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Jeffrey R. Botkin

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PRENATAL DIAGNOSIS AND THE SELECTION OF CHILDREN

JEFFREY R. BOTKIN*

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I. INTRODUCTION

For many adults, a central concern in life is the health and welfare of their children. A new baby ushers in decades of dedicated work and anxiety to foster the child's life, to limit the inevitable pain, and to provide every advantage parents can reasonably afford. For most of human history, this work began at birth¹ because, until recently, pregnancy was a black box, largely beyond parental influence other than through prayers and wholesome living. This situation has changed profoundly over the past twenty-five years. An array of technologies now can provide a detailed examination of the embryo and fetus, genetically, biochemically, and anatomically. The day is not yet here when we can effectively *change* the embryo or fetus from these perspectives, but we can effectively choose to accept or reject what we find. The ability to select our children based on detailed biologic characteristics is new. Efforts to provide the child with every advantage may begin with choosing the desired child at the very beginning. Questions over whether our society should promote or restrict this power also are new. These new capabilities will likely create one of the most difficult and divisive social debates over the next century.

This Article examines the debate from a professional perspective. Because those in the medical profession are gatekeepers for prenatal diagnostic technology, one approach to these questions is to ask what

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1. Pregnant women throughout recorded history have attempted to protect and foster their children before birth by eating good food and avoiding alcoholic drinks and physical labor during pregnancy. Until the last century, the medical community thought that maternal experiences could affect the developing child in quite specific ways. For example, a negative influence might be the sighting of a rabbit that was thought to result in a "hare lip." Alternatively, by exposing pregnant women to beautiful art and music, children gained positive influences. This tradition continues today in the recent fad over encouraging women to expose their developing fetuses to classical music.

tests and technologies the ethical practitioner should provide.² The answers to this question can be guided by professional, ethical and legal standards that are emerging in genetic medicine. This Article begins by offering three hypothetical clinical scenarios to frame the issues.

Case #1: Molly and Bert are pregnant with their third child. Molly is 36 years of age, Bert is 39, and both are in good health, as are their two other children. The pregnancy proceeds uneventfully under the guidance of their obstetrician, Dr. Owen. Dr. Owen is religiously and philosophically opposed to pregnancy termination other than for the protection of the life of the mother and, given the smooth course of this pregnancy, he does not discuss prenatal diagnosis with the couple. Dr. Owen recognizes that this failure to offer prenatal diagnosis is contrary to the prevailing standard of care. Women who will be 35 years of age or older at the time of delivery are at increased risk of bearing a child with Down syndrome and other syndromes caused by an increased number of chromosomes.³ Therefore, it has been standard practice for at least two decades to offer prenatal diagnosis to women of “advanced maternal age” to detect these conditions, if the parents so choose. Molly’s pregnancy proceeds to term, at which time she delivers a small infant girl, Alexandra, with the stigmata of Down syndrome. Chromosome analysis confirms the presence of Trisomy 21. Additional evaluation also confirms the presence of complex congenital heart disease in the infant.

Molly and Bert are shocked and saddened at the realization of Alexandra’s diagnosis and of the difficult challenges ahead for them and for their child. As they learn that prenatal diagnosis could have predicted this outcome, they become increasingly angry. Had they been offered prenatal diagnosis,⁴ they would have accepted. Upon

2. A separate approach would be to ask what sorts of prenatal tests and technologies should be used by an ethical couple. This question is less well explored than the professional standards question. Also, the question for prospective parents often becomes mired in abortion politics.

3. Down syndrome is also termed Trisomy 21. KENNETH LYONS JONES, SMITH’S RECOGNIZABLE PATTERNS OF HUMAN MALFORMATION 8-13 (5th ed. 1997). Humans normally have a total of forty-six chromosomes in each cell, twenty-three from the person’s mother and twenty-three from the father. LYNN B. JORDE ET AL., MEDICAL GENETICS 7 (Emma B. Underdown ed., 1995). The chromosomes are numbered from one through twenty-two plus the X and Y chromosomes that determine gender. *Id.* Therefore each of us normally has two #21 chromosomes. In Down syndrome, three #21 chromosomes are present, two from one parent and one from the other. JONES, *supra*, at 8-13. This extra chromosome causes the common characteristics of Down syndrome that include mild to moderate mental retardation, characteristic faces, and heart and/or bowel abnormalities. *Id.* Other less common trisomy syndromes include Trisomy 18 and Trisomy 13, both of which cause profound mental retardation and typically an early death. *Id.* at 14-23.

4. The term “prenatal diagnosis” encompasses a range of technologies. Amniocentesis is perhaps most familiar; a needle is inserted into the amniotic sac surrounding the fetus at about 16 weeks gestation. Fetal cells are isolated from the fluid and their chromo-

learning of the affected fetus, they would have regretfully, but surely, terminated the pregnancy. Molly and Bert choose to bring a legal claim against Dr. Owen for his failure to provide timely information about their reproductive risks and options.

The question for our analysis is whether the parents should have a valid legal or ethical claim. Should Dr. Owen be held legally or ethically responsible for the birth of this impaired child?

Case #2: Alice and Jack are pregnant with their first child. In their initial prenatal visit with Dr. Owen, he took a brief family history of both sides of the family to identify genetic risks to the developing child. However, Dr. Owen failed to take an adequate family history concerning cancer. Jack's sister developed breast cancer at age 37, his mother died recently of ovarian cancer at age 59, and his maternal aunt had breast cancer at age 46. This family pattern is suggestive of a heritable mutation in either the BRCA1 or BRCA2 genes. Women who are mutation carriers for BRCA1 or BRCA2 have a lifetime risk of up to eighty-five percent for breast or ovarian cancer. While there are no significant health risks to a man who is a mutation carrier for either of these genes, he can transmit the mutation to his daughters and sons. Genetic testing for BRCA1 and BRCA2 mutations has been available clinically for about seven years.

Alice's pregnancy proceeds uneventfully to term. A vigorous, healthy baby girl, Anastasia, is born. Six months later, Jack's sister learns through genetic testing that she has a BRCA1 mutation. Jack and, subsequently, Anastasia obtain genetic testing, revealing that they both carry the BRCA1 mutation. Alice and Jack are devastated. After watching the difficult death of Jack's mother and the suffering of his sister and aunt with breast cancer, they can only look forward with dread to the future of their beautiful little girl. Why didn't Dr. Owen take an adequate family history? Had they learned of their risk in a timely fashion, they would have done BRCA1 testing on the fetus and terminated the pregnancy without hesitation. They bring suit against Dr. Owen for his failure to provide timely information about their reproductive risks and options.

The question for our analysis is whether the parents should have a valid legal or ethical claim. Should Dr. Owen be held legally or ethically responsible for the birth of this child?

Case #3: Susan and Jim Jingle are pregnant with their fifth child. At only eight weeks gestation, Susan and Jim are thrilled but not ready to announce the pregnancy to the family or the public. They

some are analyzed. Chorionic villous sampling (CVS) can be performed earlier in the pregnancy. CVS involves insertion of a needle or catheter to sample cells from the fetal side of the placenta which contain the same chromosome structure as the fetus itself. Ultrasound is available to provide a detailed anatomic examination of the fetus.

recognize that this news would be met with some public fanfare because the Jingle family is a highly popular singing and musical group called, appropriately, “The Jingles.” Both Susan and Jim have perfect musical pitch, as do all of their four children. This innate talent has allowed the children to develop extraordinary musical skills at young ages, albeit with intensive training and practice beginning by age 3. There is a strong family history of perfect musical pitch on both sides of the family, and both families have had noted musicians and entertainers for generations. This kind of family history is unusual, but not so rare that it escaped the attention of geneticists.⁵ Imagine for the purposes of this Article that a molecular biologist in England recently identified a gene variant that confers perfect musical pitch in the majority of individuals who carry this variant. A prominent medical journal published the finding and, subsequently, several other investigators have confirmed the association in additional families.

Susan and Jim are hopeful that this new baby will fit in the family mold. Indeed, they are a little fearful of how they would raise a child that could not be an integral member of the family activity—and not to mention the creative and financial possibilities of a cute new Jingle in the band. They ask Dr. Owen, Susan’s obstetrician, about the possibility of having another child with perfect musical pitch. He chuckled, “Oh, who knows? These kinds of things are mostly just plain luck, although you folks have been awfully lucky with the other kids. So, I guess the chances are pretty good this one will be talented, too.” Sadly, though, this one was not talented. Susan and Jim learned of the genetic test for the “musical pitch gene” through a magazine interview late in Susan’s pregnancy. It was too late to do prenatal testing but they had their baby tested while he was a newborn. He had not inherited the trait from either parent, and so, while he was healthy, he would have no more innate musical talent than any random kid off the street. Their disappointment was further fueled by the knowledge that Susan could have had prenatal diagnosis for this trait well before the public knew she was pregnant. Dr. Owen had given them false information and he obviously did not have enough professional good sense to look up the correct answer to their question. Music is the lifeblood of their family, not some trivial trait like blue eyes or big ears. This was too important to leave to dumb luck. The Jingles brought suit against Dr. Owen, claiming that had he accurately informed Susan and Jim about the availability of a genetic test, they would have used it and terminated the pregnancy upon detection of the undesirable fetus.

5. See, e.g., Joseph Profita & T. George Bidder, *Perfect Pitch*, 29 AM. J. MED. GENETICS 763 (1988) (studying note recognition capacity in thirty-five subjects).

The question for our analysis is whether the parents should have a valid legal or ethical claim. Should Dr. Owen be held legally or ethically responsible for the birth of this child?

