



Health Matrix: The Journal of Law-Medicine

Volume 23 | Issue 1

2013

What Does Choice Really Mean?: Prenatal Testing, Disability, and Special Education Without Illusions

Deborah Pergament

Follow this and additional works at: <https://scholarlycommons.law.case.edu/healthmatrix>

 Part of the [Health Law and Policy Commons](#)

Recommended Citation

Deborah Pergament, *What Does Choice Really Mean?: Prenatal Testing, Disability, and Special Education Without Illusions*, 23 Health Matrix 55 (2013)

Available at: <https://scholarlycommons.law.case.edu/healthmatrix/vol23/iss1/6>

This Symposium is brought to you for free and open access by the Student Journals at Case Western Reserve University School of Law Scholarly Commons. It has been accepted for inclusion in Health Matrix: The Journal of Law-Medicine by an authorized administrator of Case Western Reserve University School of Law Scholarly Commons.

WHAT DOES CHOICE REALLY MEAN?: PRENATAL TESTING, DISABILITY, AND SPECIAL EDUCATION WITHOUT ILLUSIONS

Deborah Pergament[†]

CONTENTS

INTRODUCTION.....	56
I. RECENT CONTROVERSIES: PRESIDENTIAL POLITICS, AMNIOCENTESIS, AND PUBLIC EDUCATION	57
II. A BRIEF OVERVIEW OF THE PAST AND THE CURRENT STATUS OF PRENATAL GENETIC TESTING.....	63
<i>A. Prenatal Genetic Testing</i>	63
<i>B. Prenatal Screening</i>	65
<i>C. Prenatal Genetic Diagnosis and Array-Based Comparative Genome Hybridization</i>	67
<i>D. Non-Invasive Prenatal Testing</i>	69
III. LEGAL, SOCIAL, AND BIOETHICAL EXAMINATIONS OF PRENATAL GENETIC TESTING AND DISABILITY	70
IV. SHAPING CHOICES: THE PRENATALLY AND POSTNATALLY DIAGNOSED CONDITIONS AWARENESS ACT	78
V. THE ILLUSION OF SPECIAL EDUCATION: THE PRIVATIZATION OF RESOURCES AND CHOICE.....	85
<i>A. Public Special Education and the IDEA</i>	85
<i>B. Parents as Enforcers: The Privatization of “Rights” and the Illusion of Parents as Equal Members of the “Team”</i>	92
<i>C. Private Remedies: The Real Focus of the IDEA and the Illusion of Public Responsibility for Children with Disabilities</i>	98
<i>D. Vouchers and Charter Schools: The Illusion of Choice and the Ultimate Privatization of Public Education</i>	101
CONCLUSION.....	114

[†] Managing Attorney, Children’s Law Group, LLC. Clinical Instructor, DePaul University College of Law. A.B., 1991, Mount Holyoke College; M.A., M.L.S., 1993, Indiana University; J.D., 1998, Case Western Reserve University School of Law. My thanks to Ruth Farrell and Jessica Berg for inviting me to participate in the “New Technologies, New Challenges: Women and Prenatal Testing in the 21st Century” symposium. I am grateful to Nanette R. Elster, Jennifer Simokaitis and Dr. Eugene Pergament for comments on earlier drafts. This Article does not reflect the opinions or policies of DePaul University College of Law or any clients of Children’s Law Group, LLC. All errors and opinions are mine.

INTRODUCTION

Debates over prenatal testing, disability, and public education are at the very center of my everyday work as an attorney. My legal practice focuses on representing children and families in complex special education and adoption law matters. Many of the children I represent are affected by genetic syndromes, chromosomal abnormalities, spina bifida and other neural tube defects, or disabilities caused by pregnancy, birth, and neonatal complications. I also advise several educational, medical, and social service organizations. This work involves counseling medical geneticists and genetic counselors who provide prenatal genetic testing services and develop new genetic technologies.

Through these experiences, I am uniquely able to observe and participate in the debates over the ethical and legal parameters that govern women's choices about prenatal testing and the responsibilities of individual families and society in caring for the wellbeing of children with disabilities. This Article considers the experiences of families with children affected by genetic conditions and the issues raised by prenatal genetic testing technologies. It raises questions about the appropriateness of state involvement in the choices women make about prenatal testing, particularly under the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2008.¹

Paradoxically, those political and social actors that most often seek to involve the state in reproductive choice also support the privatization of responsibility for the care and education of children with disabilities. As a result, the privacy right relating to intimate relationships, the family, and decisions about whether to have a child is becoming less absolute. I argue that this is not accidental, as the expansion of public surveillance and regulation of women's reproductive decisions and the related demonizing of the exercise of reproductive choice has diverted attention from efforts to provide for the social welfare by developing the necessary response of a just society. Such a response should involve: (1) the promulgation of rational regulations governing the development, access, and use of existing and emerging prenatal genetic screening and diagnostic technologies; and (2) the development of policies that give all children, including ones affected by genetic disorders, access to meaningful educational opportunities and health care.

Part I of this Article frames the discussion surrounding recent public controversies about prenatal testing, public education, and choice. It explores the choices that some of my clients have made about prenatal genetic testing and considers their experiences in the context of recent political discourse. Part II provides a brief overview of prenatal testing

1. Prenatally and Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110-374, 122 Stat. 4501 (codified at 42 U.S.C. §§ 201, 280g-8).

and the choices pregnant women must make in light of emerging prenatal genetic testing technologies. Part III discusses the legal, social, and bioethical implications of prenatal testing and disability. Part IV discusses efforts to address these issues through legislation and the use of public policy to shape the choices resulting from the use of prenatal genetic testing. Finally, Part V examines questions related to the current efforts to constrict reproductive choices involving genetic testing while simultaneously privatizing responsibility for disability. This section considers some of the challenges that arise from not just being pregnant and giving birth but actually parenting children with disabilities. For parents of children with disabilities, educational issues are often a primary concern, and the public school system is the government institution that usually helps define parental choices and responsibilities. My examination focuses on the effects of increased privatization of public special education programs and services. I emphasize the contradictions created by public policies intended to constrict the exercise of reasonable reproductive choices while claiming that the need to foster parental choice justifies the neo-liberal state's transfer of educational services for children with disabilities to the private realms of family and market.²

I. RECENT CONTROVERSIES: PRESIDENTIAL POLITICS, AMNIOCENTESIS, AND PUBLIC EDUCATION

Professor Harold Pollack notes that “[s]ixty years ago, the birth of an intellectually disabled child was viewed as a private tragedy. Families did the best they could, for as long as they could, or turned to forbidding public institutions for help.”³ The full inclusion and equality of people with disabilities in American society is far from being achieved, but a return to the secrecy, shame, and stigma that had surrounded families with disabled children will likely never occur. Unlike the women of sixty years ago, my clients do not view their children as private tragedies; rather, they proudly advocate for them and openly share their experiences. Clients have shared stories with me about their experiences with prenatal testing and how it has affected parenting a child with disabilities. These stories reveal what influences women's choices whether to undergo prenatal testing and how they use the information that testing reveals to make decisions about their pregnancies. These

-
2. Cf. Dorothy E. Roberts, *Privatization and Punishment in the New Age of Reprogenetics*, 54 EMORY L.J. 1343, 1345 (2005) (“Rather than expand public surveillance and regulation of women's reproductive decisions, we should tackle the social conditions that limit women's options for bearing and raising healthy children who can flourish in this society.”).
 3. Harold A. Pollack, *Do Liberals Disdain the Disabled?*, N.Y. TIMES (Feb. 27, 2012), <http://www.nytimes.com/2012/02/27/opinion/do-liberals-disdain-the-disabled.html>.

stories provide insights into the complex and often transformative experience of raising children with disabilities.

I have observed that women's ethnic backgrounds, religious beliefs, language barriers, and education levels can influence their decisions about prenatal testing. These factors, however, are not predictive or uniform across cultural or ethnic groups.⁴ Some of the women I represent have refused prenatal testing for religious or cultural reasons. Yet other women with religious and personal objections to abortion have undergone prenatal testing—not with the intent to terminate an affected pregnancy, but rather to prepare for the birth and share the diagnosis with family, friends, and health professionals. I have also represented families of children who had been diagnosed prenatally with spina bifida and undergone fetal surgery. Although these children still demonstrate disabilities, their medical and education records indicate that prenatal diagnosis and surgery likely lessened the severity of their conditions.

