contention of this Comment that all medical professionals view disability in this manner, there is support for the view that the medical profession approaches disability, at least partially, in this manner. For example, Steven J. Ralston, *Reflections from the Trenches: One Doctor’s Encounter with Disability Rights Arguments*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 334, 335 (Erik Parens & Adrienne Asch eds., 2000), observes:

I cannot comment on all doctors’ medical training because it varies from medical school to medical school. In general, what I was taught in medical school and in my training is that disability—no matter what its form—is a bad thing and to be avoided at all costs. Lectures or seminars on Down syndrome or other genetic syndromes were geared toward the description of the abnormalities and the efforts that can be made to prevent the problem in the first place; that children with congenital diseases may find their lives to be rich and valuable was hardly recognized, much less stressed.

45. MO. REV. STAT. § 191.923.3 (Supp. 2008).

46. Hensel, *supra* note 3, at 175 (footnotes omitted).

47. Richard K. Scotch, *Models of Disability and the Americans with Disabilities Act*, 21 *BERKELEY J. EMP. & LAB. L.* 213, 214 (2000).

48. C. Thomas, *Disability: Getting It “Right,”* *J. MED. ETHICS*, 15, 15 (2008); see also Hensel, *supra* note 3, at 147–48 (discussing the social model of disability).

49. Hensel, *supra* note 3, at 148.

“assumptions of the inability to participate become self-fulfilling prophecies.”⁵⁰

There are admittedly limitations to the social model of disability. It is true that some individuals have severely limiting conditions that exist independently of any social construction of disability. The social model, though, “need not deny that some limitations flow directly from impairment in order to argue that externally imposed disadvantages should [nonetheless] be remedied.”⁵¹ Indeed, one need only look to a typical wrongful birth or wrongful life suit to realize that powerful external social barriers remain to prevent full acceptance of people with disabilities into society.

An important attribute of the social model of disability is that, not surprisingly, the remedy is also social in nature.⁵² By contrast to the medical model, public policy response to disability is not to “cure” the defects of the individual, but to “understand the disabling social relationships and forces (individual and collective) that work both to directly socially exclude and to undermine psychoemotional well-being of adults and children with impairments.”⁵³

A more recent theory of disability, referred to as the civil rights or minority group model of disability, views disability primarily as a function of social relationships and discrimination rather than inherent functional limitations, and uses this recognition as the foundation of a group identity for people with disabilities.⁵⁴ Because to view disability as “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,” the minority model eschews this line of thinking.⁵⁵ By encouraging the view that disability is a socially generated notion, “individual impairments take a back seat to the universal experience of discrimination and stigmatization.”⁵⁶ Because under this model “individuals with disabilities are encouraged to see themselves as members of a discrete minority group,” this model “transforms relatively powerless individuals into a unified political body insistent on the ‘eradication of exclusionary practices and structures as a matter of civil rights.’”⁵⁷

50. Scotch, *supra* note 47, at 215.

51. Crossley, *supra* note 36, at 658.

52. Thomas, *supra* note 48, at 15–16.

53. *Id.* at 16.

54. Harlan Hahn, *Feminist Perspectives, Disability, Sexuality and Law: New Issues and Agendas*, 4 S. CAL. REV. L. & WOMEN’S STUD. 97, 101 (1994); *see also* Hensel, *supra* note 3, at 149 (discussing the minority group model of disability).

55. Hahn, *supra* note 54, at 105.

56. Hensel, *supra* note 3, at 149.

57. *Id.* (quoting Crossley, *supra* note 36, at 659).

Many scholars have credited passage of the ADA, in part, to the political awareness borne out of the minority model of disability.⁵⁸ Scholars have argued that “Congress adopted a civil-rights model for addressing disability issues by using the Civil Rights Act of 1964 as a foundation for drafting and interpreting the ADA.”⁵⁹ Wrongful birth and wrongful life lawsuits are particularly unacceptable when viewed through the lens of the social or minority model of disability. Similarly, when expectant parents are unduly influenced to either undergo prenatal testing or terminate a pregnancy because of a diagnosed disability, the goals of the social and minority models of disability are directly undermined.

II. WRONGFUL BIRTH AND WRONGFUL LIFE SUITS

A. *The Origins and Expansion of Wrongful Birth and Wrongful Life Suits*

Wrongful birth and wrongful life suits are a “unique subset of medical malpractice claims arising from a defendant’s negligent failure to inform potential parents of the risk that their offspring may suffer from a congenital defect.”⁶⁰

In *Becker v. Schwartz*, the plaintiff mother gave birth to a child with Down syndrome.⁶¹ The mother “alleged that her physician neither advised her of the increased risk of [bearing a child] with birth defects [for] women over thirty-five years of age nor recommended that she have an amniocentesis.”⁶² The actionable injury in the parents’ wrongful birth suit was thus their lost choice of whether or not to carry the unborn child to term, given their hypothetical knowledge that the child would be impaired.⁶³ The parents also filed a wrongful life action on behalf of their child.⁶⁴ The operable injury in the wrongful life tort action was the child’s life itself.⁶⁵ The legal theory in the wrongful life suit was that the child asserted he would not have been born but for the doctor’s failure to recommend an amniocentesis or fully inform the parents of their chances of bearing a child with a genetic condition.⁶⁶ The

58. *Id.* at 150 & n.48.

59. Sheth, *supra* note 6, at 654.

60. *Id.* at 644.

61. *Becker v. Schwartz*, 386 N.E.2d, 807, 808 (N.Y. 1978). The court described Dolores Becker as “a retarded and brain-damaged infant who suffers, and will continue to suffer for the remainder of her life, from Down’s Syndrome, commonly known as mongolism.” *Id.*; *see also* Hensel, *supra* note 2, at 156–58 (discussing *Becker* and other early wrongful birth and wrongful life cases).

62. Hensel, *supra* note 3, at 156; *see Becker*, 386 N.E.2d at 808–09.

63. *Becker*, 386 N.E.2d at 813.

64. *Id.* at 809.

65. *Id.* at 812.

66. *Id.*

court took the approach that is currently endorsed by many jurisdictions: to deny the wrongful life claim⁶⁷ and allow the wrongful birth claim to go forward.⁶⁸

Wrongful birth and wrongful life suits are essentially an outgrowth of “wrongful conception” or “wrongful pregnancy” claims.⁶⁹ Such claims “were [usually] brought by parents against either physicians who had performed negligent sterilization procedures . . . or manufacturers who had developed faulty contraceptive products.”⁷⁰ In such a situation, “the defendants’ negligence resulted in the birth of a healthy child despite the parents’ clearly expressed desire to avoid conception.”⁷¹ Tort actions of this type have been widely accepted in most jurisdictions, in large part because they “are consistent with traditional medical malpractice and product liability actions” insofar as “the plaintiff can easily establish that, but for the physician’s negligence, the child . . . would not have been conceived.”⁷²

In such cases, courts have typically “awarded the plaintiff mothers their medical expenses and emotional distress damages associated with pregnancy and childbirth.”⁷³ The majority of courts, however, “have rejected the expansion of such damages to the costs of raising the unexpected child to adulthood,” usually because to do so would require courts to “label[] the child’s life, rather than the mother’s experience as a legally compensable ‘injury.’”⁷⁴

Medical advances allowing for sophisticated prenatal diagnosis of certain disabilities “coupled with the loosening of the fetters on abortions triggered in 1973 by *Roe v. Wade*,” have given rise to the tort actions of wrongful birth and wrongful life.⁷⁵ In wrongful birth suits, the essence of the claim is that the parents “would have aborted their unborn child had the impairment been properly diagnosed. The injury identified . . . is the parents’ lost choice over whether or not to carry [the disabled] child to term.”⁷⁶ Wrongful life suits are

67. *Id.*; see Hensel, *supra* note 3, at 161 n.118 (listing jurisdictions that have rejected wrongful life claims).

68. *Becker*, 386 N.E.2d at 813; see Sheth, *supra* note 6 at 650 n.59 (listing jurisdictions that have allowed wrongful birth claims).

69. Hensel, *supra* note 3, at 151.

70. *Id.*

71. *Id.*

72. Hensel, *supra* note 3, at 151; 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”).

73. Hensel, *supra* note 3, at 151.

74. *Id.* at 151 & n.53 (listing cases that have refused to label the child’s life as an “injury” thus refusing to provide plaintiff-mothers damages for child-rearing expenses).