II. THE LEGAL CONCEPTS OF WRONGFUL LIFE AND WRONGFUL BIRTH

Over the past twenty years, the courts have provided a partial answer to the questions posed by these cases. Wrongful life and wrongful birth are two related medical malpractice actions that have arisen since the 1973 *Roe v. Wade*⁶ decision to address claims of negligence leading to the birth of an impaired child. Health care providers are the usual defendants in these suits after the birth of a child with congenital malformations or a genetic disease. Wrongful birth actions refer to suits by the *parents* who claim harm to themselves from the birth of an ill or disabled child.⁷ Parents in these suits typically claim that, had they been adequately informed of their reproductive risk, they would have taken measures to prevent the pregnancy or birth of the affected child.⁸ Wrongful life claims are brought in similar clinical circumstances; however, these claims arise from the *child* who asserts harm from birth in an impaired condition.⁹ But for the negligence of the health care provider, the child claims she would not have been born to suffer with her condition.¹⁰ Neither of these claims is based on allegations that the defendant *caused* the impairment through negligent actions as, say, through the use of a teratogenic drug. Wrongful life and wrongful birth claims are based on allegations of inadequate or incorrect information that would have permitted the parents to avoid pregnancy or to detect the abnormality prenatally and terminate the pregnancy.¹¹

The wrongful life and wrongful birth suits have become increasingly prevalent over the past three decades for at least two reasons. First, *Roe v. Wade* established constitutional protection for abortion decisions through the first two trimesters of pregnancy. Second, medicine is offering an expanding array of technologies to evaluate the health of the fetus. In light of these developments, health care providers are seen to have parallel obligations to offer testing in a variety of clinical circumstances, and to adequately warn couples who have an increased risk of bearing a child with a heritable condition or congenital malformation. Failure to provide timely, accurate infor-

6. 410 U.S. 113 (1973).

7. See *Harbeson v. Parke-Davis, Inc.*, 656 P.2d 483, 487 (Wash. 1983).

8. *Id.*

9. *Id.* at 494.

10. *Id.*

11. Lori B. Andrews, *Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks*, 29 HOUS. L. REV. 149, 152-57 (1992).

mation according to the standard of care may leave providers liable under wrongful life and/or wrongful birth suits.

The wrongful life claim has met with limited success. To date, five state courts have recognized the wrongful life claim,¹² while nineteen have rejected this tort.¹³ The primary difficulty for the wrongful life claim has been the implicit claim that a child would prefer non-existence to existence in an impaired condition. In these circumstances, existence without the condition was never a possibility for these children. So, the choice on behalf of the child was existence with impairments or non-existence through contraception or pregnancy termination. The children must assert that, but for the negligence of the defendant, they would not exist. In response to this dilemma, most courts have adopted the reasoning first articulated in the New York case of *Becker v. Schwartz*,¹⁴ in which the fundamental philosophic problem with wrongful life suits was described:

The first, in a sense the more fundamental [problem with wrongful life claims], is that it does not appear that the infants suffered any legally cognizable injury. . . . 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. . . . Not only is there to be found no predicate at common law or in statutory enactment for judicial recognition of the birth of a defective child as an injury to the child; the implications of any such proposition are staggering.¹⁵

The few courts that have recognized the wrongful life claims often have been willing largely to overlook the philosophical problems inherent in the claim and to support the suits based on the medical needs of the child and/or the public policy advantages of deterring

12. See, e.g., *Harbeson*, 656 P.2d at 483; see also *Turpin v. Sortini*, 643 P.2d 954, 965-66 (Cal. 1982); *Quinn v. Blau*, No. CV 963256915, 1997 Conn. Super. LEXIS 3319, at *8 (Conn. Super. Ct. Dec. 12, 1997); *Rosen v. Katz*, No. 93-394A, 1996 Mass. Super. LEXIS 618 at *10-11 (Mass. Super. Ct. Feb. 14, 1996); *Procanik v. Cillo*, 478 A.2d 755, 760 (N.J. 1984).

13. *Elliot v. Brown*, 361 So. 2d 546 (Ala. 1978); *Walker v. Mart*, 790 P.2d 735 (Ariz. 1990); *Lininger v. Eisenbaum*, 764 P.2d 1202 (Colo. 1988); *Garrison v. Med. Ctr. of Del., Inc.*, 581 A.2d 288 (Del. 1989); *Haymon v. Wilkerson*, 535 A.2d 880 (D.C. 1987); *Kush v. Lloyd*, 616 So. 2d 415 (Fla. 1992); *Atlanta Obstetrics & Gynecology Group v. Abelson*, 398 S.E.2d 557 (Ga. 1990); *Siemieniec v. Lutheran Gen. Hosp.*, 512 N.E.2d 691 (Ill. 1987); *Bruggeman v. Schimke*, 718 P.2d 635 (Kan. 1986); *Pitre v. Opelousas Gen. Hosp.*, 530 So. 2d 1151 (La. 1988); *Viccaro v. Milunsky*, 551 N.E.2d 8 (Mass. 1990); *Proffit v. Bartolo*, 412 N.W.2d 232 (Mich. App. 1987); *Smith v. Cote*, 513 A.2d 341 (N.H. 1986); *Becker v. Schwartz*, 386 N.E.2d 807 (N.Y. 1978); *Flanagan v. Williams*, 623 N.E.2d 185 (Ohio Ct. App. 1993); *Nelson v. Krusen*, 678 S.W.2d 918 (Tex. 1984); *James G. v. Caserta*, 332 S.E.2d 872 (W. Va. 1985); *Dumer v. St. Michael's Hosp.*, 233 N.W.2d 372 (Wis. 1975); *Beardsley v. Weirdsma*, 650 P.2d 288 (Wyo. 1982).

14. 386 N.E.2d 807 (N.Y. 1978).

15. *Id.* at 812.

negligent medical care.¹⁶ A California court in 1980 concluded:

The reality of the “wrongful life” concept is that such a plaintiff both exists and suffers, due to the negligence of others. It is neither necessary nor just to retreat into meditation on the mysteries of life. We need not be concerned with the fact that had defendants not been negligent, the plaintiff might not have come into existence at all.¹⁷

While the trend has been against the wrongful life concept, courts in both Massachusetts and Connecticut have supported the tort within the past few years. A 1997 decision by the Connecticut Superior Court, quoting a 1983 decision, stated: “There is nothing illogical in a plaintiff saying ‘I’d rather not be suffering as I am, but since your wrongful conduct preserved my life, I am going to take advantage of my regrettable existence to sue you.’”¹⁸ A Massachusetts court was faced with a case in which a suit was brought against a physician who failed to report abnormalities on a fetal ultrasound and to repeat the examination.¹⁹ The mother gave birth to a child with heart and bowel abnormalities, and the parents relinquished the child for adoption.²⁰ The court concluded:

Corey’s parents are not entitled to recover against the defendant for the ongoing extraordinary costs that Corey will incur because of the defect (due to the fact that they are no longer his legal guardians or official parents). Nor will Corey’s adoptive parents be entitled to recover, since the defendant owed them no duty. Therefore, this Court must consider whether Corey should have this cause of action since no one else can recover the extraordinary costs. . . . In this situation, it appears fair . . . to require the negligent Doctor to pick up these costs if negligence is proven.²¹

Therefore, in order to assure adequate care to a child with disabilities, some courts have been willing to recognize wrongful life claims without explicitly declaring that life with disability can be worse than non-existence.

The New York Court of Appeals in *Becker v. Schwartz*²² deferred to philosophers and theologians on the basic question of whether ex-

16. *Curlender v. Bio-Science Labs.*, 165 Cal. Rptr. 477 (Cal. Ct. App. 1980), *disapproved of by* *Turpin v. Sortini*, 643 P.2d 954 (Cal. 1982).

17. *Id.* at 488.

18. *Quinn v. Blau*, No. CV96325691S, 1997 Conn. Super. LEXIS 3319, at *21 (Conn. Super. Ct. Dec. 12, 1997) (quoting Alexander Morgan Capron, *The Continuing Wrong of “Wrongful Life,”* in *GENETICS AND THE LAW II*, at 81, 89 (Aubrey Milunsky & George J. Anas eds., 1979)).

19. *Rosen v. Katz*, No. 93-394A, 1996 Mass. Super. LEXIS 618, at *1 (Mass. Super. Ct. Feb. 14, 1996).

20. *Id.* at *2.

21. *Id.* at *9-10.

22. 386 N.E.2d 807 (N.Y. 1978).

istence confers a harm for some children. Bioethicists, theologians, and physicians have offered a range of opinions on this question. John Lorber, a British surgeon, wrote in 1975 of the deliberate non-treatment of some severely affected children with spina bifida:

There are ethicists and moralists, as well as doctors, who consider that life must be maintained at any cost, because any life is better than no life. It may be legitimate to adhere to such principles within their own family, but is it not right to enforce such a philosophy on others who do not hold with it. To my knowledge none of the world's great religions or religious leaders believe that a severely defective innocent newborn infant would be worse off in heaven or wherever they believe their souls will go after death. Is it therefore humane to inflict an immense amount of suffering on such infants and on their families to ensure that they reach this heaven or haven in the end?²³

Margery Shaw, a geneticist and attorney, argued that "fetal abuse," through knowingly bringing a child to birth with a genetic condition, should be made analogous to child abuse in the law.²⁴ She would sanction not only wrongful life suits against negligent physicians, but similar suits against parents.