Some of the women I have represented underwent prenatal testing because of advanced maternal age and, after learning the fetus had a chromosomal abnormality, chose to continue the pregnancy. These women decided that the challenges associated with the diagnosis neither precluded a good quality of life nor detracted from the potential satisfaction of having a child. Other women have been very open in admitting that they did not wish to have a child with a disability. These women underwent prenatal testing and were told that the fetus had normal chromosomes. However, after demonstrating unusual health issues as newborns and subsequent developmental delays, these children were diagnosed with rare genetic disorders that are not tested for unless there is a known family history. Some of these mothers have since had other children after learning about the possibility of preimplantation genetic diagnosis or prenatal diagnosis for these rare disorders. These women wanted reassurance before undertaking another pregnancy and the opportunity to act on the information if the fetus was similarly affected. Other clients, concerned about the parenting challenges they already face, have elected not to have more children despite the availability of prenatal testing or knowledge that the likelihood of another affected pregnancy is statistically small.⁵

Many women who underwent prenatal diagnosis and chose to continue an affected pregnancy have shared with me that during their pregnancy and the child's infancy they felt that they exercised independent judgment and made conscious choices despite pressure from partners

-
4. Eugene Pergament & Deborah Pergament, *Reproductive Decisions After Fetal Genetic Counseling*, BEST PRACTICE & RESEARCH CLINICAL OBSTETRICS & GYNAECOLOGY 1, 13 (2012).
 5. See Maryhelen D. MacInnes, *One's Enough for Now: Children, Disability, and the Subsequent Childbearing of Mothers*, 70 J. MARRIAGE & FAM. 758, 758 (2008).

or family.⁶ Ultimately, these women relied on their own personal values and the information they received from health care professionals. They reported that the physicians and genetic counselors they consulted were knowledgeable and helpful.⁷

The women who learned about their child's disability during the prenatal period have felt sadness and loss about the diagnosis and experienced doubts about their choices. All profess love for their children and value their children's place in their family life,⁸ but many remain affected by the difficulties of constantly focusing on their child's health. Before the births of their children, several of my clients had significant experiences with disability: some had siblings with disabilities or worked as teachers, therapists, and physicians with children with disabilities. However, even these women were not fully aware of the sense of urgency, the responsibilities, and the economic and emotional demands involved in parenting a child with disabilities. They were surprised by the lack of support they received from the very institutions required to assist their children.⁹ This is the reason they come to my offices. Regardless of how they became a parent of a child with a disability, my clients believe they are "fighting for their child's educational needs to be met by institutions that are underfunded and often ill-equipped to do the job."¹⁰ They often feel that the public school system not only fails to support their choices

-
6. See Pergament & Pergament, *supra* note 4 (reporting that women making decisions about prenatal testing face pressures from others, emotions, and a lack of information).
 7. This is different from what has been reported in the medical literature. See, e.g., Brian G. Skotko, *Prenatally Diagnosed Down Syndrome: Mothers Who Continued Their Pregnancies Evaluate Their Health Care Providers*, 192 AM. J. OBSTETRICS & GYNECOLOGY 670, 671-72 (2005). The differences in this admittedly unscientific and much smaller sample may result from the fact the families I represent have access to medical geneticists and genetic counselors affiliated with academic medical centers. Most have received comprehensive genetic counseling during pregnancy and all have received genetic services after the birth and postnatal confirmation of diagnoses. My clients also tend to demonstrate the self-advocacy skills necessary to request information and attention from healthcare providers.
 8. See, e.g., Sara Eleanor Green, "We're Tired, not Sad": *Benefits and Burdens of Mothering a Child with a Disability*, 64 SOCIAL SCIENCE & MED. 150 (2007).
 9. See, e.g., Marsha Mailick Seltzer et al., *Psychosocial and Biological Markers of Daily Lives of Midlife Parents of Children with Disabilities*, 50 J. HEALTH & SOC. BEHAV. 1, 2 (2009) ("Parents of children with disabilities face a range of stressors associated with their children's behavior problems, including stigma, cost of care, and having to negotiate a fragmented service system . . .").
 10. See Margaret Storey, "Special Needs," *McCain-Palin, & the 2008 Election*, SALON (Sept. 21, 2008, 3:25 PM), http://open.salon.com/blog/margaret_storey/2008/09/19/special_needs_mccain-palinthe_2008_election.

regarding their child but has even become a source of worry, concern, and growing resentment.

On February 19, 2012, these issues became the latest front in the decades-long cultural war over abortion and a woman's right to reproductive choice, autonomy, and privacy. During an interview on CBS's *Face the Nation*, then presidential candidate Rick Santorum was asked about his comments during campaign stops and media appearances that the Affordable Care Act is designed to increase abortions and reduce overall health costs by culling the ranks of the disabled.¹¹ Santorum argued that insurance companies should not be required to pay for prenatal testing, claiming that amniocentesis "more often than not" results in abortion.¹² This sweeping overgeneralization may have been made as a provocative sound bite, but it is still worth considering in discussing the broader issues regarding the meaning of choice and prenatal testing.¹³ While Santorum indicated that he is not opposed to "general prenatal care," he sees prenatal genetic testing solely as a conduit to abortion¹⁴ and completely ignores the contribution it makes to obstetrical care.¹⁵ He failed to acknowledge the role testing plays in reassuring expectant mothers and their partners about the health of the

-
11. *Face the Nation* (CBS television broadcast Feb. 19, 2012), *transcript available at* http://www.cbsnews.com/2102-3460_162-57381060.html.
 12. *Id.*
 13. Santorum failed to consider the basic medical fact that most fetuses are not affected by Down syndrome or diagnosed with another trisomy, even among the population that has undergone chromosomal analysis after amniocentesis. See Antonio Forabosco et al., *Incidence of Non-Age-Dependent Chromosomal Abnormalities: A Population Based Study on 88965 Amniocenteses*, 17 EUR. J. HUM. GENETICS 897 (2009). The second, more complex, issue relates to the inflated description of the rate of abortions after the detection of Down syndrome by amniocentesis. Santorum claimed that "ninety percent of Down syndrome children in America are aborted." *Face the Nation*, *supra* note 11. This assertion is not supported in the scientific literature. See generally Jaime L. Natoli et al., *Prenatal Diagnosis of Down Syndrome: A Systematic Review of Termination Rates (1995-2011)*, 32 PRENATAL DIAGNOSIS 142 (2012). The review determined that weighted mean termination rate was 67 percent among seven population-based studies, 85 percent among nine hospital-based studies, and 50 percent among eight anomaly-based studies. Evidence suggests that termination rates have decreased in recent years. Termination rates also vary with maternal age, gestational age, and maternal race/ethnicity. The study concluded that a summary termination rate may not be applicable to the entire US population. *Id.*
 14. *Face the Nation*, *supra* note 11.
 15. See Eugene Pergament, *Prenatal Testing: Screening, Diagnosis, and Preimplantation Genetic Diagnosis*, in MOLECULAR GENETICS AND PERSONALIZED MEDICINE 147, 147 (D. Hunter Best & Jeffrey J. Swensen eds., 2012).

fetus, the avoidance of pregnancy complications,¹⁶ facilitating interventions like fetal surgery,¹⁷ and helping families to prepare for the birth of a child with a disability.

Santorum was also asked about his statements against the involvement of state and federal governments in public education.¹⁸ His comments demonstrated firm support for the privatization of public education. He spoke of choice in public education, including the option to have localities choose to place students in private or Christian schools.¹⁹ He advocated removing all federal mandates on education, which, although not explicitly mentioned, would include requirements to address the educational needs of children with disabilities.²⁰ Although likely unintended by the candidate, Santorum's campaign provides a starting point to consider the right to make choices regarding prenatal testing, disability, education, and the wider meaning of a political philosophy built upon inherent contradictions about parental rights to make choices regarding children with disabilities.

Santorum was not the first to employ this political strategy and to invoke a child with a disability. It was a more charged and strident recast of Sarah Palin's occasionally poignant—but still highly partisan—effort in 2008 to depict herself as the potential advocate in the White House for families of children with disabilities.²¹ Her one substantive policy speech was about special education and contained numerous references to her son with Down syndrome.²² Palin, who delivered her son at forty-four years old, openly acknowledged having an amniocen-

-
16. Letter from James N. Martin, President, Am. Coll. of Obstetricians & Gynecologists, to the 2012 Declared Presidential Candidates (Feb. 21, 2012) (providing information concerning the importance of prenatal care, including identification of fetal problems and early indicators of premature birth).
 17. Emily A. Partridge & Alan W. Flake, *Maternal-Fetal Surgery for Structural Malformations*, 26 BEST PRACTICE & RESEARCH CLINICAL OBSTETRICS & GYNAECOLOGY 669, 679 (2012) (concluding that advances in prenatal diagnosis and technical innovations in the surgical approach to the fetus have resulted in an increase in the successful clinical application of fetal intervention over the past three decades).
 18. *Face the Nation*, supra note 11.
 19. *Id.*
 20. See Trip Gabriel, *Santorum Defends Remarks on Obama and Government's Role in Education*, N.Y. TIMES, Feb. 20, 2012, at A11.
 21. Julie Bosman, *In Palin, Families of Disabled Children See a Potential White House Friend*, N.Y. TIMES, Nov. 3, 2008, at A19.
 22. See Sarah Palin, *Palin's Speech on Children with Special Needs*, REAL CLEAR POLITICS (Oct. 24, 2008), http://www.realclearpolitics.com/articles/2008/10/palins_speech_on_children_with.html.

tesis.²³ This admission is a noteworthy difference in the two candidates' discussions of their children with genetic disorders, issues related to children with disabilities, and how they discussed prenatal testing.²⁴ While Santorum expressed almost unqualified disdain for prenatal testing, Palin stepped outside the expected pro-life framework. She expressed thankfulness for the availability of amniocentesis and the chance the procedure gave her to prepare for her son's birth.²⁵ Given her avowed pro-life position, her admission that she struggled with the information and how to share it with her family reflected both unusual candor and a departure from current conservative tenets on reproductive choice issues.²⁶ Other than these personal revelations, however, she largely sidestepped the issue of prenatal testing throughout the remainder of the campaign.