75. *Kassama v. Magat*, 792 A.2d 1102, 1115 (Md. 2002) (citing *Roe v. Wade*, 410 U.S. 113 (1973)); see also Hensel, *supra* note 3, at 160 (describing the development of wrongful birth and wrongful life claims).

76. Hensel, *supra* note 3, at 142–43.

necessarily connected to wrongful birth suits. Because these suits are initiated in the child's name, the context of the suit is changed, and different implications are raised.⁷⁷ In a typical medical negligence action, of course, the disability caused by a physician is identified as the harm in the tort model.⁷⁸ In wrongful life suits, because the physician's "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."⁷⁹

Only four jurisdictions currently allow wrongful life suits.⁸⁰ Courts that have rejected wrongful life suits have usually done so either by reasoning that life with a disability is better than no life at all, therefore that life cannot constitute an injury at law;⁸¹ by finding that damages are incalculable;⁸² or by recognizing that public policy dictates rejection of the tort.⁸³ By contrast, twenty-three jurisdictions recognize wrongful birth claims⁸⁴—claims that are arguably equally as damaging to the disability rights movement.⁸⁵ One explanation for the divergent treatment of these torts is that "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."⁸⁶

The distinction between wrongful birth and wrongful life actions on the grounds that the injury identified in a wrongful birth action is simply lost choice, though, is largely an example of how much of the debate surrounding wrongful birth and wrongful life actions has become "camouflaged by the rhetoric of reproductive choice."⁸⁷ Because wrongful birth torts are reserved for the births of children bearing congenital conditions, any distinction

77. *See id.* at 144 (arguing that the issues raised by each claim are fundamentally the same).

78. *See* *Becker v. Schwartz*, 386 N.E.2d 807, 811 (N.Y. 1978).

79. Hensel, *supra* note 3, at 143 (emphasis added).

80. *See id.* at 162 n.122 (listing cases from California, New Jersey, and Washington that have recognized wrongful life suits); ME. REV. STAT. ANN. tit. 24, § 2931 (2005). *But see* *Turpin v. Sortini*, 643 P.2d 954 (Cal. 1982).

81. *See* Hensel, *supra* note 3, at 161 n.119 (listing cases that have refused to find that being born in and of itself is a "legally cognizable injury").

82. *See id.* at 161 n.120 (listing cases where courts have concluded that damages are incalculable).

83. *See id.* at 161 n.121 (listing cases that note policy reasons for rejecting wrongful life claims).

84. *See* Sheth *supra* note 6, at 650 & n.59.

85. Hensel, *supra* note 3, at 145 ("Even though the courts have treated the two torts differently, they are analytically similar and lead to equally problematic anti-therapeutic consequences.").

86. *Id.* at 143.

87. Sheth, *supra* note 6, at 660.

between wrongful birth and wrongful life actions on the basis of lost choice is disingenuous.⁸⁸ As disability rights scholar Wendy Hensel has pointed out:

In [wrongful birth] 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 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, 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.⁸⁹

Given the wrongful birth and wrongful life actions' unique focus on the child's congenital condition, is the standard tort model truly appropriate?

B. The Wrongful Reasoning and Harmful Results of Wrongful Birth and Wrongful Life Actions

While many scholars contend that wrongful birth and wrongful life suits fit comfortably within traditional tort principles,⁹⁰ there seem to be at least a few significant distinctions between these suits and a traditional tort suit. "First, wrongful birth and wrongful life [suits] broaden the traditional element of proximate cause" almost beyond recognition.⁹¹ Both these actions are, of course, premised on the condition that the parents would have chosen abortion over birth of their child. The plaintiff parents in a wrongful birth or wrongful life suit, though, simply cannot assert that the physician is the proximate cause of the birth *condition*.⁹² The physician did not cause the child to have any genetic impairment, nor could she have given the child a life free from the congenital condition with which she was born.⁹³

Wrongful birth and wrongful life claims also differ significantly "from traditional negligence claims because they involve two specific and unique comparisons."⁹⁴ Wrongful birth and wrongful life claims require (1) a comparison between the value of a child with a disability and the value of a

88. See, e.g., 23 CAUSES OF ACTION SECOND, *supra* note 9, § 4, 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)).

89. Hensel, *supra* note 3, at 166–67 (emphasis added) (footnote omitted).

90. *Id.* at 143 n.14 (listing works by various scholars who suggest that wrongful life and wrongful birth tort claims correspond with "traditional negligence principles").

91. Sheth, *supra* note 6, at 646.

92. *Id.*

93. *Id.*

94. *Id.* at 647.

child born free of diagnosable impairment, and (2) a comparison between the value of a life with a disability and nonexistence itself.⁹⁵

First, the claims require a comparison between the value of a child with a disability and the value of a child born free of impairment. As Hensel has noted:

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.⁹⁶

This is despite evidence that many families find life with a child with a disability to be a positive experience.⁹⁷

Second, wrongful birth and wrongful life claims also require a comparison between the value of a life with a disability and nonexistence itself.⁹⁸ In other words, because there is nothing a health care provider could have done to give the child a nondisabled life, “it appears inconsistent with basic tort principles [of compensation] to view the injury for which defendants are legally responsible solely by reference to plaintiff’s present condition without taking into consideration the fact that if defendants had not been negligent she would not have been born at all.”⁹⁹

As one court put it:

The sanctity of the 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. It may have been easier for the mother and less expensive for the father to have terminated the life of their child while he was an embryo, but these alleged detriments cannot stand against the preciousness of the single human life to support a remedy in tort.¹⁰⁰

Another court has noted, “[t]he necessary inquiry is objective, not subjective; the court cannot avoid assessing the ‘worth’ of the child’s life.”¹⁰¹

95. *Id.*

96. Hensel, *supra* note 3, at 154.

97. See e.g., Brian Skotko, *Mothers of Children With Down Syndrome Reflect on Their Postnatal Support*, 115 PEDIATRICS 64, 73 (2005); Patricia Bauer, *Stand Tall*, DOWN SYNDROME NEWS, Sunday, Aug. 5, 2007, at 68.

98. Sheth, *supra* note 6, at 647.

99. *Turpin v. Sortini*, 643 P.2d 954, 961 (Cal. 1982).

100. *Gleitman v. Cosgrove*, 227 A.2d 689, 693 (N.J. 1967), *overruled in part by Berman v. Allan*, 404 A.2d 8, 15 (N.J. 1979) (noting that unlike *Gleitman*, the court will recognize and allow compensation for mental and emotional distress in wrongful birth cases); see also Sheth, *supra* note 6, at 648–49 (discussing *Gleitman*).

101. See Hensel, *supra* note 3, at 174–75 & n.183 (quoting *Smith v. Cote*, 513 A.2d 341, 353 (1986)).

By devaluing the life of a child with a disability as compared to the life of a child without that particular disability, and by reducing the value of a child with a disability to below existence itself, wrongful birth and wrongful life claims significantly “discount, or even nullify, the value of life with a disability.”¹⁰² The tragedy of such reasoning is that it comes at a time when people with disabilities are enjoying significantly improved lives.¹⁰³

The logic and process of wrongful birth and wrongful life claims has a severely negatively impact on the children involved in these suits. Courts have sometimes overlooked this truism by accepting the logic that reimbursing parents for the medical and educational expenses they may incur in raising a child with a disability is a positive and appropriate response to the birth of a child with a disability.¹⁰⁴ In essence, courts have “fail[ed] to see how the parents’ recovery of extraordinary medical and educational expenses, so as to minimize the detrimental effect of the child’s impairment, is outweighed by any speculation about stigma that he might suffer.”¹⁰⁵ Far from being speculative, though, the societal stigma reinforced by the testimony and reflected by the suit itself is the very real result of his or her parents’ testimony in open court that they would have aborted the child had they known of his or her congenital condition. This testimony is necessary to establish the causation required by the tort model—some “parents have even sought to introduce their children as [demonstrative] exhibits in litigation.”¹⁰⁶

It is not difficult to see that “[s]uch testimony is emotionally crippling not only to the child suffering from physical or mental infirmities, but also to the larger disability community that seeks equality of opportunity and full participation, both of which are goals supported by the ADA.”¹⁰⁷ As opposed to “outweighing” any perceived damage to the child with a disability, awarding damages to an individual plaintiff is itself debilitating to the disability rights movement. This is because along with the delivery of damages to an individual litigant comes the demoralizing message that an individual with a disability is inherently deficient—so deficient, in fact, that his or her life may constitute an injury at law.¹⁰⁸ Simply put, the obvious implication of wrongful

102. Sheth, *supra* note 6, at 648 (citing *Phillips v. United States*, 508 F.Supp. 537, 543 (D.S.C. 1980); *Berman v. Allan*, 404 A.2d 8, 12–13 (N.J. 1979)).