[P]arents should be held accountable to their children if they knowingly and willfully choose to transmit deleterious genes or if the mother waives her right to an abortion if, after prenatal testing, a fetus is discovered to be seriously deformed or mentally defective. They have added to the burdens of the other family members, they have incurred a cost to society, and, most importantly, they have caused needless suffering in their child.²⁵

In fact, the wrongful life claim raises this odd question of the parents' responsibility for the birth of an affected child. When prenatal diagnosis detects a fetus with a genetic condition or congenital malformation, some parents choose to continue the pregnancy. Also, parents at risk for bearing a child with a genetic condition may choose to forego prenatal diagnosis and accept the risk of an affected child. As argued by Shaw, might the affected child have a wrongful life claim against the parents? The State of California was concerned enough about this possibility after the success of a wrongful life claim in the case of *Curlender v. Bio-Science*²⁶ that it passed legislation barring suits by children against parents for the harm of their existence.²⁷

23. John Lorber, *Ethical Problems in the Management of Myelomeningocele and Hydrocephalus*, 10 J. ROYAL C. PHYSICIANS 47, 58 (1975).

24. See Margery W. Shaw, *Conditional Prospective Rights of the Fetus*, 5 J. LEGAL MED. 63, 111 (1984).

25. *Id.*

26. 165 Cal. Rptr. 477 (Cal. Ct. App. 1980).

27. CAL. CIV. CODE § 43.6 (West 1982).

In contrast to these authors, James Bopp, Barry Bostrom, and Donald McKinney argue from a "right to life" perspective that one of the very foundations of modern law and civilized society is that life has enormous intrinsic value.²⁸

[W]rongful birth/life claims . . . require a new legal theory, in that life itself is considered a wrong, and death is preferred over life with disabilities. By deviating from the general principle, historically found in civilized law, that life, even with disabilities, is valuable and that only wrongful death is compensable, wrongful birth/life actions are a radical departure from fundamental legal philosophy.²⁹

Similarly, authors writing from a disabilities rights perspective assert that it is simply wrong that those with disabilities lead lives of hopeless despair.³⁰ The greatest difficulties for those with impairments, it is claimed, are often not due to the condition per se, but to the discriminatory attitudes and barriers in society. Wrongful life (and wrongful birth) suits are seen by many of these authors as reflective of an inaccurate and inappropriate attitude in society toward life with a disability.

Finally, some bioethicists claim that the assertion that life with impairments is worse than non-existence is only justifiable for a few extremely severe conditions.³¹ From the perspective of the child, even the most rudimentary awareness and existence might be sufficient to experience a life of value. According to these authors, the kinds of conditions for which wrongful life suits have been brought, such as Down syndrome or congenital rubella syndrome, would not be justified from the perspective of the child.

The limited success of the wrongful life suits is not likely to change in the next decade or two. The primary challenge to these claims is the philosophical conundrum they pose. Some courts have been willing to overlook this problem in search of support for a disabled plaintiff when adequate support for medical expenses is not otherwise available.³² We might expect this pattern to continue in the

28. James Bopp et al., *The "Rights" and "Wrongs" of Wrongful Birth and Wrongful Life: A Jurisprudential Analysis of Birth Related Torts*, 27 DUQ. L. REV. 461, 514-15 (1989).

29. *Id.* at 514.

30. See Adrienne Asch, *Reproductive Technology and Disability*, in REPRODUCTIVE LAWS FOR THE 1990S 69 (Sherrill Cohen & Nadine Taub eds., 1989); Deborah Kaplan, *Prenatal Screening and Diagnosis: The Impact on Persons with Disabilities*, in WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 49 (1994).

31. See Jeffrey R. Botkin, *The Legal Concept of Wrongful Life*, 259 JAMA 1541, 1544-45 (1988); Bonnie Steinbock & Ron McClamrock, *When is Birth Unfair to the Child?*, HASTINGS CENTER REP., Nov.-Dec. 1994, at 15.

32. See *Turpin v. Sortini*, 643 P.2d 954, 964 (Cal. 1982); *Viccaro v. Milunsky*, 551 N.E.2d 8, 13 (Mass. 1990).

future, at least until we have a more comprehensive health care financing system. But the other reason wrongful life suits are recognized or pursued is the existence of the wrongful birth claims that usually speak to the same set of events.

The wrongful birth claims have been considerably more successful in the courts. To date, twenty-six states,³³ the District of Columbia,³⁴ and five federal courts³⁵ have recognized a cause of action for wrongful birth. One state has enacted legislation recognizing the validity of wrongful birth suits.³⁶ In contrast, five state appellate courts have rejected the claim³⁷ and six states have enacted legislation barring wrongful birth suits.³⁸ Two state laws banning wrongful birth suits have been upheld as constitutional.³⁹ Although the national trend is clearly toward the recognition of the claim, wrongful birth remains controversial.

Several courts and scholars argue that the wrongful birth concept is an extension of the constitutionally protected right to privacy in abortion decisions.⁴⁰ The claim is that abortion decisions are depend-

33. See *Keel v. Banach*, 624 So. 2d 1022 (Ala. 1993); *Walker v. Mart*, 790 P.2d 735 (Ariz. 1990); *Andalon v. Superior Court*, 208 Cal. Rptr. 899 (Cal. Ct. App. 1984), *questioned in Goldstein v. Superior Court*, 273 Cal. Rptr. 270 (Cal. Ct. App. 1990); *Lininger v. Eisenbaum*, 764 P.2d 1202 (Colo. 1988); *Garrison v. Med. Ctr. of Del., Inc.*, 571 A.2d 786 (Del. 1989); *Fassoulas v. Ramey*, 450 So. 2d 822 (Fla. 1984); *Blake v. Cruz*, 698 P.2d 315 (Idaho 1984); *Goldberg v. Ruskin*, 471 N.E.2d 530 (Ill. App. Ct. 1984); *Bader v. Johnson*, 675 N.E.2d 1119 (Ind. Ct. App. 1997); *Arche v. United States Dept. of the Army*, 798 P.2d 477 (Kan. 1990); *Pitre v. Opelousas Gen. Hosp.*, 519 So. 2d 105 (La. 1987); *Reed v. Campagnolo*, 630 A.2d 1145 (Md. 1993); *Viccaro v. Milunsky*, 551 N.E.2d 8 (Mass. 1990); *Eisbrenner v. Stanley*, 308 N.W.2d 209 (Mich. Ct. App. 1981), *abrogated by Taylor v. Kurapati*, 600 N.W.2d 670 (Mich. Ct. App. 1999); *Greco v. United States*, 893 P.2d 345 (Nev. 1995); *Smith v. Cote*, 513 A.2d 341 (N.H. 1986); *Berman v. Allan*, 404 A.2d 8 (N.J. 1979), *declined to follow by Cauman v. George Washington Univ.*, 630 A.2d 1104 (D.C. 1993); *Becker v. Schwartz*, 386 N.E.2d 807 (N.Y. 1978); *Flanagan v. Williams*, 623 N.E.2d 185 (Ohio Ct. App. 1993); *Speck v. Finegold*, 439 A.2d 110 (Pa. 1981); *Jacobs v. Theimer*, 519 S.W.2d 846 (Tex. 1975); *Naccash v. Burger*, 290 S.E.2d 825 (Va. 1982); *Harbeson v. Parke-Davis, Inc.*, 656 P.2d 483 (Wash. 1983); *James G. v. Caserta*, 332 S.E.2d 872 (W. Va. 1985).

34. See *Haymon v. Wilkerson*, 535 A.2d 880 (D.C. 1987).

35. See *Robak v. United States*, 658 F.2d 471 (7th Cir. 1981); *Liddington v. Burns*, 916 F. Supp. 1127 (W.D. Okla. 1995); *Phillips v. United States*, 575 F. Supp. 1309 (D.S.C. 1989); *Gallagher v. Duke Univ.*, 638 F. Supp. 979 (M.D.N.C. 1986); *Gildiner v. Thomas Jefferson Univ. Hosp.*, 451 F. Supp. 692 (E.D. Pa. 1978).

36. ME. REV. STAT. ANN. tit. 24, § 2931 (West 1988).

37. See *Atlanta Obstetrics & Gynecology Group v. Abelson*, 398 S.E.2d 557 (Ga. 1990); *Schork v. Huber*, 648 S.W.2d 861 (Ky. 1983); *Wilson v. Kuenzi*, 751 S.W.2d 741 (Mo. 1988); *Azzolino v. Dingfelder*, 337 S.E.2d 528 (N.C. 1985); *Spencer v. Seikel*, 742 P.2d 1126 (Okla. 1987).

38. See IDAHO CODE § 5-334 (Michie 1986); MINN STAT. § 145.424 (1987 Supp.); MO. ANN. STAT. § 188.130 (West 1987); 42 PA. CONS. STAT. ANN. § 8305 (West 1990); S.D. CODIFIED LAWS 21-55-2 (Michie 1987); UTAH CODE ANN. § 78-11-24 (1986).

39. *Hickman v. Group Health Plan, Inc.*, 396 N.W.2d 10 (Minn. 1986); *Dansby v. Thomas Jefferson Univ. Hosp.*, 623 A.2d 816 (Pa. Super. Ct. 1993).

40. See *Robak v. United States*, 658 F.2d 471 (7th Cir. 1981); *Haymon v. Wilkerson*, 535 A.2d 880 (D.C. 1987); *Hickman v. Group Health Plan, Inc.*, 396 N.W.2d 10, 18 (Minn. 1986) (Amdahl, C.J., dissenting); *Smith v. Cote*, 513 A.2d 341 (N.H. 1986); *R. Keith Johns-*

ent on information about the welfare of the fetus. Therefore, reproductive choice is limited if inadequate prenatal diagnostic information is provided. It is argued that the harm in these cases is not the birth of the impaired child, but the infringement on free choice in reproductive decisions.