Palin spoke gratefully about her strong family network and alluded to her ability to access resources while acknowledging others not as fortunate.²⁷ But unlike her discussion of her experiences with amniocentesis, Palin did not step outside the expected conservative framework regarding education reform and parental responsibility.²⁸ According to Palin, problems will be solved by transferring more activities to the private sector and requiring families to assume more responsibility under the guise of giving them more choices and control over their children's educational placements.²⁹

-
23. Jodi Kantor et al., *Fusing Politics and Motherhood in a New Way*, N.Y. TIMES, Sept. 8, 2008, at A1.
 24. The question of whether the difference between Rick Santorum's and Sarah Palin's public comments on prenatal testing reflect gender differences, bona fide political beliefs, or carefully constructed policy positions is beyond the scope of this Article and will likely be the subject of academic and popular media considerations of both figures for some time.
 25. Sandra Sobieraj Westfall, *John McCain & Sarah Palin on Shattering the Glass Ceiling*, PEOPLE (Aug. 29, 2008, 8:30 PM), <http://www.people.com/people/article/0,,20222685,00.html>.
 26. See, e.g., *The Politics of Amniocentesis*, FREAKONOMICS (Sept. 11, 2008, 11:12 AM), <http://www.freakonomics.com/2008/9/11/the-politics-of-amniocentesis>.
 27. See Palin, *supra* note 22 ("The law requires our public schools to serve children with special needs, but often the results fall far short of the service they need. Even worse, parents are left with no other options, except for the few families that can afford private instruction or therapy.").
 28. *Id.*; see generally Mark Harrison, *Public Problems, Private Solutions: School Choice and Its Consequences*, 25 CATO J. 197 (2005) (providing an overview of the market approach to organizing elementary and secondary education systems).
 29. See Rayna Rapp & Faye Ginsburg, *Reverberations: Disability and the New Kinship Imaginary*, 84 ANTHROPOLOGICAL Q. 379, 397-98 (2011).

While preparing to participate in this Symposium, I considered Santorum's and Palin's comments regarding both prenatal testing and public schools in light of my own experiences representing clients involved in both issues. My mind turned to the term "New Challenges" in the program's title and the English language formulation of Jean-Baptiste Alphonse Karr's famous epigram, "the more things change, the more they stay the same."³⁰ Prenatal genetic technologies may be rapidly expanding, but access to both abortion and to public services for children with disabilities is contracting. For the last half-century, we have remained mired in questions about what rights women have to use these technologies and how to balance private and public responsibilities for children with disabilities. The current political and social climate has forced us to return to questions regarding (1) what level of control the state or any other third party should be allowed over the individual right to exercise rational choice in the utilization of prenatal genetic testing technologies and (2) the responsibilities of a just society regarding the care and education of children with disabilities.³¹

II. A BRIEF OVERVIEW OF THE PAST AND THE CURRENT STATUS OF PRENATAL GENETIC TESTING

A. *Prenatal Genetic Testing*

Over the past half-century, a remarkable evolution has occurred in the development of screening and diagnostic testing for genetic and other disorders seen in the prenatal period.³² Prenatal testing has become an integral part of routine obstetrical care and management of prospective

-
30. JOHN BARTLETT, FAMILIAR QUOTATIONS 627 (Emily M. Beck ed., 14th ed. 1968) (quoting ALPHONSE KARR, 4 LES GUÊPES 407 (1849) ("Plus ça change, plus c'est la même chose.")).
31. My formulation of these questions was influenced by Baroness Helena Kennedy's description of the role of the state in the foreword to the report of the Human Genetics Commission. HUMAN GENETICS COMMISSION, MAKING BABIES: REPRODUCTIVE DECISIONS AND GENETIC TECHNOLOGIES 5 (2006). It must be acknowledged that the Human Genetics Commission's recommendations are made in a context that recognizes the challenge these issues create for the welfare state, which is a distinctly different approach than the market oriented approach that is the dominant paradigm in the United States. "In the UK, reproductive choices are made against the background of the welfare state. In this sense, founding a family is not a purely personal issue, but can have a wider social impact. This is because some fertility treatment is subsidized by state, and services are provided for babies and children who may have higher than average care needs, because of their health and/or family circumstances. However, at this time such considerations have by and large not been taken into account by individuals or expressly addressed by the state." *Id.* at 20.
32. Pergament, *supra* note 15, at 147.

parents.³³ Reproductive genetic testing and screening methods currently used in the clinical setting include prenatal genetic screening, prenatal genetic diagnosis utilizing invasive procedures (e.g., chorionic villus sampling and amniocentesis),³⁴ and preimplantation genetic diagnosis (PGD).³⁵ Although popular images of prenatal testing and recent political discourse have focused on invasive procedures (notably amniocentesis), most pregnant women undergoing prenatal testing are now less likely to undergo invasive procedures.

Prenatal screening determines a woman's risk for a chromosomal abnormality by statistically analyzing maternal serum and ultrasound markers. The primary purpose of screening is to determine whether an invasive procedure to obtain fetal genetic material for diagnostic purposes is warranted.³⁶ Prenatal genetic testing has very recently expanded to include noninvasive prenatal testing³⁷ for the identification of trisomy 21 (Down syndrome), trisomy 18 (Edward syndrome), and trisomy 13 (Patau Syndrome) as well as for the detection of X and Y chromosomes.

33. *Id.*

34. Amniocentesis relies on the chromosomal and biochemical analysis of cultured amniotic fluid. It can be performed after a gestational age of fourteen weeks and is usually performed between fifteen and seventeen weeks. Ronald J. Wapner, *Genetic Amniocentesis and Chorionic Villus Sampling*, in QUEENAN'S MANAGEMENT OF HIGH-RISK PREGNANCY: AN EVIDENCE-BASED APPROACH 453 (John T. Queenan et al. eds., 6th ed. 2012). Chorionic villus sampling (CVS) is also an invasive procedure to obtain material that reflects the genotype of the conceptus. *Id.* The procedure is typically performed between seventy and eighty-one days after the last menstrual period and involves the withdrawal of villi of the chorion (part of the placenta) under ultrasound guidance. *Id.*

35. "[PGD] is an alternative to prenatal diagnosis for the detection of genetic disorders in [genetic parents] at risk of transmitting a genetic condition to their offspring." See Pergament, *supra* note 15, at 157. It requires the use of three integrated technologies: conventional (IVF), micromanipulation of single cells, and genetic analysis of the single cell. *Id.* at 157. It is still subject to confirmation by invasive testing. *Id.* at 160. Although PGD raises many ethical, legal, and social issues, the limited clinical use of this technology is reflected in the limited discussion of PGD and the emphasis on other forms of prenatal testing in this Article.

36. *Id.* at 153 (stating that the application of first and second trimester screening has led to corresponding reduction in the rates of invasive testing by CVS and amniocentesis).

37. Current literature often refers to noninvasive prenatal testing (NIPT) as noninvasive prenatal diagnosis (NPID). This terminology is considered by many as inaccurate and misleading because the current technology is recommended only as a highly specific screening measure for high-risk pregnancies that requires follow-up diagnostic testing. Patricia L. Devers et al., *Noninvasive Prenatal Testing/Noninvasive Prenatal Diagnosis: The Position of the National Society of Genetic Counselors*, J. GENETIC COUNSELORS, Jan. 22, 2013, <http://www.nsgc.org/Portals/0/Advocacy/nsgc%20nipt%20white%20Paper.pdf>.

Although currently not considered diagnostic for any disorder, noninvasive testing will likely evolve into a fully diagnostic process for the entire fetal genome.³⁸

In 2007, the American College of Obstetricians and Gynecologists (ACOG) issued Practice Bulletins recommending that prenatal screening using ultrasound, serum makers, and invasive prenatal testing be offered to all pregnant women, regardless of age.³⁹ The guidelines recommend that both first- and second-trimester screening be offered to women who seek prenatal care in the first trimester.⁴⁰ Most importantly, “maternal age of 35 years alone should no longer be used as a threshold to determine who is offered screening versus who is offered invasive testing.”⁴¹ Adding to the challenges of how to counsel all pregnant women about prenatal testing is the broadening range of inherited disorders that carrier screening can identify in parents and during the prenatal period as well as the introduction of noninvasive prenatal testing.⁴²

B. Prenatal Screening

To understand prenatal testing technologies, it is important to draw a distinction between prenatal screening and diagnosis. “A screening test either determines whether prospective parents are carriers of mutations (e.g., cystic fibrosis) or whether a pregnancy is at increased risk for a specific disorder (e.g., a chromosomal abnormality such as trisomy 21).”⁴³

Before 1970, reproductive risk assessment was largely based on family history, patterns of inheritance of known Mendelian diseases, and limited information about the prevalence of genetic, developmental, and other disorders in newborns.⁴⁴ During the 1970s, mid-trimester amniocentesis made actual prenatal diagnosis of some genetic disorders possible.⁴⁵ In the early 1980s, physicians began to use genetic screening of maternal

-
38. INTERNATIONAL SOCIETY OF PRENATAL DIAGNOSIS, ISPD RAPID RESPONSE STATEMENT: PRENATAL DETECTION OF DOWN SYNDROME USING MASSIVELY PARALLEL SEQUENCING (MPS) (2011).
39. American College of Obstetricians & Gynecologists, *ACOG Practice Bulletin No. 77: Screening for Fetal Chromosomal Abnormalities*, 109 OBSTETRICS & GYNECOLOGY 217, 219 (2007); *see also* American College of Obstetricians & Gynecologists, *ACOG Practice Bulletin No. 88: Invasive Prenatal Testing for Aneuploidy*, 110 OBSTETRICS & GYNECOLOGY 1459, 1462 (2007).
40. *ACOG Practice Bulletin No. 77*, *supra* note 39.
41. *ACOG Practice Bulletin No. 88*, *supra* note 39, at 1462.
42. Pergament, *supra* note 15, at 150.
43. *Id.* at 147 (defining the difference between genetic screening and testing).
44. Pergament & Pergament, *supra* note 4.
45. *Id.*

serum alpha fetoprotein widely in clinical practice.⁴⁶ The use of this type of screening in the second trimester for all pregnant women became possible with the development of statistical analyses that discriminated more accurately between affected and unaffected pregnancies.⁴⁷ By the end of the 1980s, the use of maternal serum biochemistry and detailed ultrasonographic examination in the second trimester became the standard of care.⁴⁸

In the early 1990s, clinicians in London started performing first trimester screening for trisomy 21 and other aneuploidies utilizing measurements of nuchal translucency (the amount of fluid behind the neck of the fetus) via ultrasound during the first trimester.⁴⁹ The accuracy of this screening technique has since been enhanced by using a likelihood ratio analysis based on maternal age, nuchal translucency thickness, and measurements of maternal serum proteins free-beta hCG (human chorionic gonadotropin) and PAPP-A (pregnancy-associated plasma protein).⁵⁰ These techniques were adopted into clinical use in the United States in the late 1990s.⁵¹ Screening by this combined test can identify about 90 percent of fetuses with trisomy 21 and other major aneuploidies with a false-positive rate of 5 percent.⁵² This approach has been further refined with the use of fetal nasal bone measurements⁵³ and screening for cardiac abnormalities.⁵⁴

Prenatal screening using ultrasound and maternal markers has altered the rate of invasive prenatal diagnosis. This is particularly apparent in the population of women over thirty-five years of age as increasing numbers of these women rely on the individually adjusted risk

46. Pergament, *supra* note 15, at 151.

47. *Id.*

48. *See id.* at 152.