103. *See, e.g.*, *Bauer, supra* note 97.

104. *See Lininger v. Eisenbaum*, 764 P.2d 1202, 1208 (Colo. 1988) (en banc) (finding that plaintiffs were entitled to prove and recover medical and educational expenses in a wrongful birth action).

105. *Id.* at 1207.

106. *Hensel, supra* note 3, at 172 & n.174; *see also Thornhill v. Midwest Physician Ctr.*, 787 N.E.2d 247, 261 (Ill. App. Ct. 2003) (finding that it was within the circuit court’s discretion to bar plaintiff-parent from using her child as a “demonstrative exhibit” in litigation).

107. *Sheth, supra* note 6, at 660.

108. *See Hensel, supra* note 3, at 143–54, 151.

birth and wrongful life suits is that this child *should not be alive*. As Hensel has noted, “any benefits that wrongful birth and wrongful life actions secure for the individual plaintiff come at a cost of demeaning and demoralizing anti-therapeutic messages delivered to the community of people with disabilities and to greater society.”¹⁰⁹

C. *The Perceived Benefits Do Not Outweigh the Harms*

Wrongful birth and wrongful life suits are often justified on two main grounds: “(1) they establish a means to deter negligent conduct by health care providers” and thereby preserve parental autonomy; and “(2) they compensate parents and children for injuries or losses sustained as a result of this negligent conduct.”¹¹⁰

There are, however, many strong arguments against the use of wrongful birth and wrongful life suits as means to deter negligence among health care providers. For starters, Darpana Sheth has argued that “allowing tort claims like wrongful birth and wrongful life may encourage physicians to practice defensive medicine, which could lead to increases in the cost of healthcare.”¹¹¹ An example of defensive medicine would be to order “all available diagnostic tests in an effort to avoid liability for potentially exorbitant compensatory damages, regardless of the cost or need for the diagnostic test.”¹¹² ACOG’s most recent Practice Guidelines offering “practical recommendations for implementing Down syndrome screening in practice,”¹¹³ arguably, represent such defensive medicine and are discussed below in Part III.

Moreover, the health care provider’s duty of care—her duty to provide expectant mothers with accurate information so they can decide whether or not to continue a pregnancy—is undermined where testing itself becomes a duty on the part of expectant mothers, and the existence of these causes of action creates incentives, pressuring women to terminate pregnancies. The unintended consequence of wrongful birth and wrongful life suits is often that health care providers may, in their fear of litigation, overstate the effects of certain disabilities and thus not provide the “informed consent” each woman is guaranteed.¹¹⁴ Courts have openly expressed concern “that physicians, uncertain of the distress parents might feel about bearing a child with genetic abnormalities, would resort to recommending abortion, fearing a wrongful

109. *Id.* at 164.

110. Sheth, *supra* note 6, at 664; *see also* Kassama v. Magat, 792 A.2d 1102, 1114 (Md. 2002); Canesi v. Wilson, 730 A.2d 805, 811 (N.J. 1999).

111. Sheth, *supra* note 6, at 665.

112. *Id.*

113. *See* ACOG 77, *supra* note 14, at 217.

114. *See* Stephanie S. Gold, *An Equality Approach to Wrongful Birth Statutes*, 65 *FORDHAM L. REV.* 1005, 1039 (1996); *see also* Hensel, *supra* note 3, at 168–71.

birth lawsuit.”¹¹⁵ One need not look far for examples of such situations. A set of parents, thinking their child had one disability, exercised their right for a selective abortion, only to discover their child had a completely different disability.¹¹⁶ Another set of parents received a telephone call informing them that their child had a genetic impairment; in the same phone call, they were reassured that the doctor had already scheduled the abortion for the next day.¹¹⁷

“Under such circumstances, what exactly is the meaning of informed consent?”¹¹⁸ Some have argued that selective abortions in the atmosphere under which information is currently presented to women offer less of a choice, and more of a mandate:

The new technology of prenatal diagnosis and selective abortion offers new choices, but it also creates new structures and new limitations on choice. Because of the society in which we live, the choices are inevitably couched in terms of production and commodification, and thus do not move us to see new levels of genuine choice.¹¹⁹

Defensive medicine, insofar as it may place excessive pressure on a woman to have an abortion, frustrates rather than enhances a woman’s right to informed procreative choice.

Adrienne Asch, a disability rights scholar and staunch pro-choice advocate, has noted, as defensive medicine becomes the standard, disability rights advocates’ fears will be realized that “it will be very difficult for most families to consider bringing children with diagnosable disabilities into the world if they know that the society believes that their births should have been prevented.”¹²⁰ Parental autonomy demands that “at least the decisions [to have eugenic abortions] will be those of the people ultimately raising children, and not society, in the form of its insurance carriers and clinicians as gatekeepers.”¹²¹ Social pressure, like defensive medicine, drains parental autonomy. The argument that wrongful birth and wrongful life actions actually promote parental autonomy is thus inaccurate and misleading.

It is worth noting as well, that the low correlation between the incidence of medical negligence and associated lawsuits indicates that there is little evidence to show that malpractice suits actually target and reduce medical negligence.¹²² Because relatively few patients injured by medical malpractice

115. McEntire, *supra* note 8, at 778 (citing *Azzolino v. Dingfelder*, 337 S.E.2d 528, 535 (N.C. 1985)).

116. RAYNA RAPP, TESTING WOMEN, TESTING THE FETUS 130 (1999).

117. KIM KLUGER-BELL, UNSPEAKABLE LOSSES 86 (1998).

118. RAPP, *supra* note 116, at 130.

119. BARBARA KATZ ROTHMAN, THE TENTATIVE PREGNANCY 14 (1986).

120. Asch, *supra* note 27, at 340.

121. *Id.* at 339.

122. See Michelle M. Mello & Troyen A. Brennan, *Deterrence of Medical Errors: Theory and Evidence for Malpractice Reform*, 80 TEX. L. REV. 1595, 1616 (2002).

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.¹²³ The particularly low correlation between the incidence of children born with a congenital condition and the incidence of wrongful birth and wrongful life lawsuits seems to further weaken the argument that these suits truly serve any deterrent purpose.¹²⁴

Furthermore, if medical negligence is really the issue addressed by wrongful birth and wrongful life claims, there are other mechanisms that have been proven more effective. Mandatory specialized training in the field of genetic testing for obstetricians, gynecologists, and primary care physicians involved in prenatal testing would be one such solution. Section 191.923 of the Missouri Code mandates:

When a prenatally diagnosed condition, including but not limited to Down Syndrome, becomes known as a result of one or more prenatal tests, the physician or other health care professional who requested or ordered prenatal tests . . . shall provide the patient with current information about the conditions that were tested for, the accuracy of such tests, and resources for obtaining support services for such conditions.¹²⁵

This seems a far more rational way to promote informed consent than adopting and adapting tort models to a situation that requires parents to avow, in open court, that they would have aborted their child had the physician fully informed them of their fetus’ genetic condition. Further, legislative mandates such as these reach the people intended—all expectant parents of children with congenital conditions—rather than the few who choose to pursue compensation through tort action.¹²⁶ Disciplinary action by state medical licensing boards and increased federal and state regulation of laboratories that conduct genetic testing are other alternatives to reducing medical negligence.¹²⁷

The second reason often offered in defense of wrongful birth and wrongful life suits—that they compensate parents and children for injuries or losses sustained as a result of a health care provider’s negligent conduct—is similarly inaccurate and deceiving.¹²⁸ Advocates of the system argue that these claims operate “as a type of supplemental insurance that spreads such financial hardships to parties who are more likely to be able to bear the cost.”¹²⁹ This is

123. *Id.* at 1618.