In contrast, other commentators and courts argue that there is no basis for wrongful birth suits under the umbrella of privacy as articulated in *Roe v. Wade*.⁴¹ The constitutional right of privacy in reproduction and abortion only prevents state interference with abortion decisions, it is argued, and imposes no positive duties on health care providers to provide information about the fetus.⁴² Two state courts (Minnesota and Pennsylvania) have examined these arguments and held that the state laws barring wrongful birth suits are constitutional.⁴³ Therefore, to date, the provision of prenatal diagnostic information has not been held to be a protected right under the Constitution.

Other commentators and courts argue that wrongful birth suits fall more appropriately under the patient's right of informed consent.⁴⁴ Informed consent relates specifically to the amount and type of information that health care providers must provide to patients about medical options.⁴⁵ It is argued that, in the context of the medical condition of pregnancy, couples should be told the risk of a problem for the child in order to decide whether to obtain prenatal diagnosis. Under the current foundation for wrongful birth, as recognized by the majority of the courts, physicians are held to the prevailing standard of care for the provision of timely and accurate information about the welfare of the child.

While there is prevalent support for the wrongful birth claim in the judicial system, there remains a debate over the appropriate calculation of damages in courts recognizing the tort. Courts have considered several options that attempt to balance the benefits and costs

ton, *Medical Malpractice and "Wrongful Birth": A Critical Analysis of Wilson v. Kuenzi*, 57 UMKC L. REV. 337 (1989); Kathryn J. Jankowski, Note, *Wrongful Birth and Wrongful Life Actions Arising From Negligent Genetic Counseling: The Need for Legislation Supporting Reproductive Choice*, 17 FORDHAM URB. L.J. 27 (1989); Note, *Wrongful Birth Actions: The Case Against Legislative Curtailment*, 100 HARV. L. REV. 2017 (1987).

41. See Bopp et al., *supra* note 28, at 466-68; John Lyons, Recent Development, *To Be or Not to Be: The Pennsylvania General Assembly Eliminates Wrongful Birth and Life Actions*, 34 VILL. L. REV. 681 (1989).

42. Lyons, *supra* note 41, at 694-95.

43. *Hickman*, 396 N.W.2d 10; *Dansby*, 623 A.2d 816.

44. See Harbeson v. Parke-Davis, Inc., 656 P.2d 483, 490-91 (Wash. 1983); Jeffrey R. Botkin & Maxwell J. Mehlman, *Wrongful Birth: Medical, Legal, and Philosophical Issues*, 22 J.L. MED. & ETHICS 21, 23 (1994); Pamela Sarsfield Fox, Note, *Legislative Prohibition of Wrongful Birth Actions*, 44 WASH. & LEE L. REV. 1331, 1354-55 (1987).

45. RUTH R. FADEN & TOM L. BEAUCHAMP, A HISTORY AND THEORY OF INFORMED CONSENT 98-100 (1986).

of having and raising an impaired child.⁴⁶ One method of calculation is to award the parents a monetary sum equal to the costs of the continued pregnancy, the delivery, and the medical costs incurred by the child's impairment. These are seen as the additional costs directly incurred because of the claimed negligence of the physician. An additional award might be added to compensate for the emotional pain and suffering of bearing and raising a child with a disability. A third element that courts have variously considered is an offset to either of these damages for the benefits that a child brings to a family. Therefore, the damages for emotional pain might be reduced by the jury's estimate of the child's positive value to the family.

Clearly, the emotional pain from bearing and raising an impaired child and the emotional benefits of raising any child are highly value-laden. As a result, many courts have been unwilling to allow these kinds of calculations (or, in some circumstances, state law does not permit these kinds of awards or offsets).⁴⁷ The majority of the courts have awarded damages for the medical costs incurred by the child's unwanted medical condition while the child is a minor.⁴⁸

The broad recognition of the wrongful birth claim reflects and confirms the responsibility of physicians to provide timely and accurate information about reproductive risks to prospective parents. But this is a vague standard. What information must be provided to prospective parents? Court decisions have not articulated a broad standard because the cases deal with individual claims and circumstances. The single largest number of wrongful birth cases have been brought for failure to provide information about the risk of Down syndrome to women of "advanced maternal age."⁴⁹ Other conditions that have led to wrongful birth suits include congenital rubella syndrome,⁵⁰ spina

46. Frederick W. Bogdan, *Wrongful Birth: Who Owes What to Whom and Why?*, 40 WASH. & LEE L. REV. 123, 136-38 (1983); John H. Scheid, *Benefits vs. Burdens: The Limitation of Damages in Wrongful Birth*, 23 J. FAM. L. 57, 68-78 (1984-85).

47. Bogdan, *supra* note 46, at 136-38; Scheid, *supra* note 46, at 68-78.

48. See *Bader v. Johnson*, 675 N.E.2d 1119 (Ind. Ct. App. 1987), *superseded by Bader v. Johnson*, 732 N.E.2d 1212 (Ind. 2000).

49. See, e.g., *Phillips v. United States*, 575 F. Supp. 1309 (D.S.C. 1989); *Simmons v. W. Covina Med. Clinic*, 260 Cal. Rptr. 772 (Cal. Ct. App. 1989); *Garrison v. Med. Ctr. of Del., Inc.*, 571 A.2d 786 (Del. 1989); *Haymon v. Wilkerson*, 535 A.2d 880 (D.C. 1987); *Atlanta Obstetrics & Gynecology Group v. Abelson*, 398 S.E.2d 557 (Ga. 1990); *Hickman v. Group Health Plan, Inc.*, 396 N.W.2d 10 (Minn. 1986); *Wilson v. Kuenzi*, 751 S.W.2d 741 (Mo. 1988); *Berman v. Allan*, 404 A.2d 8 (N.J. 1979); *Alquijay v. St. Lukes-Roosevelt Hosp. Ctr.*, 473 N.E.2d 244 (N.Y. 1984); *Becker v. Schwartz*, 386 N.E.2d 807 (N.Y. 1978); *Azzolino v. Dingfelder*, 337 S.E.2d 528 (N.C. 1985); *James G. v. Caserta*, 332 S.E.2d 872 (W.Va. 1985).

50. See *Robak v. United States*, 658 F.2d 471 (7th Cir. 1981); *Walker v. Mart*, 790 P.2d 735 (Ariz. 1990); *Blake v. Cruz*, 698 P.2d 315 (Idaho 1984); *Proffitt v. Bartolo*, 412 N.W.2d 232 (Mich. Ct. App. 1987), *overruled by Taylor v. Surender Kurapati*, 600 N.W.2d 670 (Mich. Ct. App. 1999); *Eisenbrenner v. Stanley*, 308 N.W.2d 209 (Mich. Ct. App. 1981), *overruled by Taylor v. Surender Kurapati*, 600 N.W.2d 670 (Mich. Ct. App. 1999); *Smith v. Cote*, 513 A.2d 341 (N.H. 1986); *Procanik v. Cillo*, 478 A.2d 755 (N.J. 1984); *Gleitman v.*

bifida,⁵¹ Tay-Sachs disease,⁵² sickle cell anemia,⁵³ cystic fibrosis,⁵⁴ and a number of other rare conditions.⁵⁵ Many of the conditions for which wrongful birth cases have been brought have only one case for that condition. Clearly there are only a few general rules emerging from this pattern of tort litigation to guide practitioners.

The alleged negligence in these cases falls into three categories. First, there are relatively well-defined population groups that are at increased risk for certain genetic conditions. Examples include sickle cell disease in individuals of African origin and Tay-Sachs disease in Ashkenazi Jews. The other prime example is women of advanced maternal age. The professional error here is not identifying couples who are at risk for conditions amenable to prenatal diagnosis and providing them timely information about test availability. A second category involves errors in making a correct diagnosis when suggestive signs or symptoms are present. Pregnant women who contract a rubella infection (German measles) are at risk for delivering a child with congenital malformations. A misdiagnosis of this subtle infection in the pregnant woman has been the event leading to a wrongful birth suit in several cases.⁵⁶ A third category is comprised of cases in which an older child or other family member was misdiagnosed or misinformed about a genetic condition. The *Shroeder v. Perkel*⁵⁷ case was brought after a physician failed to make a timely diagnosis of cystic fibrosis in a boy before the birth of a second affected child. Occasionally, suits will arise from simple laboratory error as well, that is, prenatal diagnosis was provided but the information returned to the couple was wrong.

Within each of these categories, there is a range of information that might be provided to prospective parents. For the purposes of this discussion, we will focus primarily on the question of risk notification. What kinds of conditions should prompt an alert from the physician? I have framed the discussion thus far primarily in the

Cosgrove, 227 A.2d 689 (N.J. 1967), *abrogated by* Berman v. Allan, 404 A.2d 8 (N.J. 1979); Jacobs v. Theimer, 519 S.W.2d 846 (Tex. 1975).

51. See Keel v. Banach, 624 So. 2d 1022 (Ala. 1993); Reed v. Campagnolo, 630 A.2d 1145 (Md. 1993); Dansby v. Thomas Jefferson Univ. Hosp., 623 A.2d 816 (Pa. Super. Ct. 1993).

52. See Gildiner v. Thomas Jefferson Univ. Hosp., 451 F. Supp 692 (E.D. Pa. 1978); Munro v. Regents of the Univ. of Cal., 263 Cal. Rptr. 878 (Cal. Ct. App. 1989); Goldberg v. Ruskin, 471 N.E.2d 530 (Ill. App. Ct. 1984).

53. See Dorlin v. Providence Hosp., 325 N.W.2d 600 (Mich. Ct. App. 1982), *overruled by* Taylor v. Surender Kurapati, 600 N.W.2d 670 (Mich. Ct. App. 1999).