49. Kypros H. Nicolaides et al., *Fetal Nuchal Translucency: Ultrasound Screening for Chromosomal Defects in First Trimester of Pregnancy*, 304 BRIT. MED. J. 867, 867 (1992) (examining the significance of fetal nuchal translucency at 10-14 weeks' gestation in the prediction of abnormal fetal karyotype).

50. Pergament, *supra* note 15, at 152.

51. *Id.*

52. *Id.*

53. Simona Cicero et al., *Maternal Serum Biochemistry at 11-13 (+6) Weeks in Relation to the Presence or Absence of the Fetal Nasal Bone on Ultrasonography in Chromosomally Abnormal Fetuses: An Updated Analysis of Integrated Ultrasound and Biochemical Screening*, 25 PRENATAL DIAGNOSIS 977, 977 (2005).

54. Kypros H. Nicolaides, *Nuchal Translucency and Other First-Trimester Sonographic Markers of Chromosomal Abnormalities*, 191 AM. J. OBSTETRICS & GYNECOLOGY 45, 57 (2004).

figure for Down syndrome to make a decision about invasive testing.⁵⁵ The use of these screening tests has lowered the gestational age of prenatal diagnosis and potential abortion.⁵⁶ Increased use of first trimester screening has also affected pregnancy management and outcome.⁵⁷ Certain biophysical markers (maternal weight, height, ethnic background, age, and obstetrical history) and certain biochemical markers are associated with preeclampsia, gestational diabetes mellitus, small-for-gestational-age fetuses, and preterm delivery.⁵⁸ Identification of these risk factors is increasingly being used to structure prenatal care to avoid pregnancy complications associated with delivering newborns at significantly increased risk for lifelong disabilities.⁵⁹

C. Prenatal Genetic Diagnosis and Array-Based Comparative Genome Hybridization

A screening test is neither a definitive test nor a diagnostic test.⁶⁰ The information obtained from screening tests is typically used to aid in a decision whether to proceed with diagnostic testing.⁶¹ Diagnostic testing involves chorionic villus sampling (CVS) or amniocentesis.⁶² Two innovations are changing the practice of prenatal testing: array-based comparative genome hybridization (aCGH)⁶³ and noninvasive prenatal testing.⁶⁴

Array-based comparative genome hybridization is one of several recent developments in laboratory analysis for chromosomal and single-gene abnormalities found in samples obtained from amniocentesis or

-
55. Pergament, *supra* note 15, at 153.
56. Allan S. Nadel & Marisa L. Likhite, *Impact of First-Trimester Aneuploidy Screening in a High-Risk Population*, 26 FETAL DIAGNOSIS & THERAPY 29, 29 (2009).
57. Kypros H. Nicolaides, *Turning the Pyramid of Prenatal Care*, 29 FETAL DIAGNOSIS & THERAPY 183, 183 (2011) (proposing that the traditional pyramid of care should be inverted, with the main emphasis placed in the first rather than third trimester of pregnancy); *see also* Joseph R. Wax et al., *Biophysical and Biochemical Screening for the Risk of Preterm Labor*, 30 PRENATAL SCREENING & DIAGNOSIS 693 (2010).
58. Nicolaides, *supra* note 57, at 183.
59. *Id.*
60. Pergament & Pergament, *supra* note 44.
61. *See generally* Pergament, *supra* note 15, at 151-52.
62. Joe Leigh Simpson, *Invasive Procedures for Prenatal Diagnosis: Any Future Left?*, 26 BEST PRACTICE & RESEARCH CLINICAL OBSTETRICS & GYNAECOLOGY 625, 625 (2012).
63. *Id.* at 626.
64. ISPD RAPID RESPONSE, *supra* note 38 (discussing the commercial availability of non-invasive tests based on the presence of cell-free fetal nucleic acids in paternal plasma in the United States, China, and Europe).

CVS. Although conventional chromosome analysis remains the “gold standard,” it is not capable of identifying the submicroscopic deletions or duplications of DNA from chromosomes that are often associated with congenital malformations and significant developmental disabilities.⁶⁵ These can be identified by aCGH.⁶⁶ The method has already been established for fast and accurate detection of chromosome abnormalities in the postnatal period, allowing for diagnosis of syndromes and better clinical management of children who are demonstrating developmental delays and have normal chromosome analysis using conventional karyotyping.⁶⁷

While aCGH permits fast and accurate detection of chromosome abnormalities in the postnatal period, its use in the prenatal setting poses several clinical and ethical challenges.⁶⁸ First, because aCGH increases the statistical likelihood of identification of clinically significant variations, it results in more women being told that a fetus has some type of chromosomal abnormality.⁶⁹ Second, standards have not yet been established for whether the aCGH platform should be applied using target arrays or genome-wide arrays.⁷⁰ While target arrays focus on specific genomic disorders, genome-wide arrays allow for the potential detection of every known genetic disorder.⁷¹ The higher resolution of aCGH analysis can also identify chromosomal variations that are either benign or of uncertain clinical significance.⁷²

Medical geneticists, genetics counselors, and their legal and ethics advisors are currently struggling to develop practice policies and informed consent procedures to address the challenges resulting from using this technology in prenatal diagnosis.⁷³ Clinicians must help patients make decisions based on a chromosomal analysis that is significantly more sensitive than was available with previous methods of prenatal testing.⁷⁴ This sensitivity requires patients to confront choices

65. Pergament, *supra* note 15, at 154-55.

66. *Id.* at 154.

67. *Id.* at 154-55; see generally S. Hussain Askree & Madhuri R. Hegde, *Array Comparative Genomic Hybridization in Cytogenetics and Molecular Genetics*, in *MOLECULAR GENETICS & PERSONALIZED MEDICINE* 21, 27-28, (D. Hunter Best & Jeffrey J. Swensen eds., 2012).

68. See Andrew Pollack, *Clinical Trial is Favorable for a Prenatal Test*, N.Y. TIMES, Aug. 8, 2012, at B1.

69. Pergament, *supra* note 15, at 155.

70. *Id.*

71. *Id.*

72. *Id.*

73. See *id.* at 159.

74. The sensitivity of aCGH is also presenting other unique psychosocial challenges as the technology allows the routine use of chromosome analysis

about pregnancies demonstrating chromosomal variations that are anomalous but uncertain to cause developmental or other disabilities.⁷⁵ This information further complicates the choices women must make about prenatal testing, forcing them to decide how much information they wish to learn and what to do when an analysis reveals uncertain information.

D. Non-Invasive Prenatal Testing

For the last two decades, the risk of miscarriage associated with invasive procedures, even when performed by the most skilled and experienced physicians under state-of-the-art ultrasound guidance, has fueled research into noninvasive prenatal diagnostic techniques.⁷⁶ Until recently, clinicians and researchers considered the development of reliable non-invasive prenatal methods as the “holy grail” of clinical prenatal genetics.⁷⁷ The clinical availability of noninvasive prenatal testing represents a paradigm shift. With non-invasive testing, the risk of miscarriage is eliminated. In fact, the only physical risk to the mother is from a simple blood draw.

The widespread availability and use of these technologies will undoubtedly make prenatal testing near-universal, sparking debates over the choices that are available to women for prenatal testing and, potentially, abortion.⁷⁸ These technologies will identify more easily and precisely those disabilities that are not life-threatening but life-limiting; disabilities that often require expensive medical treatment and educational and therapeutic services to ensure both the highest quality of life and achievement. The potential for non-invasive testing technologies to avoid disabilities will likely intensify, rather than resolve, existing tensions over the proper care and education of children with disabilities.

for determination of non-paternity and consanguinity and the detection of adult onset conditions. *Id.*

75. *See id.*

76. P. Benn et al., *Non-Invasive Prenatal Diagnosis for Down Syndrome: The Paradigm Will Shift, but Slowly*, 39 *ULTRASOUND OBSTETRICS & GYNECOLOGY* 127, 127 (2012).

77. Mark I. Evans & Michael Kilpatrick, *Noninvasive Prenatal Diagnosis: 2010*, 30 *CLINICS LABORATORY MED.* 655, 655 (2010) (“Looking for fetal cells and now nucleic acids has been the holy grail of prenatal diagnosis for more than a century.”).

78. *Cf.* Peter A. Benn & Audrey R. Chapman, *Practical and Ethical Considerations of Noninvasive Prenatal Diagnosis*, 301 *JAMA* 2154, 2154 (2009) (“Noninvasive prenatal diagnosis differs from current approaches because all women would receive a definitive diagnosis immediately following the blood test.”).