124. *Id.*; see also Sheth, *supra* note 6, at 665.

125. MO. REV. STAT. 191.923.3 (Supp. 2008).

126. See Sheth, *supra* note 6, at 665.

127. *Id.*

128. *Id.* at 666.

129. *Id.*

inaccurate, though, because the focus of a wrongful birth or wrongful life suit is not the individual or family's need for financial assistance.¹³⁰ States have entirely differed in their application and valuation of damages and the amount of recovery they have allowed for wrongful birth and wrongful life suits.¹³¹ Thus, these claims "may provide substantial, but unnecessary, financial support to some families and provide no relief to other families with compelling need for financial support."¹³²

More importantly, financial recovery is neither available to all parents who bear children with disabilities nor to all children born with such disabilities. Rather, "recovery is limited to cases where parents testify that they would have aborted the child or where children testify that they should have been aborted . . . '[O]nly to those willing to openly disavow their self-worth and dignity.'"¹³³ In the words of Darpana Sheth, "[b]y compensating those who devalue children with congenital defects and denying recovery to those who embrace these children, wrongful birth and wrongful life claims create a perverse system that sends a negative message about the value of life with disability."¹³⁴

Wrongful birth and wrongful life suits may promote an unhealthy attitude toward disabilities, escalate physician liability, and promote defensive medicine. None of these results happen in a vacuum. As societal values shift, national advisory groups and physician practice groups such as the ACOG respond to insulate themselves from liability, the amalgam of interests implicated by these suits may coalesce to form policy prescriptions that are not optimal for society.

III. ACOG PRACTICE GUIDELINES

In January 2007, the ACOG published Practice Guidelines setting forth a new set of guidelines for testing for certain congenital conditions.¹³⁵ These Practice Guidelines are ACOG's recommendations to all practicing obstetricians and gynecologists in the United States and are "designed to aid practitioners in making decisions about appropriate gynecological care."¹³⁶ Thus, they are very influential and affect the everyday procedures of physicians across the country. The stated goal of this bulletin was to "offer

130. *Id.*

131. *See* Hensel, *supra* note 3, at 160; *see also* Sheth, *supra* note 6, at 650–53.

132. Sheth, *supra* note 5, at 666.

133. *Id.* (quoting Hensel, *supra* note 3, at 171).

134. *Id.*

135. *See* ACOG 77, *supra* note 14.

136. *Id.* at 217.

practical recommendations for implementing Down syndrome screening in practice.”¹³⁷

There are currently a variety of prenatal screening and testing medical techniques available to obstetricians and their patients. There are ways to obtain fetal tissue samples by amniocentesis or chorionic villus sampling and to test these tissue samples for genetic conditions such as Down syndrome.¹³⁸ These tests, though, fall under the category of “invasive” tests.¹³⁹ These techniques carry a certain, not insignificant, amount of risk to the fetus, and for that reason, it is “not . . . appropriate to examine every pregnancy this way.”¹⁴⁰

As a result, screening tests have been developed to try to identify those pregnancies at “high risk.”¹⁴¹ Screening tests are not as invasive.¹⁴² However, they are more likely to be wrong.¹⁴³ Screening tests do not provide definite confirmation that a fetus has a certain condition.¹⁴⁴ Screening tests provide an adjusted estimate of the chances a certain fetus bears a certain condition.¹⁴⁵ “There are ‘false-positives’ or ‘screen-positives’ ([when a] test states the patient [or fetus] has the condition when the patient really doesn’t) and ‘false-negatives’ ([when a] patient [or fetus] has the condition but the test states he/she doesn’t).”¹⁴⁶

“Because the [chance] of having a baby with Down syndrome [rises] above the 1 in 250 mark [at age 35] for women,” the typical standard of care for the last twenty-five years or so was “to offer the screen for Down syndrome to all mothers 35 years and older.”¹⁴⁷ This changed in January 2007, due to the ACOG Practice Guidelines.¹⁴⁸

The essence of the January 2007 ACOG Practice Guidelines is that “[i]deally, all women should be offered aneuploidy screening before 20 weeks of gestation, regardless of maternal age” and “[s]creening and invasive diagnostic testing for aneuploidy should be available to all women who present for prenatal care before 20 weeks of gestation regardless of maternal age.”¹⁴⁹

137. *Id.*

138. Len Leshin, *Prenatal Screening for Down Syndrome*, 23 J. PERINATAL MED. (1995), <http://www.ds-health.com/prenatal.htm>.

139. *Id.*

140. *Id.*

141. *Id.*

142. *Id.*

143. Leshin, *supra* note 138.

144. *Id.*

145. *Id.*

146. *Id.*

147. *Id.*

148. *See ACOG 77, supra* note 14, at 217.

149. *Id.* at 219, 224.

This clinical recommendation was welcomed with less than enthusiasm by many in the disability community, and understandably so. When this new development is combined with the knowledge that the abortion rate for fetuses with Down syndrome amongst mothers who have had prenatal testing hovers between eighty to ninety percent, it is not difficult to see that “what is antiseptically called ‘screening’ for Down syndrome is, much more often than not, a search-and-destroy mission” that will result in an abortion.¹⁵⁰ Though stated in clinically neutral terms, “the implicit message the American College of Obstetricians & Gynecologists seems to be sending is this: even though racial, cultural and ethnic diversity are valued and supported in our society, genetic diversity is not. It seems that it’s more important to be ‘normal’ than to be ‘human.’”¹⁵¹

The National Down Syndrome Society (NDSS), a nonprofit organization with more than 200 affiliates nationwide representing the more than 350,000 Americans with Down syndrome and their families, responded to ACOG’s recommendations with a resolution containing two call-to-action points:

[First,] [c]hallenging and strongly encouraging health care professionals and organizations like ACOG to partner with NDSS and other Down syndrome organizations to ensure the wide-spread proliferation of balanced, accurate and up-to-date information to expectant parents; and

[Second,] [u]rging health care professionals, policymakers, and the Down syndrome community to work together to ensure that expectant parents are not unduly influenced to undergo prenatal testing or to terminate a pregnancy after receiving a prenatal diagnosis of Down syndrome.¹⁵²

The National Down Syndrome Congress (NDSC) condemned the ACOG recommendations on the grounds that they “convey tacit approval for terminating pregnancies where the fetus has Down syndrome.”¹⁵³ The NDSC cited several concerns. The main concern, of course, was that “[t]he primary medical reason for first trimester screening is to encourage earlier diagnostic testing in ‘at risk’ pregnancies, in order to facilitate early terminations. Other reasons for prenatal diagnosis, such as hospital selection and delivery management, do not require first trimester testing.”¹⁵⁴

150. George F. Will, *Golly, What Did Jon Do?*, NEWSWEEK, Jan. 29, 2007, at 72.

151. Bauer, *supra* note 97, at 70.

152. NAT’L DOWN SYNDROME SOC’Y, NATIONAL DOWN SYNDROME SOCIETY RESPONDS TO AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS’ NEW RECOMMENDATIONS FOR PRENATAL TESTING (2007), http://ndss.yorkandchapel.com/index.php?view=article&catid=54%3Apublic-relations&id=153%3Aposition-papers&format=pdf&option=com_content&Itemid=140.

153. Press Release, Nat’l Down Syndrome Cong. (Jan. 23, 2007), <http://www.ndscenter.org/resources/position.php> (follow “January 23, 2007 NDSC Press Release regarding ACOG screening recommendations” hyperlink).