54. See Schroeder v. Perkel, 432 A.2d 834 (N.J. 1981).

55. See Botkin & Mehlman, *supra* note 44, at 24.

56. See Robak v. United States, 658 F.2d 471 (7th Cir. 1981); Walker v. Mart, 790 P.2d 735 (Ariz. 1990); Blake v. Cruz, 698 P.2d 315 (Idaho 1984); Jacobs v. Theimer, 519 S.W.2d 846 (Tex. 1975).

57. 432 A.2d 834 (N.J. 1981).

context of tort litigation. A description of the case law permits several basic conclusions. First, there is a clear tradition supporting a minimum standard of risk communication, at least in many jurisdictions.⁵⁸ There is a reasonably broad social consensus that, for example, an older pregnant woman should be informed of the increased risk of Down syndrome and other aneuploid syndromes. Or, we can conclude that Ashkenazi couples should be warned of their risk of bearing a child with Tay-Sachs disease. But the second conclusion is that we cannot rely on tort litigation alone to provide sufficient guidance to health care providers. This is true in part because case law is primarily reactive. Further, and perhaps most importantly, the law speaks to the minimum standard of professional behavior. What the professional must do to avoid successful litigation is a different standard than what we would expect professionals to do to promote informed decision-making for couples during pregnancy. The primary standard should be based on our analysis of personal, professional, and social ethics, which may be a different standard than that dictated by law. However, the law asks the correct questions in addressing the ethical issues involved in defining a professional standard.

The remainder of this Article examines the concept of risk from two perspectives. The first relates to the probability of the occurrence of an adverse event. The second relates to the severity of that adverse outcome. We might decide that it is important to warn prospective parents about a serious potential outcome even when the probability is remote. In contrast, a common but relatively trivial outcome may not be deemed worthy of mention.

The knowledge at the base of each of these categories will enlarge with the expansion of genetic knowledge and prenatal diagnostic technology. Before returning to the arguments about limits on professional responsibilities to provide information in this context, this Article will briefly review current developments in prenatal diagnosis.

III. THE TECHNOLOGY OF PRENATAL DIAGNOSIS

Prenatal diagnosis requires the ability to image the fetus or to have access to embryonic or fetal tissue for analysis. The most familiar techniques are ultrasound, amniocentesis, and chorionic villous sampling. Ultrasound involves the transmission of sound waves into the body through an external probe and the measurement of the returning waves as they bounce off tissues in the body. The images created produce a depiction of the external anatomy of the developing fetus as well as internal structures like the brain, heart and kidneys.

58. See, e.g., *Canesi v. Wilson*, 730 A.2d 805, 812 (N.J. 1999).

Ultrasound is thought to be entirely safe. The primary limitation of the technology is that the fetus must be large enough and sufficiently developed to analyze the structure of the major organs. The remarkable advancement in recent years has been the advent of three-dimensional ultrasound. This technology combines two-dimensional images through digital addition to create stunning three-dimensional images of the fetus. These images look much like true photographs. From a medical perspective, these images provide detailed information about external and internal anatomy and can detect abnormalities of the brain, spine, limbs, bowel, heart, and kidneys. As this technology continues to improve, prospective parents can expect to have detailed color images of their child from mid-pregnancy onward.

Amniocentesis involves the insertion of a needle through the mother's abdomen or through the vagina into the amniotic fluid sack surrounding the fetus. Several cc's of fluid are removed for analysis. This fluid contains cells that have been sloughed by the developing fetus. These cells, in turn, contain all the genetic material of the fetus. Therefore, a genetic analysis of the fetus can be performed without removing tissues directly from its body. Amniocentesis generally is performed at about fifteen to eighteen weeks gestation. The primary reason to perform amniocentesis is for chromosome analysis. However, other genetic tests can be performed on the cells. As the number of genetic tests available expands, the number of conditions for which the fetus can be tested through amniocentesis will expand in parallel. The procedure carries a small risk of inducing labor and the subsequent loss of the pregnancy. The usual figure quoted is one pregnancy loss for every two hundred procedures.⁵⁹ While this risk may seem relatively low, it should be remembered that amniocentesis as a screening tool is conducted on a large number of women who will not have affected fetuses. Therefore, an expected "cost" to screening programs is the occasional loss of a normal fetus in the effort to detect fetuses with specific abnormalities. Of course, it also must be remembered that amniocentesis only detects conditions for which professionals are specifically looking. That is, a normal amniocentesis does not warrant the general conclusion that the fetus is healthy.

Chorionic villous sampling ("CVS") involves sampling of tissue where the placenta interdigitates with the wall of the uterus. Since the placenta is a product of conception, it has the same genetic material as the fetus. CVS is conducted by inserting a needle through the abdomen or a catheter through the cervix under ultrasound guidance to suction the tissue. The primary advantage of CVS is that it can be

59. Sherman Elias et al., *Amniocentesis and Fetal Blood Sampling*, in *GENETIC DISORDERS AND THE FETUS: DIAGNOSIS, PREVENTION AND TREATMENT* 53-82 (Aubrey Milunsky ed., 4th ed. 1998).

conducted at nine to twelve weeks gestation, although it can be performed as early as six weeks and as late as fifteen weeks. Recall that amniocentesis is usually conducted at fifteen to eighteen weeks. Therefore CVS permits an earlier diagnosis if an abnormality is detected. It is generally thought that an earlier termination is associated with less physical and psychological trauma for the woman. The risk of pregnancy loss for CVS is thought to be slightly higher than for amniocentesis—approximately one percent.⁶⁰

Fetal cell isolation is a fascinating new approach to prenatal diagnosis that has yet to emerge into clinical practice. Research has shown that a tiny number of blood cells from the fetus leak through the placenta and into the mother's circulation during the early weeks of pregnancy.⁶¹ These cells can be distinguished from the mother's cells and successfully separated in the laboratory. This means that by eight weeks gestation, a simple blood test from the mother can provide a sufficient number of fetal cells to do a genetic analysis. Not only does this procedure eliminate the risks associated with amniocentesis and CVS, it also provides an even earlier diagnosis. To date, it has been easier to detect the cells of male fetuses in the maternal circulation due to the presence of the Y chromosome in males. The accuracy of fetal cell isolation has not yet been considered great enough to use this approach outside the research context.

As these brief descriptions illustrate, a goal of prenatal diagnostic technology has been to move the point of diagnosis earlier and earlier in pregnancy. Preimplantation genetic diagnosis ("PGD") takes this effort to the logical extreme by enabling genetic testing in the embryo before it is even implanted in the uterus. This approach requires fertilization of the egg in the laboratory, that is, *in vitro* fertilization ("IVF"). The fertilized egg is permitted to grow to an eight to twelve cell mass at which point a cell is removed for analysis. This cell removal does not injure the embryo. The single cell can then be analyzed to determine if there are any genetic abnormalities. Typically during IVF, approximately ten to twelve embryos are created. Using PGD on several of the embryos permits a determination of which embryos are "affected" and which are not. One or more embryos

60. See Mark I. Evans et al., *Prenatal Diagnosis of Chromosomal and Mendelian Disorders*, in *FETAL DIAGNOSIS AND THERAPY: SCIENCE, ETHICS, AND THE LAW* 17, 27 (Mark I. Evans et al. eds., 1989); Canadian Collaborative CVS-Amniocentesis Clinical Trial Group, *Multicentre Randomised Clinical Trial of Chorion Villus Sampling and Amniocentesis*, 1 *LANCET* 1, 6 (1989); George G. Rhoads et al., *The Safety and Efficacy of Chorionic Villus Sampling for Early Prenatal Diagnosis of Cytogenetic Abnormalities*, 320 *NEW ENG. J. MED.* 610, 615 (1989).

61. Diana W. Bianchi, *Fetal cells in the mother: from genetic diagnosis to diseases associated with fetal cell microchimerism*, 92 *EUROPEAN J. OBSTETRICS, GYNECOLOGY & REPROD. BIOLOGY* 103, 105 (2000).

without the genetic condition would be transferred to the uterus in hopes of initiating a pregnancy.

Initially PGD was done primarily for couples at high risk for bearing a child with a genetic condition. Some couples chose PGD in order to avoid the choice of pregnancy termination. Of course, PGD generally involves the discarding of embryos but many couples still feel that PGD is less ethically troubling than other forms of prenatal diagnosis. In more recent years, PGD has become common in couples undergoing IVF for fertility reasons as a way of checking the genetic health of the embryos prior to transfer to the uterus. Although PGD often costs tens of thousands of dollars, more than 700 children have been born world-wide following this procedure. To date, there do not appear to be risks to the children who are produced from PGD.