III. LEGAL, SOCIAL, AND BIOETHICAL EXAMINATIONS OF PRENATAL GENETIC TESTING AND DISABILITY

The widespread availability and use of screening and diagnostic testing and recent technological advances in prenatal diagnosis have challenged social activists, legal scholars, and bioethicists to examine many interrelated issues concerning prenatal testing. These concerns include how testing affects the experiences of women during and after pregnancy and more broadly influences attitudes about the role of people with disabilities in American society.⁷⁹ These examinations consider prenatal genetic technologies within the historic context of the eugenics movement⁸⁰ and the potential coercive use of prenatal testing through legal mandates⁸¹ or by implicit social pressures on women and their partners.⁸² Another area of concern is the role prenatal genetic testing plays in the avoidance of the birth of children with disabilities and the subsequent exacerbation of long-standing discrimination against those with disabilities.⁸³

Disability is often discussed using distinct models.⁸⁴ The *medical model* of disability equates it with illness and considers disability as an

-
79. Although the discussion of clinical practice and procedures is dated, the essays that resulted from the National Institutes of Health Workshop “Reproductive Genetic Testing: Impact on Women,” provide an excellent framework for understanding many of the ethical and social questions raised by prenatal testing. *See generally* WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994).
80. *See, e.g.*, Sonia Mateu Suter, *The Routinization of Prenatal Testing*, 28 AM. J. L. & MED. 233, 234-37 (2002); *see generally* RUTH SCHWARTZ COWAN, HEREDITY AND HOPE: THE CASE FOR GENETIC SCREENING 12-116 (2008) (providing an overview of the history of both eugenics and genetic testing and supporting the use of genetic technologies).
81. *Cf.* Michael J. Malinowski, *Choosing the Genetic Makeup of Children: Our Eugenics Past—Present, and Future?*, 36 CONN. L. REV. 125, 211-15 (2003).
82. R. Alto Charo & Karen Rothenberg, “*The Good Mother*”: *The Limits of Reproductive Accountability and Genetic Choice*, in WOMEN & PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 105, 114 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994) (“Women are often subjected to communal, as well as personal, pressures to shape their reproductive decisions.”).
83. Deborah Kaplan, *Prenatal Screening and Diagnosis: The Impact on Persons with Disabilities*, in WOMEN & PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 49, 50 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994) (outlining the three types of prevention that are given as reasons for utilizing prenatal testing).
84. *See* Mary Crossley, *The Disability Kaleidoscope*, 74 NOTRE DAME L. REV. 621, 649-67 (1999). There are some who would argue that a fourth model exists: disability as a *culture* with a distinct group identity, language, and

undesirable impairment of human function.⁸⁵ The *social model* considers the construction of disability as representing a confluence of a person's physical or mental traits and the surrounding environment.⁸⁶ This model considers disability as a social construction, like race, that can be stigmatized by a society that collectively struggles to understand, accommodate, and accept difference—especially when such difference raises the perception of weakness and vulnerability.⁸⁷ By directing attention not at the individual with a disability but at the array of social choices that create most of the disadvantage attached to disability, the overarching policy implication is to encourage a focus “not on rehabilitation or charity but on eliminating the physical, social, and attitudinal barriers that make some physical and mental impairments disabling.”⁸⁸ The *minority group model* of disability uses the social model as a foundation but transforms it from an identity to a political call to action.⁸⁹ The minority model is also called the “civil rights” approach because of its focus on addressing systemic issues related to the social, political, and legal practices that result in the exclusion of people with disabilities from equal participation in society.⁹⁰

While acknowledging the long history of discrimination and abuse against those with disabilities, I choose to analyze disability in a way that emphasizes understanding it as an identity that is highly individualistic and dependent upon myriad cultural factors in all realms, including cultural, physical, and psychological attributes and experience.⁹¹ This view recognizes that disability is part of the human condition and acknowledges that there will likely always be adults and children with disabilities due to a wide range of causes that may or may not be detectable, preventable, or curable. These reasons might include acute

rituals. *See generally* CAROL PADDEN & TOM HUMPHRIES, *INSIDE DEAF CULTURE* (2005); Daniela Caruso, *Autism in the U.S.: Social Movement and Legal Change*, 36 AM. J.L. & MED. 483, 537 (2010). The decision not to include this model in the overall discussion of disability is not intended as a judgment about Deaf culture or the “Aspie” movement. I question, however, the usefulness of distinguishing the cultural model from the social model.

85. Crossley, *supra* note 84, at 649-54.
86. Adam M. Samaha, *What Good is the Social Model of Disability?*, 74 U. CHI. L. REV. 1251, 1251 (2007).
87. Crossley, *supra* note 84, at 654-59 (discussing the social model of disability); *see also* Samuel R. Bagenstos, *Subordination, Stigma, and “Disability”*, 86 VA. L. REV. 397, 427 (2000).
88. Samuel R. Bagenstos & Margo Schlanger, *Hedonic Damages, Hedonic Adaption, and Disability*, 60 VAND. L. REV. 745, 780 (2007).
89. Crossley, *supra* note 84, at 659-66.
90. *Id.* at 660-62.
91. *Id.* at 667.

illness, injury, infectious disease, or any other acquired health condition.⁹² The limitations of prenatal testing must also be considered within this view because such testing depends upon the application of technologies by fallible humans and may also reflect conscious choices not to test for certain conditions. Therefore, no test can be considered perfect or an absolute guarantee that a child will be born free from all genetic conditions.

This pragmatic approach acknowledges that formal law reflects an awkward view of the otherness of people with disabilities. This view is demonstrated by the unresolved definition of what “disability” and “equality” mean in educational policy development and implementation. Does equality mean merely including students with disabilities with those without disabilities? Or does it mean ensuring equality of opportunity, achievement, and advancement?⁹³ Most importantly, this view acknowledges that the tension surrounding the education of children with disabilities reflects a more global ambivalence, including responsibility for the education of children with disabilities.⁹⁴

92. Cf. Neal Halfon et al., *The Changing Landscape of Disability in Childhood*, 22 FUTURE OF CHILDREN 13, 15, 19-23 (2012) (providing a historical and statistical overview of the changing rates of disability and the evolution of notions of disability).

93. This critique is influenced by the work of Professor Ruth Colker who argues that “[t]he field of disability discrimination is undertheorized; it conflates “separate” and “unequal.” Ruth Colker, *Anti-Subordination Above All: A Disability Perspective*, 82 NOTRE DAME L. REV. 1415, 1415 (2007). Professor Colker has theorized that an integrationist perspective has played “an important historical and structural role in helping to close some horrendous disability-only institutions” but fails to recognize that the government needs to retain some disability only services but protect against the coercive use of those facilities by developing policies that reflect an anti-subordination perspective. *Id.* at 1416-17. In the realm of special education, this is particularly important for the provision of high quality, effective services that reflect an equitable distribution of resources and educational expectations that emphasize educational gains. *See id.*

94. *But see* John F. Muller, *Disability, Ambivalence, and the Law*, 37 AM. J.L. & MED. 469, 508-13 (2011) (arguing that ambivalence pervades our encounters with disability and that the law should express this ambivalence rather than strive for abstract conceptual clarity). I disagree with Muller on several points, including his presentation of the disability rights movement as somewhat monolithic in its alignment with the political left, particularly on the issue of abortion. Moreover, I would argue that the law already evidences, albeit without the intentionality Muller advocates, an ambivalent view of disability and the role of children and adults with disabilities in society. By focusing on access and inclusion as the primary goals instead of the maximization of potential for independent functioning (at whatever level possible for the individual) while simultaneously withdrawing resources to support those who are dependent, we perpetuate an ambivalent view of the place of the disabled within our society and our responsibilities in addressing their needs.

Over the past four decades, in response to the burgeoning use of genetic testing, social activists, scholars, lawyers, physicians, and bioethicists have debated the potential impact of carrier screening programs and prenatal diagnosis on society, individual women, and families. The feminist response to questions about prenatal testing, disability, and women has not been at all monolithic or simplistic.⁹⁵ Some feminist commentators have argued that the availability of reproductive choices, including prenatal testing, enhances the autonomy of women by allowing them to have access to information—the prenatal embodiment of the Jeffersonian maxim that “knowledge is power, that knowledge is safety, and that knowledge is happiness.”⁹⁶

This view also influenced the reproductive rights movement. Although most often focused on advocating against challenges to women’s individual choices and interference with personal autonomy and procreative liberty, the reproductive rights movement has sometimes relied (not without considerable debate and controversy) on public support for women’s right to act on the knowledge they receive from prenatal testing to have an abortion after the diagnosis of fetal anomalies.⁹⁷

-
95. See Isabel Karpin & Kristen Savell, *PERFECTING PREGNANCY: LAW, DISABILITY & THE FUTURE OF REPRODUCTION* 42 (2012) (noting “a uniform feminist response to prenatal testing technologies may be neither possible or desirable” because “these technologies are[] . . . ‘always potentially both’ ‘liberatory [and] socially controlling . . . depending on the weight various social and individual experiences hold in a particular woman’s life.’” (citation omitted)).
 96. *JEFFERSON HIMSELF: THE PERSONAL NARRATIVE OF A MANY-SIDED AMERICAN* 324 (Bernard Mayo ed., 1942); see also *Lifchez v. Hartigan*, 735 F. Supp. 1361 (N.D. Ill.), *aff’d* 915 F.2d 260 (7th Cir. 1990), *cert. denied sub nom* Scholberg v. Lifchez, 498 U.S. 1069 (1991) (holding that the constitutional right to privacy protects a couple’s decision to use genetic diagnostic tests on a conceptus, including embryo biopsy). “[W]ithin the cluster of constitutionally protected choices . . . must be . . . the right to submit to a medical procedure [to obtain information about the fetus through prenatal testing,] which can lead to a decision to abort.” *Id.*
 97. See, e.g., *GENERATIONS AHEAD, BRIDGING THE DIVIDE: DISABILITY RIGHTS AND REPRODUCTIVE RIGHTS AND JUSTICE ADVOCATES DISCUSSING GENETIC TECHNOLOGIES* 4 (2009) (discussing “fetal anomalies” as a justification for supporting abortion rights). The fetal anomaly argument has been criticized as justifying eugenic thinking. *Id.* Another criticism reflects inherent tensions within the feminist community resulting from claims of moral superiority by women who have abortions after prenatal diagnosis over women who have abortions for other reasons. See Roberts, *supra* note 2, at 1358-59 (distinguishing the “fetal defect” argument from other feminist prochoice claims). “This perverse moral distinction between ordinary and so-called ‘medical abortion’ reinforces the reproductive stratification that separates women whose childbearing is punished from those whose childbearing is technologically promoted by distinguishing even between the kinds of abortions they have.” *Id.* at 1359.