154. *Id.*

Another concern was that “the recommended screenings [would] produce numerous false positives, potentially leading to unnecessary patient distress and possible termination of pregnancies where medical concerns do not exist.”¹⁵⁵ For instance, “[a]pproximately 65% of pregnant women seeking prenatal care received Maternal Serum Alpha-Fetoprotein (MSAFP) screening by the early 1990s.”¹⁵⁶ The MSAFP screen, though, has high false positive rates and the “vast majority” of women who receive abnormal results carry fetuses without abnormality.¹⁵⁷ According to the American Pregnancy Association, as many as one in twenty women tested will receive abnormal MSAFP results, while only a range of one in sixteen to one in thirty-three women receiving these abnormal results actually carry a fetus with a birth defect.¹⁵⁸ Therefore, ninety-four to ninety-seven percent of the women who are told something may be wrong based on MSAFP results are carrying a fetus that does not have any of the defects that MSAFP screens.¹⁵⁹

As prenatal testing has become more routine, the “manner of obtaining consent for the tests, the delivery of test results, and the decision-making process that follows” have all been impacted.¹⁶⁰ One significant change is that obstetricians often handle the brunt of the prenatal testing responsibilities, where prior this was done largely by geneticists.¹⁶¹ This could potentially threaten informed consent because “obstetricians often lack the training in non-directiveness given to genetic counselors and may unabashedly recommend or encourage testing.”¹⁶² Accordingly, one recommendation of the NDSC was that:

All screening and diagnostic tests need to be fully explained to patients, who should be provided the opportunity to decline or give their informed consent for testing. If patients decline certain tests, physicians and other medical personnel should respect the individual’s wishes and not overtly or covertly pressure patients to undergo undesired screenings.¹⁶³

When “obstetricians . . . fail [to explain] to patients . . . the purpose or limitations of screening tests, such as when an obstetrician incorporates screening tests as standard care, patients [may be] surprised and confused

155. *Id.*

156. Angela M. Hannemann, Comment, *A New Routine: Assisting Patients in Responding to Prenatal Diagnosis*, 90 MARQ. L. REV. 337, 337 (2006).

157. Sonia Mateu Suter, *The Routinization of Prenatal Testing*, 28 AM. J.L. & MED. 233, 252 (2002).

158. Am. Pregnancy Ass’n, Maternal Serum Alpha-Fetoprotein Screening (MSAFP), <http://www.americanpregnancy.org/prenataltesting/afp.html> (last visited June 22, 2009).

159. *See id.*

160. Hannemann, *supra* note 156, at 341.

161. Suter, *supra* note 157, at 242.

162. Hannemann, *supra* note 156, at 341.

163. Press Release, Nat’l Down Syndrome Cong. *supra* note 153.

[when told of] abnormal results.”¹⁶⁴ For example, “[p]hysicians have routinely described MSAFP screening . . . as ‘a simple blood test [to see] how [the] baby is developing.’”¹⁶⁵ Under such circumstances, “[a] woman is likely to ‘consent’ . . . without understanding” the full consequences of her actions, without considering “whether she wants the information the test provides, or [without] being aware of the test’s accuracy limitations.”¹⁶⁶ Importantly, the result of this state of affairs could be that “[t]his same directiveness and lack of information may permeate the entire decision-making process as patients determine whether to test further and whether to continue pregnancy.”¹⁶⁷

Others in the disability community were similarly disenchanted with ACOG’s recommendations and the ramifications of the new policy. An entire population of people—a population that is “increasingly finishing high school, living more independently and holding jobs”—was seemingly being devalued.¹⁶⁸ At least one court has noted 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.”¹⁶⁹ As Patricia Bauer has noted:

What’s gone undiscussed in the news coverage of the guidelines seems to be a general assumption that reasonable people would want to screen for Down syndrome. And since nothing can be done to mitigate the effects of an extra 21st chromosome in utero, the further assumption is that people would be reasonable to terminate pregnancies that are so diagnosed.¹⁷⁰

Many worried that, in an era of wrongful birth and wrongful life suits and increasing emphasis on early screening, it had become “better for business to deliver only babies that the medical profession calls ‘good outcomes.’”¹⁷¹ Emphasis on clinical outcomes and avoidance of lawsuits had inadvertently led one researcher to theorize that the ACOG and the doctors it represents:

have embarked upon the elimination of an entire class of people who have a history of oppression, discrimination and exclusion. . .[and] in the process [young parents] are giving away much of what defines America at its best: a society that assumes responsibility for those who are vulnerable, a society that

164. Hannemann, *supra* note 156, at 341 (citing Lori B. Andrews, *Prenatal Screening and the Culture of Motherhood*, 47 HASTINGS L.J. 967, 990 (1996)).

165. *Id.* (second and third and alterations in original) (quoting Andrews, *supra* note 164, at 990).

166. *Id.*

167. *Id.*

168. Patricia E. Bauer, *The Abortion Debate No One Wants to Have*, WASH. POST, Oct. 18, 2005, at A25.

169. *Kassama v. Magat*, 792 A.2d 1102, 1123 (Md. 2002).

170. Patricia E. Bauer, *What’s Lost in Prenatal Testing*, WASH. POST, Jan. 14, 2007, at B7.

171. Bauer, *supra* note 97, at 70.

accepts those who are different, a society marked by generosity, liberty and freedom of thought.¹⁷²

One side effect of the drastically increased number of fetuses with disabilities being aborted would be the necessarily decreased pool of peers for persons born with disabilities. Another fear of disability rights advocates was that ACOG's Practice Guidelines would lead to a state of affairs where abortion of a fetus with a disability became the standard of care. This is hardly an impractical fear given the current abortion rate of fetuses with Down syndrome.¹⁷³ Asch has pointed out that "enumerating a set of testable genetic diseases tells people who currently have those conditions that it would be better if prospective parents went to considerable lengths to prevent the births of children with those conditions."¹⁷⁴

In such an environment, it would not be unimaginable that insurance companies could begin to deny coverage for babies with Down syndrome and other disabilities because their parents had failed to comply with accepted standards of care. At least one HMO has openly contemplated "withdraw[ing] 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."¹⁷⁵

Indeed, in *Curlender v. Bio-Science Laboratories*,¹⁷⁶ an early California case to accept a wrongful life claim, 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.¹⁷⁷ "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.'"¹⁷⁸ Though the California legislature stepped in to insulate parents from such liability,¹⁷⁹ the mere mention of such an action shows that it is not inconceivable that states could honor such a claim in the future. If ACOG's recommendations are seen as evidence that eugenic abortion has truly become the "standard of care," it would certainly seem to increase the likelihood of such a potential claim.

172. *Id.*

173. Hannemann, *supra* note 156, at 339; Will, *supra* note 150, at 72.

174. Asch, *supra* note 27, at 339.

175. Abby Lippman, *Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*, 17 AM. J.L. & MED. 15, 35 (1991).

176. 165 Cal. Rptr. 477 (Cal. Ct. App. 1980).

177. *Id.* at 488; *see also* Hensel, *supra* note 3, at 159–60.

178. Hensel, *supra* note 3, at 159 (alteration in original) (citing *Curlender*, 165 Cal. Rptr. at 488).

179. CAL. CIV. CODE § 43.6 (West 2007); *see also* Hensel, *supra* note 3, at 159–60.

As selective abortion becomes more the rule than the exception, a refusal to abort a fetus with a disability “may be considered a personal assumption of the risk of all of the struggles and hardships that follow the child’s birth.”¹⁸⁰ Insurance considerations aside, disability is thus transformed from a societal issue into an individual concern, undermining all work of the disability rights movement.¹⁸¹ Under such circumstances any cohesive civil rights view of disability would collapse back into medical model thinking and “society’s assessment of the individual’s worth will be limited to the capability of current medical techniques to identify and correct impairments.”¹⁸²

Furthermore, while the ACOG recommendations are certainly intended to reduce the number of lawsuits directed at gynecologists and obstetricians, they invariably increase the potential pool of plaintiffs who can allege that a physician has breached his or her duty to the mother.¹⁸³ Because the standard of care is now to recommend screening tests for all women, rather than just women over thirty-five, the potential pool of plaintiffs who can allege that a physician has breached his or her duty to the mother is vastly increased.¹⁸⁴ For instance, in *Becker v. Schwartz*,¹⁸⁵ the plaintiff-mother had to prove that the standard of care for a mother of her age was to be informed of her risk of bearing a child with Down syndrome.¹⁸⁶ Now, any potential mother bearing a child with Down syndrome who was not informed of her chances of bearing such a child may be able to show that a physician has potentially breached her duty simply by reference to the ACOG’s Practice Guidelines.