PGD offers particularly interesting possibilities in the future for the genetic selection of children because it may reduce the ethical burdens of such selections. Pregnancy termination is a profoundly important decision in a woman's life so it is unlikely that many women would choose to terminate a pregnancy for what might be considered trivial reasons. Of course cultural norms and pressures have a strong influence. For example, prenatal ultrasound for fetal gender identification followed by pregnancy termination for female fetuses has become relatively common in India and China. Data from a 2000 census in China indicates that the male to female ratio for newborn infants is as high as 135 males per 100 females in some of the more prosperous provinces, due primarily to the availability of prenatal ultrasound.⁶² Requests for prenatal diagnosis for gender selection in the United States are uncommon but not entirely unfamiliar. Anecdotally, these requests are often from individuals with a cultural background that favors male children. Nevertheless, it is unlikely that cultural norms in the United States will change so significantly in the foreseeable future that pregnancy termination for mild or trivial conditions will become commonplace, even with the advent of chemical abortions that may reduce the physical burdens and increase the privacy of termination decisions.⁶³

PGD offers an interesting alternative to pregnancy termination with several significant advantages. The obvious advantage is the avoidance of pregnancy termination. Again, embryos are often discarded or frozen indefinitely in the process, but many couples find this less ethically troubling than abortion. The other key advantage

62. Ted Plafker, *Sex Selection in China Sees 117 Boys Born for Every 100 Girls*, 324 BRIT. MED. J. 1233, 1233 (2002).

63. See Alisa B. Goldberg et al., *Misoprostol and Pregnancy*, 344 NEW ENG. J. MED. 38 (2001) (discussing the medical aspects of chemical abortion); Irving M. Spitz et al., *Early Pregnancy Termination with Mifepristone and Misoprostol in the United States*, 338 NEW ENG. J. MED. 1241 (1998) (discussing the physical burdens of chemical abortions).

is the ability to select from a number of embryos. Following hormone stimulation of the woman, approximately ten to twelve oocytes (eggs) can be retrieved through a laparoscopic procedure. Following fertilization and removal of the embryos that fail to develop properly, a couple may have their choice of half a dozen embryos. In this context, gender selection can be performed as well as selection based on any other genetic criteria for which testing is available. While a couple might be primarily interested in avoiding use of an embryo with serious deleterious mutation, the technology offers the opportunity for much more fine-grained selections.

While this technology is available now, two other technical advances will increase the power of PGD. The first is the potential ability to harvest eggs in large numbers from tissue samples of the ovary. Currently a woman's ovaries must be stimulated with hormones to produce mature eggs capable of fertilization. In the foreseeable future, it will be possible to mature eggs in the laboratory. The prospect is for the ability to take a slice of ovary through laparoscopic surgery and to mature dozens or hundreds of eggs through hormone stimulation in a dish. Following fertilization with her partner's sperm and subsequent PGD, the couple would have a wide selection of potential children from which to choose. Why not a baby girl for the first pregnancy with one set of traits, and a boy for the next pregnancy with a different, desirable set of biologic characteristics?

The second set of emerging technologies, and the potential weakness in this hypothetical scheme, is the genetic tests themselves. The sequencing of the human genome is virtually complete. This sequence, along with the genome sequences of a number of experimental organisms, will permit rapid progress in the identification of genes associated with diseases, physical traits, physiologic characteristics and, potentially, mental characteristics. Along with the sequence information comes the ability to conduct tens of thousands of genetic tests simultaneously. Therefore, to the extent that we understand how gene sequences function separately and together in the body, we can potentially gain enormous volumes of genetic information from small tissue samples and possibly even single cells.

The challenge in predicting this kind of capability is the current uncertainty over the relative contributions of genes, environment, and random variation in the development of complex characteristics. It is well recognized that for many "simple" genetic conditions involving only one gene locus, the disease severity in siblings can be quite different even though siblings share much of the same genetic background and similar environments. It is clear that the expression of single genes is profoundly influenced by other genes (perhaps many other genes), environmental influences, and random variations as organisms develop and age. On the other hand, we know that genes

play a significant role in complex traits such as intelligence. Children having bright parents are not guaranteed to be bright themselves, but they have a significant statistical advantage compared to children of parents with average or less than average intelligence. So, it is important to dismiss simple notions of “genetic determinism,” that is, the belief that genes are the essential determinants of biologic characteristics. Yet, to my mind, it is a mistake to dismiss genes as a significant component of complex traits.

The important question for this discussion is whether a detailed knowledge of an embryo’s genetic makeup will permit any accurate predictions of the future traits of that individual as a child or an adult. Are there simply too many intervening influences between implantation and, say, grade school to make predictions meaningful? My own guess is that such predictions will be much like predicting the weather. The weather, too, is the result of an enormous number of factors that interact in complex ways. So it may be impossible to predict the weather in a given location at a given time with great accuracy, but with more data and more knowledge about interactions, some reasonably accurate predictions are increasingly possible. In two or three decades, the embryologist could say to a couple,

“With a healthy pregnancy, no significant injuries or illnesses as an infant, and a stimulating early environment, embryo #56 has an eighty percent chance of achieving an IQ above 120, and a thirty percent chance of an IQ above 140. He also is likely to have limited athletic ability and a seventy percent chance of moderate obesity by adolescence. Embryo #31 on the other hand . . .”

IV. ETHICAL ISSUES IN THE BIOLOGIC SELECTION OF CHILDREN

We can now return to the central question of this discussion. What should be the professional’s responsibility to provide prenatal diagnostic information? In addressing this set of issues, we should assume that professionals are functioning within a broad social context that determines professional norms. That is, these questions are too important to leave to physicians alone. Physicians act as the gatekeepers but we can hope they will fulfill this role with the general guidance and approval of society.

The history of wrongful birth litigation offers some general parameters. We can say with assurance that prenatal diagnosis is here to stay and that there are definitive obligations in many jurisdictions to offer services to certain at-risk groups. There are also a few well-articulated professional standards that have their roots, to some degree, in the fear of litigation. As noted, it is well-accepted that obstetricians should alert women of “advanced maternal age” to their increased risk for bearing a child with Down syndrome or other ane-

uploid syndromes and make them aware of prenatal diagnostic capabilities.⁶⁴ Similarly, the American College of Obstetrics and Gynecology's Department of Professional Liability issued a statement in 1985 indicating that obstetricians should immediately begin to advise women about the availability of the alpha-fetoprotein test ("AFP"). This tests the pregnant woman's blood to provide predictive information about whether the fetus might be affected with a neural tube defect such as spina bifida.⁶⁵ The statement advised: "It is equally imperative that every prenatal patient be advised of the availability of this test and that your discussion about the test and the patient's decision with respect to the test be documented in the patient's chart."⁶⁶

On the other hand, based on legal liability considerations, we cannot claim that all potential prenatal diagnostic information must be provided to couples. As noted, a challenge to the constitutionality of a state law prohibiting wrongful life and wrongful birth torts has not been supported in two cases.⁶⁷ This means that prenatal diagnosis is not tightly linked to the notions of privacy or liberty in the abortion context. Women have a constitutionally protected right to make a decision about pregnancy termination in the first two trimesters of pregnancy. At least according to the two courts which have decided this issue, there is not a parallel constitutional right to ob-

64. Physicians need not provide these services themselves. Professionals can fulfill their obligations through the provision of information alone. It may then be up to the woman to find someone who provides the service, or who would provide the service at a price or location that the woman can manage.

65. Spina bifida is one form of "neural tube defect" that is characterized by an abnormality in the development of the coverings of the spine. JONES, *supra* note 3, 608-09. Children born with spina bifida (also termed myelomeningocele) typically have a protruding sack or open tissue at some location along the length of the spine. *Id.* The skin and bony protection of the spine are missing due to the failure of the neural tube to close early in fetal development. The spinal cord is exposed, leading to abnormal development and malfunction. *Id.* These children usually lack motor and sensory function in the areas of the body served by that portion of the spinal cord and below.

Another form of neural tube defect is anencephaly, in which the scalp, upper skull, and cerebral hemispheres of the brain are missing. *Id.* Children with anencephaly are either stillborn or die within days of delivery unless artificially supported. *Id.* Neural tube defects during fetal development lead to leakage of a chemical called alpha-fetoprotein into the amniotic fluid and subsequently into the pregnant woman's blood stream in small concentrations. Aubrey Milunsky, *Maternal Serum Screening for Neural Tube and Other Defects*, in GENETIC DISORDERS AND THE FETUS, *supra* note 59, at 635-701. An increase in the pregnant woman's blood alpha-fetoprotein level can indicate that the fetus is affected with a neural tube defect, although there are a number of other normal and abnormal causes of such an elevation. *Id.* Currently, a battery of three or four chemical tests is performed on maternal serum to evaluate the pregnancy for risk of neural tube defects and several other conditions, including Down syndrome. *Id.*

66. George J. Annas, *Is a Genetic Screening Test Ready When the Lawyers Say It Is?*, HASTINGS CENTER REP., Dec. 1985, at 16, 17 (quoting the American College of Obstetricians and Gynecologist's Department of Professional Liability's "Alert" issued in May 1985).

67. See *Etkind v. Suarez*, 519 S.E.2d 210, 215 (Ga. 1999); *Dansby v. Thomas Jefferson Univ. Hosp.*, 623 A.2d 816, 818 (Pa. Super. Ct. 1993).

tain any and all information on which a termination decision might be based. More specifically, women have a right to decide whether they wish to remain pregnant at all; they might not have the right to decide whether they wish to remain pregnant with a specific fetus.

From an ethical perspective, there also is no discernable right to be offered or to obtain a full genetic analysis of the fetus. Privacy rights are typically framed as negative rights, that is, one has the right to be left alone or to prevent access to personal information.⁶⁸ Privacy rights cannot be used to compel the assistance of others or compel the provision of information, even if the subsequent use of the information is a private matter.⁶⁹ More plausibly, the ethical foundation of prenatal diagnostic information is the right to make an informed decision about important health issues like reproduction. If so, then prenatal diagnostic choices are akin to many other choices in medical relationships. Typically in other areas of medicine, providers are required to provide some information but not all conceivable information about available choices.