Other feminist, social-justice-oriented examinations focus on the possibility of prenatal testing becoming culturally or even legally mandatory⁹⁸ and leading to the questioning of women who do not undergo all available procedures⁹⁹ (or lack the resources to access these procedures¹⁰⁰) and the increased tolerance of eugenic policies.¹⁰¹ The use of prenatal testing for gender selection has also created apprehensions about allowing free choice because of concerns that widespread use for that purpose will result in the further subordination of girls and women.¹⁰² Another unresolved dilemma concerns balancing the responsibilities and choices of women and their partners with the rights of their potential offspring to have an open future and whether these individual choices should incur liability.¹⁰³

The overarching concern has been ensuring the right to choose not to undergo prenatal testing by recognizing that informed choice can only be made if a woman receives all the information relevant to the decision

-
98. Karen H. Rothenberg & Elizabeth J. Thomson, *Women and Prenatal Testing: An Introduction to the Issues*, in WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 1, 1-2 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994); see Charo & Rothenberg, *supra* note 82, at 107-09 (describing how choice may be illusory for many women because of the pressures that may be exerted on them regarding their reproductive decisions).
 99. Charo & Rothenberg, *supra* note 82, at 107 (“A woman’s decision to conceive, abort, or bear a child with genetic disorders may be subject to questions of personal, as well as communal accountability.”).
 100. See Mary B. Mahowald, *Genetic Technologies and Their Implications for Women*, 3 U. CHI. L. SCH. ROUNDTABLE 439, 445-46 (1996) (“Chief among the material factors that affect women significantly are those that limit the availability of genetic services Because of their financial inability to follow-through on test results, some poor women decline to avail themselves of genetic tests and counseling where the costs would be covered by others.”).
 101. LORI B. ANDREWS, FUTURE PERFECT: CONFRONTING DECISIONS ABOUT GENETICS 80-81, 90-103 (2001).
 102. See generally Kimberly Kristin Downing, *A Feminist Is A Person Who Answers “Yes” to the Question, “Are Women Human?”: An Argument Against the Use of Preimplantation Genetic Diagnosis for Gender Selection*, 8 DEPAUL J. HEALTH CARE L. 431 (2005).
 103. The discussions about the responsibilities of parents to provide children with a right to an open future considers several implications of prenatal genetic testing, including the use of preimplanation genetic diagnosis to have a child with a particular disability so that the child be part of their own culture or community, and the constraints that should be placed on these choices through public policy and tort liability. See generally Dena S. Davis, *Genetic Dilemmas and the Child’s Right to an Open Future*, 28 RUTGERS L.J. 549, 555, 559-67 (1997) (discussing these issues within the context of Feinberg’s concept of “the child’s right to an open future”).

and feels free of coercion or persuasion.¹⁰⁴ The discussions of the potential for coercion focused attention on the possible abusive use of reproductive technologies not only in totalitarian states but also through social pressure in more democratic societies.¹⁰⁵ These discussions included considerations of the potential risk of prosecution for women who declined prenatal testing or tort actions undertaken by children born with disabilities against mothers for refusing to undergo testing or providing treatment that might have improved their outcomes.¹⁰⁶ The most disturbing scenarios have not yet materialized. However, the debate over prenatal testing continues to be informed by the potential social and moral consequences of women feeling that they cannot exercise free agency because they are pressured to submit to prenatal testing—an action that represents one of the first acts of responsible mothering.¹⁰⁷

Disability scholars and activists have focused on the potential abuses of prenatal testing and its meaning in the context of the historic treatment of people with disabilities. The most ardent disability rights critique, the *expressivist* argument, considers the fetal anomaly argument an anathema. The expressivist argument holds that the use of prenatal testing is fundamentally incompatible with the belief that society can work both to decrease the incidence of disability and support people living with disabilities.¹⁰⁸ “Simply put, the argument is that prenatal testing sends the message to people with disabilities that their lives are

-
104. ANDREWS, *supra* note 101, at 103-06 (discussing protecting the right to refuse genetic testing). It is important to note the emergence of a corollary issue; state laws providing tort immunity to physicians who deliberately withhold information from patients to prevent abortions. These laws allow physicians to withhold results obtained from maternal serum screenings, ultrasounds, CVS, amniocentesis, or noninvasive prenatal testing if the physician believes the woman may have an abortion. Such a law been enacted in Arizona. *See* S.B. 1359, 50th Leg., 2nd Reg. Sess. (Ariz. 2012). This law may have unintended consequences, including inappropriate management of pregnancies because a woman will not be prepared for the delivery of a newborn with complications resulting from an undisclosed disability.
 105. *See* Charo & Rothenberg, *supra* note 82, at 107-14, 117-22.
 106. *See* Kimberly M. Mutcherson, *Making Mommies: Law, Pre-Implantation Genetic Diagnosis, and the Complications of Pre-Motherhood*, 18 COLUM. J. GENDER & L. 313, 324 (2008).
 107. Abby Lippman, *The Genetic Construction of Prenatal Testing: Choice, Consent, or Conformity*, in WOMEN & PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 105, 114 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994) (discussing how prenatal testing is viewed within other established behaviors that connote responsible mothering).
 108. Mary B. Mahowald, *Aren't We All Eugenacists? Commentary on Paul Lombard's "Taking Eugenics Seriously"*, 30 FLA. ST. U. L. REV. 219, 227-29 (2003).

not worth living.”¹⁰⁹ It cannot be reconciled with efforts to include people with disabilities. No distinctions can be made about what conditions are acceptable to select for or unacceptable to select for because some condition, group, or person will always be deemed unacceptable.¹¹⁰

The more nuanced *disability rights* critique does not focus on an absolute approach to the morality of abortion, though it still considers the choice to use prenatal testing if followed by selective abortion as morally problematic and the result of misinformation.¹¹¹ For those who identify as both pro-choice feminists and as disability rights activists, the goal of the disability rights movement concerning abortion is the right *not to* have an abortion and to make choices reflecting the belief that raising a child with a disability is not necessarily undesirable.¹¹² This critique views continuing, persistent, and pervasive discrimination as the major problem people with disabilities confront.¹¹³ Prenatal diagnosis is viewed as an extension of that discrimination because it reinforces the medical model of disability by drawing attention away from solving the societal discrimination people with disabilities face.¹¹⁴ Accordingly, this critique holds that using prenatal genetic tests has pernicious effects on the lives of existing disabled people by expressing a hurtful view of them and reducing human diversity—with the ultimate result of hindering the societal goal of recognizing and promoting equality.¹¹⁵ Proponents of the disability rights critique believe that women who choose to undergo prenatal diagnosis may reject an otherwise desired child, believing that the child’s disability will diminish their parental experience. This suggests that these women are unwilling to accept any significant

109. *Id.* at 229.

110. *Cf. id.* (stating a formulation of prenatal testing that a single trait standing for a whole obliterates the whole with “no need to find out about the rest” (internal quotation omitted)). *But see* Janet Malek, *Deciding Against Disability: Does the Use of Reproductive Genetic Technologies Express Disvalue for People with Disabilities?*, 36 J. MED. ETHICS 217, 217 (2010) (arguing the expressivist objection is misguided and that the use of reproductive genetic technologies to prevent disability in future children does not convey a negative message about those with disabilities).

111. *See* Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315-16 (2003).

112. *See generally* Marsha Saxton, *Disability Rights and Selective Abortion*, in *ABORTION WARS: A HALF CENTURY OF STRUGGLE, 1950–2000* (Rickie Solinger ed., 1998).

113. Asch, *supra* note 111, at 320-21 (citing Peter Singer, *Severe Impairment and the Beginning of Life*, 99 APA NEWSL. PHI. & MED. 246, 247-48 (2000)).

114. *See id.*

115. *Id.* at 333 (citing Adrienne Asch, *Why I Haven’t Changed My Mind About Prenatal Diagnosis: Reflections and Refinements*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 234 (Erik Parens & Adrienne Asch eds., 2000)).

departure from more conventional parental dreams for that child and fail to consider that parenting a child with a disability can provide the child-rearing experience they desire.¹¹⁶

Those who come to disability advocacy as a result of being the parent or caretaker of a person with disabilities are divided about prenatal testing and its impact on the resources available to care for those with disabilities.¹¹⁷ Some embrace the loss-of-support argument and believe that prenatal genetic testing will diminish the acceptance of people with disabilities and may discourage government funding for research and social and educational services.¹¹⁸ Among parents of children and young adults with intellectual disabilities like Down syndrome, the loss-of-support argument extends to the realm of social interactions—a fear that without the birth of children with Down syndrome, it will be a lonelier world for those with Down syndrome.¹¹⁹

There are those who also personalize the moral dimensions. “Some caregivers regard such tests—which can lead to abortions after unfavorable results—as an affront to the equal humanity of their loved ones.”¹²⁰ In contrast, “[o]thers quietly note the value of such testing[] and even suggest that terminating a pregnancy is sometimes the better course.”¹²¹ The willingness to support termination among disability advocates and caretakers usually involves the diagnosis of severe disabilities like anencephaly or syndromes that result in death during infancy or childhood such as Tay-Sachs disease¹²² or spinal muscular atrophy (types

116. *Id.* at 316 (“[M]ost people seek in child rearing . . . ‘to give ourselves to a new being who starts out with the best we can give, and who will enrich us, gladden others, contribute to the world, and make us proud.’” (quotation omitted)).