Due in large part to the work of disability rights groups, ACOG issued another monthly bulletin in December 2007, urging that “[a]fter the diagnosis of a chromosomal abnormality, the patient should receive detailed information, if known, about the natural history of individuals with the specific chromosomal finding.”¹⁸⁷ The bulletin also urged that patients be referred to a genetic counselor, clinical geneticist, or groups such as the NDSS and NDSC upon screening or definite results that their fetus has a genetic condition.¹⁸⁸

180. Hensel, *supra* note 3, at 179–80.

181. ROTHMAN, *supra* note 119, at 9.

182. Hensel, *supra* note 3, at 181.

183. See *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.”); see also Hensel, *supra* note 3, at 142.

184. See *ACOG 77*, *supra* note 14, at 217. The vast majority of children, including children with Down syndrome, are born to mothers under the age of thirty-five. Will, *supra* note 150.

185. 386 N.E.2d 807 (N.Y. 1978).

186. *Id.* at 811, 813

187. *ACOG Practice Bulletin No. 88: Invasive Prenatal Testing for Aneuploidy*, 109 OBSTETRICS & GYNECOLOGY 1459, 1464 (2007) [hereinafter *ACOG 88*].

188. *Id.*

While it is certainly laudable that ACOG would reach out to disability rights groups to help promote informed consent and proper genetic counseling, this does not alter the fact that the accepted standard of care in current medicine is to urge any means possible to identify a fetus with Down syndrome or select other fetal chromosomal abnormalities. This begs the question: Where is the line drawn between an “acceptable” and an “unacceptable” disability? Or, in legal parlance, between a non-actionable and an actionable disability?¹⁸⁹ Wrongful birth and wrongful life suits have been raised in instances of children born with Tay-Sachs disease, Down syndrome, and congenital blindness, to name a few.¹⁹⁰ Within the range of diagnosable congenital conditions, it seems a slippery slope to begin labeling certain conditions beyond hope.¹⁹¹

Particularly troubling is that, at the time a disability is diagnosed, the only information that can be accurately communicated to parents is the identification of the disability and perhaps some expected parameters of the disability.¹⁹² To categorize certain disabilities as actionable but others as non-actionable thus ignores the variation within a given disability. The testing only tells physicians and mothers that a fetus has a certain trait; it cannot predict how severely or mildly that trait will be represented in the child.¹⁹³ Success stories abound for disabilities as various as Down syndrome,¹⁹⁴ cystic fibrosis,¹⁹⁵ and spina bifida.¹⁹⁶ Wrongful birth and wrongful life suits thus ignore the potential richness of a life with a disability.¹⁹⁷ Essentially, “[t]he individual *is* the impairment, and the value of existence is judged on that basis alone.”¹⁹⁸

The problem of differentiating between actionable and non-actionable conditions is again raised surrounding the issue of late-onset diseases. “Huntington’s Disease, for example is a . . . debilitating and fatal condition that

189. See Hensel, *supra* note 3, at 182–83.

190. *Id.* at 181–82 & nn.219–21 (listing cases for each respective condition).

191. See *e.g.*, *id.* at 181–90 (discussing the problem of “line drawing”).

192. *Id.* at 183.

193. *Id.*

194. See Hensel, *supra* note 3, at 183 & n.227; see *e.g.*, Priscilla Anderson, *Down’s Syndrome: Cost, Quality and Value of Life*, 53 SOC. SCI. & MED. 627 (2001) (detailing interviews of people with Down syndrome discussing the quality of their lives).

195. See Hensel, *supra* note 3, at 183 & n.228 (“[A] child with cystic fibrosis ‘might die from it, survive with physical disability, or suffer no noticeable impairment’”) (quoting Edward J. Larson, *The Meaning of Human Gene Testing for Disability Rights*, 70 U. CIN. L. REV. 913, 922 (2002)).

196. See Alison Davis, *Yes, the Baby Should Live*, 31 NEW SCIENTIST 54 (1985). Davis, who has spina bifida, writes, “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.” *Id.*

197. Hensel, *supra* note 3, at 183.

198. *Id.* (emphasis added).

begins in adulthood,” but which can now be detected prenatally.¹⁹⁹ Would such a condition justify a jury verdict declaring the person’s life a compensable damage?²⁰⁰ Such a claim has not been raised yet, but would not stray too far theoretically from a typical wrongful birth or wrongful life action. When one takes into account that the life expectancy of individuals with Huntington’s disease is less than for individuals with Down syndrome, and that expenses associated with Huntington’s disease far outweigh those associated with Down syndrome, the application of wrongful birth and wrongful life lawsuits to certain disabilities and not others seems particularly arbitrary and irresponsible.²⁰¹

With an accepted standard of care that currently targets a population of people who may live rich and fulfilling lives, and with the ability to diagnose a myriad of disorders—including late-onset disorders—it seems a scary proposition to have state-sanctioned lawsuits declaring people’s lives to be legally compensable injuries. It is thus necessary and proper for legislative bodies to step in and protect the interests imperiled by wrongful birth and wrongful life lawsuits.

IV. LEGISLATIVE SOLUTIONS

A. *Wrongful Birth and Wrongful Life Actions Should Be Left to the Legislative Branch*

State legislatures should pass legislation to preclude wrongful birth and wrongful life causes of action. The legitimacy of wrongful birth and wrongful life actions, even if not defeated by the ADA, is more properly resolved by the legislative branch. The statutory approach in states that have chosen to pass legislation regarding wrongful birth and wrongful life actions is to disavow both actions.²⁰²

199. See Hensel, *supra* note 3, at 184; Suter, *supra* note 157, at 237 (“With the rapid identification of numerous genes through the Human Genome Project, scientists began to isolate genes associated with late-onset conditions.”).

200. See Hensel, *supra* note 3, at 185 & n. 237. The question raised, of course, is whether a portion of a rich and fulfilling life can be offset by avoidable (via abortion) pain and suffering. Some scholars have compared and contrasted wrongful birth and wrongful life cases with right-to-die cases. See, e.g., Michael B. Kelly, *The Rightful Position in “Wrongful Life” Actions*, 42 *Hastings L.J.* 505, 548 (1991). To the extent that right-to-die issues are raised by the question posed, this is not the intent of the author. Such questions far exceed the scope of this Comment.

201. See generally Suter, *supra* note 157.

202. See Sheth, *supra* note 5, at 652 n.71; see also IDAHO CODE ANN. § 5-334 (1986) (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 (1998) (same); MINN. STAT. ANN. § 145.424 (1993) (banning wrongful birth and wrongful life claims alleging a child would have been aborted); MO. REV. STAT. § 188.130 (2000) (same); N.D. CENT. CODE § 32-03-43 (1993)

Missouri is one of the states to take initiative in rejecting both wrongful birth and wrongful life actions. Section 188.130 of the Missouri Code provides that:

1. No person shall maintain a cause of action or receive an award of damages on behalf of himself or herself based on the claim that but for the negligent conduct of another, he or she would have been aborted.
2. No person shall maintain a cause of action or receive an award of damages based on the claim that but for the negligent conduct of another, a child would have been aborted.²⁰³

The two portions of this provision are intended to apply to wrongful life and wrongful birth causes of action, respectively.

Only one state has passed legislation approving of wrongful birth and wrongful life actions.²⁰⁴ Nine, however, have disapproved of these causes of action.²⁰⁵ This is in stark contrast to the number of states that have accepted some form of wrongful birth action via judicial approval.²⁰⁶ It seems a fair question to ask: Why the discrepancy?

Some courts have come to the conclusion that the legislature is the more appropriate place for debate and decisionmaking, especially when dealing with questions that have such broad implications for society.²⁰⁷ If, after the robust public debate encouraged by the legislative format, many states have decided to preclude wrongful birth and wrongful life causes of action, it would seem to indicate that some of the twenty-three jurisdictions that have allowed these causes of action via judicial approval might also decide to ban wrongful birth and wrongful life tort actions.

In four of the nine states that have prohibited wrongful birth and wrongful life causes of action, the statutes have never been challenged.²⁰⁸ Of cases that

(precluding wrongful life actions); 42 PA. CONS. STAT. ANN. § 8305(B) (1993) (precluding wrongful birth and wrongful life claims alleging that “a person once conceived would not or should not have been born”); S.D. CODIFIED LAWS § 21-55-1 (1987) (banning wrongful life); UTAH CODE ANN. § 78-11-24 (1993) (banning claims alleging that a person would not have been permitted to have been born alive but would have been aborted); MICH. COMP. LAWS ANN. § 600-2971 (West 2004) (banning both wrongful birth and wrongful life actions).