Some authors contend that the ethical standard for the provision of prenatal diagnostic information should be all-inclusive. That is, all information that each individual woman or couple requires to make a decision should be provided.⁷⁰ Adrienne Asch argues that such a standard permits full choice and avoids the divisive and destructive task of "line-drawing" whereby some conditions are deemed sufficiently severe to warrant prenatal diagnosis while others are not.⁷¹ She would prefer to limit the adverse consequences of prenatal diagnosis per se on those with disabilities by improving education about life with disabilities and otherwise fighting inaccurate and discriminatory attitudes.⁷² She trusts that, with time, couples will choose not to use or abuse prenatal diagnosis without the need to place artificial limits through professional standards.⁷³

There are at least several difficulties in promoting what I will call a "comprehensive standard." The first is the simple pragmatic concern over how such extensive and complex information could be managed in a professional encounter. Presumably this standard requires that all conditions be discussed for which tests are available, without respect to the prevalence of the condition or the relative risk of the pregnancy. Even if a variety of different conditions are col-

68. Kimberly A. Johns, *Reproductive Rights of Women: Construction and Reality in International and United States Law*, 5 CARDOZO WOMEN'S L.J. 1, 24 (1998).

69. See Tracie B. Loring, Comment, *An Analysis of the Informational Privacy Protection Afforded by the European Union and the United States*, 37 TEX. INT'L L.J. 421, 431 (2002).

70. See Asch, *supra* note 30, at 90-91.

71. *Id.* at 87-88.

72. *Id.* at 88.

73. See *id.* at 87-92.

lapsed into logical categories, such as all the conditions that cause profound intellectual disabilities, the task would remain formidable. Obviously visits to the obstetrician (or family practitioner or nurse-midwife) need to address a host of issues concerning the pregnancy other than prenatal diagnosis so the time is limited to discuss these issues. Further, care providers do not consistently address these issues at all at the present time. One observational study of obstetricians and nurse-midwives in 1998 found that sixty percent of first prenatal visits addressed family history, sixty percent subsequently addressed maternal serum markers ("AFP"), and thirty-four percent discussed ultrasound in the second trimester.⁷⁴ For women of 35 years and older, ninety-eight percent were counseled about amniocentesis or CVS. Notably, the discussion of prenatal diagnosis for women less than 35 years took an average of 2.5 minutes while for women 35 and older, the discussion lasted an average of 6.9 minutes.⁷⁵ Of course, we also need to consider the time it would take to explain all of the results of testing. If thousands of tests are being conducted, dozens or even hundreds of results may be sufficiently abnormal to warrant discussion.⁷⁶

So from a practical standpoint, it is hard to imagine how expectations for a vastly expanded discussion about prenatal diagnosis could be accommodated.⁷⁷ Significantly lengthening the visits would require additional professional personnel, mechanisms to pay for the expanded services, and marked improvements in provider education to permit accurate patient counseling. These changes would necessitate a fundamental restructuring of prenatal services. If prenatal di-

74. Barbara A. Bernhardt et al., *Prenatal Genetic Testing: Content of Discussions Between Obstetric Providers and Pregnant Women*, 91 OBSTETRICS & GYNECOLOGY 648, 648 (1998).

75. *Id.*

76. The concepts of test sensitivity and specificity are important here but beyond the scope of this discussion. Suffice it to say that screening tests are designed to be highly sensitive but not necessarily specific. When a large population is screened, there is almost always a significant number of false positive test results for each true positive. In the case of maternal serum AFP screening for neural tube defects, for every one hundred women with an initially positive test result, only two will have an infant affected with a neural tube defect. See Aubrey Milunsky et al., *Predictive Values, Relative Risks, and Overall Benefits of High and Low Maternal α -Fetoprotein Screening in Singleton Pregnancies: New Epidemiologic Data*, 161 AM. J. OBSTETRICS & GYNECOLOGY 291, 293 (1989).

77. An alternative approach to a comprehensive standard would be to simply perform all of the prenatal diagnostic tests for couples that choose prenatal diagnosis without offering education and separate choice about the different kinds of tests on the complete panel. This would save time on the front end of the testing sequence but would not eliminate the need to discuss the results of the tests at the other end. Such an approach would not uphold the ideal of informed consent and would pose some difficult dilemmas for couples who received more information than they really wanted. Of course there would be pressure from the professional community to limit the number of tests on the panel to a select number of relatively severe and relatively common conditions, but that temptation would have to be resisted if we wanted a truly comprehensive standard.

agnosis becomes an increasingly important medical service, these kinds of changes certainly are feasible. We might envision a whole new set of professional services to specifically address these needs, involving new professionals, new payment mechanisms, and new educational technologies. Until such time, a comprehensive standard could not be layered onto the current system of prenatal care.

A second concern with a comprehensive standard for information is that it does not permit an obvious distinction between what information is ethically desirable (presumably all) and what information might be mandatory. By mandatory here I mean that professionals could be held legally liable for damages if the information was not provided. Does a comprehensive standard mean that professionals could be successfully sued for *any* relevant information that they failed to provide to a couple upon the birth of an affected child? There are many rare conditions, mild conditions, and non-disease related conditions that are or will be amenable to prenatal diagnosis. It is one thing to claim that all these capabilities should be discussed with prospective parents, and quite another to assert that failure to do so should result in legally enforceable damages. Unless we are willing to say that a comprehensive standard is both ethically and legally mandatory, then a line-drawing exercise will be necessary to distinguish between omissions that merit sanction and those that do not.

A third concern with the comprehensive standard relates to the goals that such a standard seeks to gain. The concern is that line-drawing between different heritable or congenital conditions is hurtful to the community of those with disabilities. This sounds plausible, although we should not assume that those with disabilities, and those who have given birth to children with disabilities, are all in agreement with this point. In any case, the question is whether the promotion of a comprehensive standard ultimately will be less injurious to those with disabilities. Surely a social standard to encourage extensive discussion of these capabilities will promote actual use of the technology. A parallel effort can be made to reduce or eliminate discriminatory attitudes toward those with disabilities, but it seems highly likely nonetheless that prenatal diagnosis for an expanding list of conditions would become increasingly utilized. If so, then it also seems possible that disability will be seen less as an acceptable form of human diversity and more as an avoidable burden that people should choose to prevent. The basic point here is that a comprehensive standard for prenatal diagnostic information seems like a very poor strategy for promoting tolerance for disability.

These considerations leave our quest for professional standards for prenatal diagnosis on a broad middle ground. Some information is required in certain circumstances but all potential information need not nor cannot be provided. In my view, this requires some line-

drawing. That is, we, as a society, must make a determination of what kinds of information and tests should be offered for prenatal diagnosis and which need not be offered. If we accept this general premise, we must decide on a principle or set of principles by which such a line could be drawn. In my view, such a line should be drawn as a matter of professional standard, not as a matter of law or regulation. Further, as I will outline below, I believe the correct ethical analysis is provided by the wrongful birth torts. More specifically, the key question is whether the condition often results in tangible harms to the parents.

The concept of a general "line" in this context is consistent with recommendations of the majority of public bodies that have commented on this issue. Of course, there will be many arguments about where a line should be placed on a spectrum of disease severity and disease prevalence, but the basic concept of a line is familiar. A number of scholars and authoritative committees have raised concerns over the use of prenatal diagnosis for "mild" conditions or "trivial" indications. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research focused primarily on prenatal diagnosis for sex selection, stating:

The idea that it is morally permissible to terminate pregnancy simply on the ground that a fetus of that sex is unwanted may also rest on the very dubious notion that virtually any characteristic of an expected child is an appropriate object of appraisal and selection. Taken to an extreme, this attitude treats a child as an artifact and the reproductive process as a chance to design and produce human beings according to parental standards of excellence, which over time are transformed into collective standards. . . . [T]he Commission concludes that although individual physicians are free to follow the dictates of conscience, public policy should discourage the use of amniocentesis for sex selection.⁷⁸

The Committee on Assessing Genetic Risks of the Institute of Medicine took a more concrete stand and recommended that:

prenatal diagnosis not be used for minor conditions or characteristics. In particular, the committee felt strongly that the use of fetal diagnosis for determination of fetal sex or use of abortion for the purpose of preferential selection of the sex of the fetus is a misuse of genetic services that is inappropriate and should be discouraged by health professionals. . . . The committee believes this issue warrants careful scrutiny over the next three to five years as the availability of genetic testing becomes more widespread, and espe-

78. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. AND BIOMED. AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS 57-58 (1983).

cially as simpler, safer technologies for prenatal diagnosis are developed.⁷⁹

The American Medical Association's Council on Ethical and Judicial Affairs supports limitation of prenatal diagnostic services to more serious conditions. The council suggests: "Selection to avoid genetic disorders would not always be appropriate. . . . [S]election becomes more problematic as the effects of the disease become milder and as they become manifest later in life."⁸⁰ The Council states that a variety of factors influence whether prenatal selection for specific conditions would be ethically acceptable. The Council encouraged additional work on the appropriate uses of prenatal diagnosis stating: "[I]t is important to begin discussion of the issue now to ensure that appropriate ethical guidelines are in place when new applications become available."⁸¹

Several scholars have taken similar positions. Thomas Murray concludes, "[i]n short, we should not offer to provide prenataly information about traits or afflictions that are not substantial burdens on parent and child. We certainly should not assist couples in a misguided quest for the child that embodies their ideal collection of traits, including gender."⁸² Several authors have attempted to draw more lines to preclude specific uses of prenatal diagnosis. Stephen Post, Peter Whitehouse and Jeffrey Botkin argued against the use of prenatal diagnosis for familial Alzheimer disease.⁸³ Carson Strong argued for no restrictions on prenatal diagnosis for disease related conditions.⁸⁴ Strong's analysis would support a clinician who refused services for diagnosing nondisease related characteristics.⁸⁵ Dena Davis has written about the circumstance in which deaf parents consider using prenatal diagnosis to assure that their child also will be deaf.⁸⁶ Davis concludes:

A decision, made before a child is even born, that confines her forever to a narrow group of people and a limited choice of careers, so violates the child's right to an open future that no genetic counseling team should acquiesce in it. The very value of autonomy that

79. COMM. ON ASSESSING GENETIC RISKS, DIV. OF HEALTH SCIENCES POL'Y, INST. OF MED., ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 105 (Lori B. Andrews et al. eds., 1994).