117. Pollack, *supra* note 3.

118. *Id.*

119. Amy Harmon, *Prenatal Test Puts Down Syndrome in Hard Focus*, N.Y. TIMES, May 9, 2007, at A1.

120. Pollack, *supra* note 3.

121. *Id.*

122. See *Tay-Sachs Disease*, A.D.A.M. MEDICAL ENCYCLOPEDIA, <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002390/> (last updated Nov. 17, 2010) (defining Tay-Sachs disease as a “deadly disease of the nervous system passed down through families”).

I and II)¹²³: life-threatening, as opposed to life-altering or life-limiting, conditions.¹²⁴

IV. SHAPING CHOICES: THE PRENATALLY AND POSTNATALLY DIAGNOSED CONDITIONS AWARENESS ACT

There are various medical, social, economic, and personal rationales underlying whether to use prenatal testing and what information a woman may learn from undergoing testing. For some women, the purpose of prenatal testing is solely for information gathering—to provide reassurance about their pregnancy or to give their health care providers and families time to prepare for the delivery and care of a child with a diagnosed disability. Regardless of one's rationale for testing, prenatal testing indisputably allows women to learn about potential fetal health and may compel them to make choices in response to that knowledge. Whether consciously understood or acknowledged, women make choices regarding the use of prenatal testing and the resulting information in a complex environment of conflicting opinions and agendas about pregnancy, abortion, disability, motherhood, and parental and family responsibilities.¹²⁵ All pregnant women, especially those women carrying fetuses affected by genetic conditions, must confront questions and face choices that lend themselves to an entire body of philosophical literature: What makes for a “good life?” What is the measure and value of health and human capacity?¹²⁶

For the minority of women who receive test results revealing a fetal anomaly, their choices are both limited in number and infinite in potential challenges. In the very small subset of cases where medical intervention is possible, some women might seek fetal surgery in an effort to ameliorate the effects of an anomaly.¹²⁷ The other choices are

123. See *Spinal Muscular Atrophy*, A.D.A.M. MEDICAL ENCYCLOPEDIA, <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001991/> (last updated Feb. 1, 2012) (defining spinal muscular atrophy as a “group of inherited diseases that cause muscle damage and weakness, which get worse over time and eventually lead to death”).

124. See Sonia M. Suter, *A Brave New World of Designer Babies?*, 22 BERKELEY TECH. L.J. 897, 966 (2007); see also Bonnie Steinbock, *Disability, Prenatal Testing, and Selective Abortion*, in PRENATAL TESTING AND DISABILITY RIGHTS 108, 109 (Erik Parens & Adrienne Asch eds., 2000) (noting that even many of those “who are almost always opposed to abortion” will accept it in cases involving “a severe disability in the fetus”).

125. Suter, *supra* note 124.

126. Asch, *supra* note 111, at 322-23 n.9.

127. See Eveline H. Shue et al., *Maternal-Fetal Surgery: History and General Considerations*, 39 CLINICS PERINATOLOGY 269, 269 (2012). In discussing the issues and questions raised by this Article, it is important to consider that fetal surgery for spina bifida is not curative; successful outcomes ameliorate the severity of life-long impairments. Children born after these

preparing to parent a child with a disability, placing the child for adoption,¹²⁸ or terminating the pregnancy.

An essential starting point in the examination of the meaning of those choices for women regarding prenatal testing and disability is acknowledging that “because a child’s disability is viewed as a private problem for the family, the gendered attribution of responsibilities for family health to women obligates them to deal with it alone whether by avoiding, reducing or managing disability.”¹²⁹ Pregnant women face these responsibilities in terms of the immediate issue of fetal health. After birth, for both biological and social reasons, women remain overwhelmingly in the highly stressful position of primary caretaker and must begin to confront future issues related to nurturing, rearing, and educating children.¹³⁰ These stresses are exacerbated considering that the caregiver role is seen as an operation in the private sphere with little or no systemic supports.¹³¹ Stresses are further compounded when women must confront these challenges alone and in poverty.¹³²

Proponents of expanding prenatal testing to all women recognize these concerns. In an interview with the *New York Times*, Dr. Deborah Driscoll, lead author of the ACOG Practice Bulletins, acknowledged

procedures will often still require early intervention therapeutic and special education services. See Enrico Danzer et al., *Fetal Myelomeningocele Surgery: Preschool Functional Status Using the Functional Independence Measure for Children (WeeFIM)*, 27 CHILD’S NERVOUS SYS. 1083 (2011).

128. Several organizations provide information and resources for families seeking to make adoption plans for a child with Down syndrome and families seeking to adopt a child with Down syndrome. See, e.g., *National Down Syndrome Adoption Network*, DOWN SYNDROME ASS’N OF GREATER CINCINNATI, http://dsagc.com/programs_adoption.asp (last visited Feb. 18, 2013).
129. Abby Lippman, *Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*, 17 AM. J.L. MED. 15, 39 (1991).
130. See also Rapp & Ginsburg, *supra* note 29, at 390 (describing the striking gender differences among mothers and fathers regarding changing work trajectories and involvement in efforts to support their child’s differences).
131. See Philip N. Cohen & Mriuna Petrescu-Parhova, *Gendered Living Arrangements of Children with Disabilities*, 68 J. MARRIAGE & FAMILY 630, 635 (2006) (finding that based on data on disabilities from the 2000 Census, children (aged five to fifteen years) with disabilities live disproportionately with women and are more likely to live with their single parent mothers).
132. See Mark Stabile & Sara Allin, *The Economic Costs of Childhood Disability*, 22 FUTURE OF CHILDREN 65, 69-78 (2012); see also PETER D. BRANDON & DENNIS P. HOGAN, THE EFFECTS OF CHILDREN WITH DISABILITIES ON MOTHERS’ EXITS FROM WELFARE 3, 14 (2001); Karen Syma Czapanskiy, *Disabled Kids and Their Moms: Caregivers and Horizontal Equity*, 19 GEO. J. ON POVERTY LAW & POL’Y 43, 46 (2012) (analyzing the socio-economic causes of the inequities experienced by families of children with disabilities).

“there are many couples who do not want to have a baby with Down syndrome They don’t have the resources, don’t have the emotional stamina, don’t have the family support. We are recommending this testing be offered so that parents have a choice.”¹³³

Those opposed to prenatal testing because of opposition to abortion have routinely criticized the information prospective parents are given by health professionals providing prenatal testing about what it is like to have and raise a child with Down syndrome. Opponents of prenatal testing have argued that health professionals too often focus on only dire outcomes and the hardest challenges rather than the positive experiences. According to these critics, this counseling places undue pressure on parents to terminate pregnancies affected with Down syndrome and consequently reduces the number of individuals living with Down syndrome.¹³⁴ Even supporters of prenatal testing and healthcare professionals acknowledge the negative impact of the model of disability and the difficulties clinicians face in providing a balanced description of Down syndrome when counseling patients.¹³⁵

In 2007, Senator Sam Brownback introduced legislation, co-sponsored by Senator Edward Kennedy, called the Prenatally and Postnatally Diagnosed Conditions Awareness Act.¹³⁶ Congress passed the Act on September 25, 2008 by a voice vote, and President George W. Bush signed the bill into law on October 8, 2008.¹³⁷ Groups across the political spectrum hailed the passage of the Act and considered it an opportunity to elevate the national discourse around disability and to provide additional information to women who choose to raise children with disabilities without including anti-choice language or provisions.¹³⁸ The Act is intended to increase the provision of scientifically sound information and support services to patients receiving a positive diagnosis for Down syndrome or other prenatally and postnatally

133. Harmon, *supra* note 119, at A22; *see also ACOG Practice Bulletin No. 88*, *supra* note 39; *ACOG Practice Bulletin No. 77*, *supra* note 39, at 219.

134. *See* Brian G. Skotko, *With New Prenatal Testing, Will Babies with Down Syndrome Slowly Disappear?*, 94 ARCHIVES OF DISEASE IN CHILDHOOD 823, 825 (2009) (“Parents who have children with DS have already found much richness in life with an extra chromosome. Now is the time for the rest of us to discuss the ethics of our genetic futures.”).

135. Catriona Hippman et al., *What Is a “Balanced” Description? Insight from Parents of Individuals with Down Syndrome*, 21 J. GENETIC COUNSELING 35 (2011).

136. S. 1810, 110th Cong. (2007).

137. *See S. 1810 (110th): Prenatally and Postnatally Diagnosed Conditions Awareness Act*, GOVTRACK, <http://www.govtrack.us/congress/bills/110/s1810> (last visited Feb. 18, 2013).