203. MO. REV. STAT. § 188.130.

204. See ME. REV. STAT. ANN. tit. 24, § 2931 (2000); see also *Thibeault v. Larson*, 666 A.2d 112 (Me. 1995) (interpreting section 2931 to authorize recovery of damages for wrongful birth).

205. See sources cited *supra* note 202.

206. See *supra* text accompanying notes 61–68; see also *Sheth*, *supra* note 6, at 650 n.59.

207. See *e.g.*, *Becker v. Schwartz*, 386 N.E.2d 807, 812 (N.Y. 1978); see also *supra* Part II.

208. Julie F. Kowitz, Note, *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, 256–57 (1995). The four states are Idaho, Indiana, North Dakota, and South Dakota. *Id.* n.106. Utah has only one case arising under its statute, and

have challenged the constitutionality of statutes prohibiting wrongful birth and wrongful life statutes, the claim is that these statutes unduly burden a woman's access to an abortion.²⁰⁹ No such challenge has thus far been successful.²¹⁰

Courts have typically rejected constitutional challenges to statutes barring wrongful birth and wrongful life causes of action either by reasoning that the statute's effect does not constitute state action²¹¹ or that the statute's bar on these causes of action does not affect the right to terminate a pregnancy.²¹² While it is certainly important that wrongful birth and wrongful life actions not be legislatively prohibited for the express purpose of restricting a woman's access to an abortion, courts have thus far rejected such analysis.²¹³ The logic of denying such a challenge seems to hold up. A ban on wrongful birth and wrongful life actions—brought after a child's birth—has seemingly no effect on a woman's access to prenatal services such as an abortion.²¹⁴

the opinion explicitly states that it does not consider the constitutionality of the statute. *C.S. v. Nielson*, 767 P.2d 504 (Utah 1988).

209. *See e.g.*, *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833 (1993).

210. *See e.g.*, *Hickman v. Group Health Plan, Inc.*, 396 N.W.2d 10 (Minn. 1986); *Wilson v. Kuenzi*, 751 S.W.2d 741 (Mo.banc 1988); *Azzolino v. Dingfelder*, 337 S.E.2d 528 (N.C. 1985); *Edmonds v. W. Pa. Hosp. Radiology Assocs.*, 607 A.2d 1083 (Pa. Super. Ct. 1992).

211. *See e.g.*, *Hickman*, 396 N.W.2d at 10 (finding lack of state action and therefore no constitutional violation); *Edmonds*, 607 A.2d at 1083 (upholding statute based on lack of state action).

212. *See e.g.*, *Hickman*, 396 N.W.2d at 14 (stating that the statute barring wrongful birth suits “does not directly interfere with the woman's right to choose a safe abortion”); *Edmonds*, 607 A.2d at 1087 (concluding that statute “neither regulates nor directly affects [abortion] rights”).

213. *Hickman*, 396 N.W.2d at 10; *Edmonds*, 607 A.2d at 1087.

214. According to Darpana M. Sheth,

wrongful birth and wrongful life claims may violate Title II of the ADA in three respects. First, wrongful birth and wrongful life claims discriminate against individuals protected by the ADA, namely the children [involved in the actions] Second, . . . these causes of action discriminate against [the children involved in the lawsuits] on the basis of their disabilities Third, judicial and legislative recognition and state enforcement of wrongful birth and wrongful life claims constitute discrimination by a public entity.

Sheth, *supra* note 6, at 655. That wrongful birth and wrongful life suits may violate the ADA does not appear to have been litigated at this point, but may in the future present a persuasive argument that these suits are void as in violation of the ADA. *See id.* at 655–64. *But see* Kowitz, *supra* note 208 (arguing that “statutes barring wrongful life and wrongful birth actions absolutely contradict the principles of informed consent espoused in *Casey*” and that under the statutory safe harbor physicians might be more likely to withhold information regarding “the health of the fetus” which “is so integral to informed choice that its omission substantially obstructs a woman's right to choose abortion”).

B. State and Federal Legislation Is Necessary to Establish Informed Genetic Counseling

It is now nationally recognized that there is a vast deficiency in data needed to better “understand the epidemiology of prenatally diagnosed conditions, to monitor trends accurately, and to increase the effectiveness of health intervention.”²¹⁵ The reason for such a deficiency is undoubtedly due to the unique confluence of factors discussed in this Comment.

Recognizing that “[t]he extent and quality of the information provided to patients both before [prenatal] testing and upon delivery of the test results is a matter of critical importance because these results demand decisions concerning whether to abort, proceed with further tests, plan for adoption, or make special birth arrangements,”²¹⁶ Missouri passed legislation regarding prenatal testing and women’s access to counseling.²¹⁷ Section 191.923 of the Missouri Code states that “pregnant women who choose to undergo prenatal screening should have access to timely and informative counseling about the conditions being tested for, the accuracy of such tests, and resources for obtaining support services for such conditions.”²¹⁸

The rationale of Section 191.923 of the Missouri Code is that “[i]nformed consent is a critical component of all genetic testing and prenatal screening . . . and the counseling that follows may lead to the unnecessary abortion of unborn humans with Down syndrome or other prenatally diagnosed conditions.”²¹⁹ The legislation implicitly recognizes that “directiveness and lack of information may permeate the entire decision-making process”²²⁰ if a concerted effort is not made at the very beginning of the process to honor and promote informed consent.

In the modern legal setting, including the availability of wrongful birth and wrongful life suits, physicians are very aware that the “clearest evidence of compliance is to have a patient take the test . . . prompt[ing] many healthcare professionals, at a minimum, to *encourage* . . . screening.”²²¹ Legislation thus may be necessary to counter this impulse to practice defensive medicine.

215. Prenatally and Postnatally Diagnosed Conditions Awareness Act, S. 1810, 110th Cong. § 2(a)(2) (2007) (as introduced in the Senate, July 18, 2007) (enacted as Prenatally and Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110-374, 122 Stat. 4051 (2008) (to be codified at 42 U.S.C. § 280g-8)); *accord* Prenatally Diagnosed Condition Awareness Act of 2007, H.R. 3112, 110th Cong. § 2(a)(2) (2007) (as introduced in House, July 19, 2007).

216. Hannemann, *supra* note 156, at 338.

217. MO. REV. STAT. § 191.923 (Supp. 2008) (introduced as H.B. 818, 94th Gen. Assem. (Mo. 2008)).

218. § 191.923.1.

219. *Id.*

220. Hannemann, *supra* note 156, at 341.

221. Suter, *supra* note 157, at 253.

Section 191.923 of the Missouri Code and the Prenatally and Postnatally Diagnosed Conditions Awareness Act, by making informed consent the focal point of the legislation,²²² recognize the tendency toward defensive medicine and promote an entire process that is instead permeated by non-directiveness and support. Missouri's legislation states, more specifically:

When a prenatally diagnosed condition, including but not limited to Down Syndrome, becomes known as a result of one or more prenatal tests, the physician or other health care professional who requested or ordered prenatal tests . . . shall provide the patient with current information about the conditions that were tested for, the accuracy of such tests, and resources for obtaining support services for such conditions.²²³

The statute goes on to establish support services such as “a clearinghouse of information concerning supportive services providers, information hotlines specific to Down Syndrome or other prenatally diagnosed conditions, resource centers, education, other support programs for parents and families, and the alternatives to abortion services program under [Missouri law].”²²⁴

The Prenatally and Postnatally Diagnosed Conditions Awareness Act offers many of the same resources.²²⁵ The legislation calls for “the expansion and further development of the National Dissemination Center for Children with Disabilities,”²²⁶ “the establishment of a national registry . . . of families willing to adopt newborns with Down syndrome or other prenatally or postnatally diagnosed conditions,”²²⁷ and “the establishment of awareness and education programs for health care providers who provide, interpret, or inform parents of the results of prenatal tests for Down syndrome or other prenatally or postnatally diagnosed conditions.”²²⁸

In keeping with its emphasis on informed consent, the legislation mandates that upon receipt of a positive prenatal or postnatal diagnosis,²²⁹ parents be

222. See Prenatally and Postnatally Diagnosed Conditions Awareness Act, S. 1810, 110th Cong. § 2(a)(1) (2007) (as introduced in the Senate, July 18, 2007) (“Informed consent is a critical component of all genetic testing.”).

223. § 191.923.3.