80. Council on Ethical and Judicial Affairs, Am. Med. Ass'n, *Ethical Issues Related to Prenatal Genetic Testing*, 3 ARCHIVES FAM. MED. 633, 638-39 (1994).

81. *Id.* at 641.

82. THOMAS H. MURRAY, THE WORTH OF A CHILD 139 (1996).

83. See Stephen G. Post et al., *Selective Abortion for Familial Alzheimer Disease*, 79 OBSTETRICS & GYNECOLOGY 794 (1992).

84. CARSON STRONG, ETHICS IN REPRODUCTIVE AND PERINATAL MEDICINE: A NEW FRAMEWORK 137-48 (1997).

85. *Id.* at 146.

86. Dena S. Davis, *Genetic Dilemmas and the Child's Right to an Open Future*, HASTINGS CENTER REP., Mar.-Apr. 1997, at 7, 14.

grounds the ethics of genetic counseling should preclude assisting parents in a project that so dramatically narrows the autonomy of the child to be.⁸⁷

What are the competing considerations for developing a “line”? As we have seen, there is an expanding array of technical developments that permit an analysis of the embryo and fetus, potentially with less physical risk to the prospective mother. Since these tools are available and many couples wish to avoid the birth of a child with disabilities, there is an impetus to ensure that couples are aware of these options. To the extent that a child with a significant disability can have an adverse effect on the parents in terms of heartache, worry, time, effort, and money, the avoidance of these impacts promotes the welfare of the parents. We can say that failure to provide information about prenatal risks for a child with a significant disability is contrary to the interests of the parents. This concept is consistent with the basic rationale of the wrongful birth suits. However, this rationale weakens as the adverse impact on the parents weakens. The rationale virtually disappears for conditions that do not have a significantly adverse effect on the parents.⁸⁸ This includes, arguably, non-health conditions, mild or treatable conditions, and conditions that do not affect children.

Some in the disability rights advocacy community argue that children with disabilities do not have adverse effects on parents and families.⁸⁹ In my view, the advocates are correct that often, very often, the adverse effects are overstated. The literature does not support the notion that children with significant disabilities are a common trigger for divorce, or a source of chronic sorrow, or dysfunction in families. Such impacts occasionally occur, most often in couples with marginal coping skills to begin with, but they are not the norm. The literature tends to suggest that most families cope quite well with the demands of a disabled child and that the child is loved and supported as his or her own person and for what he or she brings to the family. I believe many or most of these parents would not consider the disabled child to have caused a negative impact on the family. So these issues are by no means straightforward. Yet, I think we can also say that successful coping with a significant disability requires an enormous investment of time, energy, money and lost opportunities. Even though a good outcome is often achieved, the path is difficult. Further, many parents who have had a child with, say, Tay Sachs disease or cystic fibrosis use prenatal diagnosis to prevent

87. *Id.* at 14.

88. See generally Jeffrey R. Botkin, *Fetal Privacy and Confidentiality*, HASTINGS CENTER REP., Sept.-Oct. 1995, at 32, 37 (discussing the burdens on parents of disabled children).

89. See Asch, *supra* note 30, at 85.

the birth of a second affected child. So we certainly cannot conclude that all parents of disabled children view the experience as rewarding on the whole. The basic point here is that although families typically cope very well with the challenges of a disabled child, the experience is sufficiently demanding that many reasonable, sensitive people would choose to forgo that challenge. Further, the magnitude of that challenge can be used as a criterion for whether prenatal diagnostic information should be offered.

We might also question whether disabilities have adverse effects on the children themselves to the extent that prenatal diagnosis and pregnancy termination would be a preferred alternative *for the child*. In my view, criticisms of the wrongful life concept are valid, and it cannot be argued that prenatal diagnosis and pregnancy termination are justified on behalf of the child. While there may be rare exceptions to this general conclusion, it is valid for the great majority of conditions for which prenatal diagnosis is available.

Also in support of a duty to offer prenatal diagnostic information is the respect we hold for a certain protected sphere of decision-making around our reproductive lives. John Robertson argues that couples should be free to do what they want with their reproductive lives unless someone else is injured or risks injury on the process.⁹⁰ This makes sense, although agreement will break down on how we define injury and risk of injury in this context. Obviously, a big part of the abortion debate is whether “someone” of moral significance is being terminated. In any case, the basic point here is that we, as a society, may want to show somewhat more deference to reproductive decisions compared to other kinds of medical decisions.

In contrast, there are a number of important considerations that work to limit the provision of information. The basic fact that embryos are discarded through PGD and fetuses are terminated through other forms of prenatal diagnosis raises serious ethical concerns. For those who believe that prenatal life should be afforded full moral status, this whole enterprise is ethically unacceptable. For many others, embryos and fetuses do not have full moral status as persons but they have sufficient moral status to preclude destruction for trivial reasons. Society is likely to remain divided on the moral status question, but I believe there is sufficient consensus that public policy about prenatal diagnosis should not promote or condone discarding embryos or terminating fetuses for less than weighty reasons.

A more subtle set of considerations relate to the nature of the parent-child relationship. Parents have broad control over their chil-

90. See John A. Robertson, *Genetic Selection of Offspring Characteristics*, 76 B.U. L. REV. 421, 428 (1996).

dren's environment, including discipline, diet, religion and education. Fine-grained prenatal selections could extend this control to the biologic nature of children. To some extent, parents can alter the biology of children through surgery or medications, but these interventions are tightly regulated through the medical profession. Any such interventions would only be justified based on the welfare of the child. A surgeon would not perform plastic surgery on a child at the behest of a parent's request unless the surgeon was convinced it was in the best interest of the child first and foremost. The immediate point is that society does exert some control over the parent-child relationship to limit the control parents have over many aspects of their children's lives.

More to the point, however, is the question of whether the selection of children for desirable characteristics will improve the quality of children's lives or of the parent-child relationship. Parents do try to influence and control the lives of their children to a significant extent, but, ultimately, children mature and move toward their own independent goals in life. This is always a complex and often difficult transition. Many people experience this transition first as a child and second as a parent. These are both central relationships in life. What will prenatal diagnosis and selection add to this relationship? To the extent that strong parent-child relationships are founded on a core of unconditional love, biologic selections may prove to be damaging to this central bond in life. This is a nebulous and hypothetical concern but sufficiently ominous to sustain a policy against broad-based prenatal diagnosis for non-health traits and mild conditions.

Finally, the impact of extensive prenatal diagnosis on those with disabilities must be considered. At the present time it is probably fair to say that social supports for those with disabilities have increased in recent decades despite the development of prenatal diagnostic technologies. This only means that there is no simple relationship between these social spheres. If prenatal diagnosis becomes a significant and important part of pregnancy management, then concerns over the impact of this technology on those with disabilities is entirely reasonable. If many prospective parents routinely seek their perfect child through extensive selections, then perhaps those parents who choose to forgo this technology will be seen as negligent. If social resources are devoted to selecting "the best" children, perhaps the disabled children who slip through the net will be the responsibility of their parents to muddle through as best they can. Or, darker still, perhaps withholding or withdrawing life-sustaining care often will be deemed appropriate for "defective" children who slip through the prenatal screen. Some will argue that any of these may come to pass in decades hence as long as we tolerate prenatal diagnosis at all.

But surely the risks are greater if we foster the extensive and detailed selection of children.

Each of these considerations deserves more attention than I can devote here. Nevertheless, we can return to the cases at the beginning and see how this discussion might guide us to a decision. In Case #1, Dr. Owen failed to provide Molly and Bert information about the increased risk of Down syndrome by virtue of Molly's age. A child with Down syndrome was born. Do they have a legal and ethical claim against Dr. Owen, who chose not to inform them of the risk? In most jurisdictions a legal claim would have a strong foundation and, under my analysis, a strong claim for ethical criticism as well. This has become a familiar enough situation that relatively clear answers are available.

Case #2 is more problematic. The physician failed to take a full family history and a child was born with an increased risk of breast and ovarian cancer as an adult. To date, there is no clear standard that encourages obstetricians to take a family history of cancer since cancer is not immediately relevant to the health of the mother or fetus. No cases have been brought as of yet to explicitly raise this issue. Further, there is a general consensus that BRCA1/BRCA2 testing should not be offered in the context of prenatal diagnosis, nor are children generally offered genetic testing for adult onset conditions unless preventive measures are appropriate in childhood. The analysis above supports this general consensus. From my perspective, risk of an adult onset disease in a child does not cause a sufficient impact on the parents to warrant prenatal diagnosis as a standard of care.

Case #3 was developed as a situation in which prenatal diagnosis for a "trivial" and non-health related condition (perfect musical pitch) might seem plausible. Further, the error of the physician was providing false information, not the potentially more excusable error of omission in failing to inform about testing capabilities. There are no legal cases to address such a claim, nor can we expect one in the foreseeable future. From an ethical perspective, this analysis provides no support for the parent's claim of injury. The notion that a healthy child embodies a harm to the family because he lacks an extraordinary talent is not sustainable. While perhaps we understand the parent's sentiments in this situation, the use of this powerful technology for such a selection is contrary to a set of values that we must seek to protect. Prenatal diagnosis has appropriate uses, but our society must carefully articulate those uses before we lose too much in the name of progress.