224. *Id.*

225. Prenatally and Postnatally Diagnosed Conditions Awareness Act sec. 3, § 399R(b)(1).

226. *Id.* § 399R(b)(1)(B)(ii).

227. *Id.* § 399R(b)(1)(B)(iv).

228. *Id.* § 399R(b)(1)(B)(v).

229. While it has gone largely undiscussed during the course of this Comment, there is certainly great room for improvement regarding the state of affairs surrounding postnatal diagnosis of congenital condition and the subsequent delivery of this news to new parents. See Skotko, *supra* note 97, at 73. Skotko concludes with ten recommendations for health care professionals: (1) “[T]he person to deliver postnatal diagnosis should be a physician,” (2) obstetricians “should coordinate their messages with neonatologists and pediatricians,” (3) diagnoses “should be delivered once the mother is settled and as soon as a physician suspects the diagnosis,” (4) “whenever possible, the physician should make the announcement with both

provided “[u]p-to-date, evidence-based, *written* information concerning the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes.”²³⁰

The legislation further requires that the Government Accountability Office later “submit report[s] . . . concerning the effectiveness of current healthcare and family support programs serving as resources for the families of children with disabilities.”²³¹

CONCLUSION

That we are being propelled in the direction of Brave New World is obvious. But no less obvious is the fact that we can, if we so desire, refuse to co-operate with the blind forces that are propelling us. For the moment, however, the wish to resist does not seem to be very strong or very widespread.²³²

The availability of wrongful birth and wrongful life lawsuits has led to a situation where the legal climate of America has great sway over physician practices.²³³ For example, in the 1970s, ACOG’s legal department began advising that obstetricians use the newly minted technology of Alpha-Fetoprotein screening kits in order to provide a legal defense to any actions brought against them for the birth of a child with a defect.²³⁴ The routinization of prenatal testing and the use of “testing as a standard of care has been largely rooted in legal rather than medical necessity.”²³⁵ In such a climate, it is not difficult to see that ACOG’s most recent Practice Guidelines are at least in part due to the increased liability that directly results from wrongful birth and wrongful life tort actions. Thanks to the human genome project, prenatal screening tests are available earlier in pregnancies and are available to diagnose more disorders.²³⁶

parents present in a private setting,” (5) “when delivering [a diagnosis], the physician should first congratulate the parents on the birth of their child and should not forget to talk about the positive aspects” of the congenital condition diagnosed, (6) health care professionals should keep their personal opinions to themselves,” (7) “mothers should be provided with up-to-date printed materials,” (8) “parents should be provided access to other families who have children with” the same congenital condition, (9) “after the initial diagnosis . . . , parents should be offered a private hospital room,” and (10) “all physicians should be cognizant of the realities and possibilities of” modern day life with the diagnosed congenital condition. *Id.* at 74–76.

230. Prenatally and Postnatally Diagnosed Conditions Awareness Act sec. 3, § 399R(c)(1)(A) (emphasis added).

231. *Id.* § 399R(d).

232. ALDOUS HUXLEY, *BRAVE NEW WORLD REVISITED*, 23–24 (1958).

233. See Hannemann, *supra* note 156, at 342.

234. *Id.*

235. *Id.*

236. See Hensel, *supra* note 3, at 142 & n.5.

As Asch has noted, “[p]romoting informed reproductive choice may be the stated goal of test developers, but the generally expected and desired result of a disability diagnosis is the termination of that particular pregnancy in hopes that the next one will yield an embryo or fetus free of a detectable trait.”²³⁷ Thus, society seems to have determined that it is more worthwhile and efficient to “‘solve’ problems of disability by prenatal detection and abortion, rather than by expending those resources in improving” conditions for members of the community with disabilities.²³⁸

ACOG’s most recent Practice Guidelines “offer practical recommendations for implementing Down syndrome screening in practice.”²³⁹ While clinically neutral, the Practice Guidelines are representative of a larger and disturbing trend: the devaluation of the lives of the disabled. This societal trend is evident not only by the continued acceptance of wrongful birth and, in fewer jurisdictions, wrongful life actions, but also by the implicit acceptance of eugenic abortions.

The ACOG Practice Guidelines will form the crux of how prenatal screening tests will be used by physicians around the country. Are there appropriate safeguards in place to ensure that expectant mothers who agree to prenatal testing have done so with full, informed consent? Evidence seems to indicate that with the system currently in place, this question must be answered in the negative.²⁴⁰ Are women who choose to abort a fetus with a congenital condition doing so with full, accurate information and after appropriate non-directive counseling? The current abortion rate for fetuses with Down syndrome juxtaposed with the 214 family-long waiting list to adopt a child with Down syndrome²⁴¹ seems to indicate to this author that there is a fundamental disconnect between the information presented to women following a prenatal diagnosis of a congenital condition and the actual potential of these individuals. The full potential of many people with such congenital conditions to live a rich and fulfilling life and to bring joy to those around them seems too often to be overlooked.

Legislation is necessary to remedy this disconnect. Missouri’s tort reform to protect health care providers from wrongful birth and wrongful life actions is a model that should be duplicated by other states. While national legislation

237. Asch, *supra* note 27, at 336 (quoting Adrienne Asch, *Why I Haven’t Changed My Mind About Prenatal Diagnosis: Reflections and Refinements*, in *PRENATAL TESTING AND DISABILITY RIGHTS* *supra* note 44, at 234, 240).

238. *Id.* at 333.

239. See ACOG 77, *supra* note 14, at 217.

240. See Andrews, *supra* note 164, at 974–75; Suter, *supra* note 157, at 256.

241. Will, *supra* note 150 (“At least 85 percent of pregnancies in which Down syndrome is diagnosed are ended by abortions.”); see also 151 CONG. REC. S2982 (daily ed. Mar. 17, 2005) (statement of Sen. Brownback) (“For some conditions that can be detected in the womb, such as Down Syndrome, we are aborting 80 percent or more of the babies who test positive.”).

banning such causes of action is unlikely,²⁴² there is a strong argument that statutes and judicial decisions allowing wrongful birth and wrongful life actions violate the ADA.²⁴³ In addition, state legislators who wish to make their states friendlier for obstetricians to practice and who recognize the damage done to people with disabilities and to society's conception of disability by these tort actions should enact legislation similar to Section 188.130 of the Missouri Code to eliminate the legal threat posed by wrongful birth and wrongful life suits and to reinforce the equality for citizens with disabilities promised by the ADA.

With the recent ACOG Practice Guidelines, federal legislation modeled on Section 191.923 of the Missouri Code is necessary to ensure that informed consent is a prerequisite to prenatal testing and that any genetic counseling upon diagnosis of a congenital condition is done in a non-directive manner. The Prenatally and Postnatally Diagnosed Conditions Awareness Act, signed into law in October 2008 by President Bush, will help to ensure that a pregnant woman never "feel[s] that her options are limited by a lack of public support for the types of social services that could help her, her family, and her baby."²⁴⁴

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242. While it is true that many pro-choice scholars oppose wrongful birth and wrongful life actions for reasons presented throughout this Comment, this does mean the issue has become depoliticized. While no challenges to state legislation banning wrongful birth and wrongful life actions on the grounds that such legislation unduly burdens a woman's right to an abortion have been successful, these challenges surely have not escaped the notice of the U.S. Congress. While the author would certainly advocate this national legislation, it is unlikely that Congress would attempt to pass such legislation. See discussion *supra* Part IV.B; see also Liz Townsend, *Pro-Life News in Brief*, NATIONAL RIGHT TO LIFE NEWS, Nov./Dec. 2008, <http://www.nrlc.org/news/2008/NRL11/BriefNews.html>. Townsend quotes Senator Brownback as saying, in reference to the Prenatally and Postnatally Diagnosed Conditions Awareness Act, "President Bush signed into law a bill that will help an untold number of expecting parents who learn that their unborn child may be born with a disability . . . This is a great victory for the culture of life we should all seek to promote." It is evident, then, that even the Prenatally and Postnatally Diagnosed Conditions Awareness Act—certainly less controversial than any federal attempt to ban wrongful birth and wrongful life suits—overcame its share of partisan hurdles on its way to passage.

243. See discussion *supra* Part IV.A.

244. 151 CONG. REC. H9919 (daily ed. Sept. 25, 2008) (statement of Rep. Ryan).

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