138. Rebecca Dresser, *Prenatal Testing & Disability: A Truce in the Culture Wars?*, HASTINGS CENTER REP., Mar. 2009, 7-8 (discussing the collaboration and compromise that resulted in the Act’s passage).

diagnosed conditions.¹³⁹ The Act's focus is exclusively on collection and dissemination of information instead of research, funding, provision of services, or other actions designed to address the actual needs of families and children. This is likely one reason passage was supported by such divergent and diverse groups. Although the Act places no mandates or requirements on health professionals, professional organizations, including the National Society of Genetic Counselors, use the language of the Act as a guidepost in issuing practice guidelines.¹⁴⁰

According to Professor Rebecca Dresser, the Act reflects an attempt to find common ground among pro-choice, pro-life, and disability advocates and marks a promising sign of compromise in the culture war over prenatal diagnosis in reproductive choice.¹⁴¹ Because the Act situates women's choices about pregnancy within the standard informed consent framework and references to "up-to-date [and] evidence based" information, it may help rebuff the impact of recent laws that ostensibly promote informed choice, but in fact require the delivery of inaccurate and partisan information about the risks and outcomes of abortion.¹⁴² But given the current political climate and recent state legislative enactments, Professor Dresser's predication may prove overly optimistic. Prenatal diagnosis via currently established modalities is still legal and will likely remain so, but outright prohibitions are not the only means to restrict women's abilities to make choices about pregnancy.¹⁴³ Currently existing laws will likely have a chilling effect on women's access to choices even as the standards of care and technology make prenatal testing one of the cornerstones of obstetrical patient care. These include measures that require the dissemination of potentially medically suspect

139. Prenatally and Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110-374, 122 Stat. 4501 (codified at 42 U.S.C. §§ 201, 280g-8).

140. See Kathryn B. Sheets et al., *Practice Guidelines for Communicating a Prenatal or Postnatal Diagnosis of Down Syndrome: Recommendations of the National Society of Genetic Counselors*, 20 J. GENETIC COUNSELING 432, 436 (2001) (citing the Prenatally and Postnatally Diagnosed Condition Awareness Act of 2008 in providing practice guidelines for genetic counselors); see also Devers et al., *supra* note 37.

141. Cf. Dresser, *supra* note 138, at 7.

142. See *id.* at 8.

143. The term "restrict" is an intentional acknowledgement that even as the Court has whittled away at the right to abortion over the last two decades, the core right to choose an abortion remains protected. See *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833, 840-41 (1992) (upholding certain restrictions on a woman's right to access abortion including forced waiting period and informed consent requirements); *Gonzales v. Carhart*, 550 U.S. 124, 168 (2007) (upholding a Congressional ban on a second-trimester abortion procedure termed "partial birth abortion").

information,¹⁴⁴ medically unnecessary ultrasound scans prior to abortions,¹⁴⁵ and laws personifying embryos and fetuses.¹⁴⁶ The most

-
144. *See, e.g.*, S.D. CODIFIED LAWS § 34-23A-10.1(e)(i)-(ii) (2005) (requiring physicians to advise women seeking abortions that they face an increased risk of suicide and suicidal thoughts if they obtain the procedure); *see also* Planned Parenthood Minnesota v. Rounds, 683 F.3d 889, 905-06 (8th Cir. 2012) (holding that requiring disclosure to patients seeking an abortion of an increased risk of suicide ideation and suicide was constitutional because the suicide advisory was non-misleading and relevant to the patient's decision to have an abortion, therefore it did not violate physicians' free speech rights). *Cf.* Vignetta E. Charles, et al., *Abortion and Long-term Mental Health Outcomes: A Systemic Review of the Evidence*, 78 CONTRACEPTION 436 (2008) (suggesting "few, if any, differences between women who had abortions and their respective comparison groups in terms of mental health sequelae").
145. *See, e.g.*, TEX. HEALTH & SAFETY CODE ANN. § 171.012 (West 2012), requires that a pregnant woman certify in writing her understanding that (1) Texas law requires an ultrasound prior to obtaining an abortion, (2) she has the option to view the sonogram images, (3) she has the option to hear the fetal heartbeat, and (4) she is required to hear the medical explanation of the sonogram unless she falls under the narrow exceptions to this requirement. The three exceptions are (1) pregnancy as a result of rape or incest which has been reported or, if it has not been reported, was not reported because the woman reasonably risks retaliation resulting in serious bodily injury, (2) a minor taking advantage of judicial bypass procedures to avoid parental notification, or (3) a fetus with an irreversible medical condition or abnormality. If seeking to avoid the description of the sonogram images, the woman must indicate within which exception she falls. *But compare* Carolyn Jones, *We Have No Choice: One Woman's Ordeal with Texas' New Sonogram Law*, TEXAS OBSERVER, Mar. 15, 2012 (describing a personal experience of being compelled to undergo a sonogram and read and listen to information about fetal development and abide by a waiting period before an abortion of a fetus with a lethal anomaly because the medical personnel did not know that the diagnosis of a fetal anomaly excused compliance with the newly enacted measure).
146. *See, e.g.*, ALA. CODE § 26-23B-2(5) (2011) (finding that a fetus feels pain after twenty weeks and subjecting a fetus to painful stimuli may cause disabilities later in life); Pain-Capable Unborn Child Protection Act, 2013 ARK. ACTS 171 (banning abortions for women past twelve weeks of pregnancy), ARK. CODE ANN. § 20-16-1104 (West 2011) (requiring the physician notify the patient of potential risk of the surgery as well as the availability of anesthetics to reduce the pain of the fetus); IDAHO CODE ANN. § 18-503(5) (2011) (finding that anesthesia is used to reduce the pain of the fetus during surgical procedures); MINN. STAT. ANN. § 145.4242 (West 2011) (stating that consent is only determined after, among other requirements, the female is given notice of the availability of anesthetics to reduce the pain of the fetus); MO. ANN. STAT. § 188.027 (West 2012) (requiring the physician to notify the patient that anesthetic is available to alleviate pain to the fetus during the procedure); NEB. REV. STAT. §§ 28-3, 104-05 (2010) (finding that an unborn fetus feels pain after twenty weeks, anesthesia will reduce the pain felt during a medical procedure, and a doctor must notify the patient of these facts before performing the procedure); OKLA. STAT. ANN. tit. 63, § 1-738.9 (2006) (requiring the

obvious example is providing physicians with immunity from tort liability for *intentionally* not telling a woman her fetus has an anomaly detected by ultrasound or other form of prenatal testing.¹⁴⁷ These measures will likely restrict women's right to choose termination after prenatal testing even if there is not an absolute prohibition on abortions.¹⁴⁸

Professor Mary Mahowald has argued that

while individuals are unable to care adequately for a child in some instances, the same is hardly true for society as a whole, at least in the developed world. Collectively, society has all the resources necessary to care adequately for all of its people: healthy newborns, those with disabilities, or anyone who needs care that is not available through parents or other family members. Accordingly, society in general does not have the justification that some pregnant women may have for testing and abortion of fetuses whose subsequent care may be impossible for them to provide.¹⁴⁹

Professor Mahowald's argument is based on the belief that an enlightened society generally accepts these additional costs and burdens as just, recognizing that any one of us might have been born with or acquire such a disease or disability.

This formulation raises the question about whether the Act and similar measures intended to ensure "balance" in the presentation of information about the lives of children and adults with genetic conditions truly promotes both informed consent and choice, given the privatization of responsibility for disability and the fact that pregnant women's choices are being increasingly constricted. Depending on a family's ability to access services from public schools and other government institutions, the disclosure of information as embodied by the Act on "the range of outcomes for individuals living with the diagnosed condition,

physician to notify the patient if anesthetics would reduce the pain of the fetus during the procedure).

147. See, e.g., S.B. 1359, 50 Leg., 2nd Reg. Sess. (Ariz. 2012); ARIZ. REV. STAT. § 12-719 (relieving physicians from liability for damages based on a claim that but for an act or omission of the defendant, a child or children would not or should not have been born).

148. See *Gonzales v. Carhart*, 550 U.S. 124, 171 (2007) (Ginsburg, J., dissenting) ("[A]t stake in cases challenging abortion restrictions is a woman's 'control over her [own] destiny.'"). A comprehensive discussion of the issue of the intersection of prenatal genetic testing and abortion and the related relationship between technological innovations in prenatal testing and current law and practice is beyond the scope of this Article. For such discussion, see Rachel Rebouché & Karen Rothenberg, *Mixed Messages: The Intersection of Prenatal Testing and Abortion*, 55 HOW. L.J. 983, 986 (2012).

149. Mahowald, *supra* note 108, at 232.

including physical, developmental, educational, and psychosocial outcomes” may actually present an unrealistic and unattainable—or even coercive—picture of the choice to parent a child with a disability.¹⁵⁰

-
150. *But cf.* Dov Fox & Christopher L. Griffin, Jr., *Disability-Selective Abortion and the Americans with Disabilities Act*, UTAH L. REV. 845 (2009). Professors Fox and Griffin argue that the public meaning of particular practices can interact with existing norms to generate “expressive externalities” on social relations and behaviors. They suggest that the ADA may have encouraged prospective parents to terminate pregnancies affected by Down syndrome by giving rise to demeaning media depiction and social conditions that reinforced negative understandings and expectations among prospective parents about what it means to have a child with a disability. They do not claim to have detected a causal statistical relationship between the ADA and changes in the Down syndrome birthrate and acknowledge that “[t]he absence of data on actual Down-selective terminations and of comprehensive interview responses by prospective parents who face this decision caution against drawing broad conclusions.” *Id.* at 847, 883. Nevertheless, they argue that the statistical evidence is suggestive of a correlation of the impact of disability-selective abortion and may give reason to advance public education campaigns to correct misleading social perceptions. *Id.* at 871, 893. I find Professors Fox and Griffin’s arguments intriguing and appreciate their acknowledgement that their “findings [do not] justify restrictions on a woman’s constitutional right to terminate a pregnancy for any reason, at least until the third trimester.” *Id.* at 893. But, I would argue that even more caution is required as suggested by their own caveat that a complex array of legal, material, economic, technological, social, familial, and medical factors might reasonably inform prenatal testing and selective abortion for Down syndrome indicates the limits of formal law in creating a causal connection between the dissemination of information either in public information campaigns or in individual private consultations by women with their health care providers and any resulting individual private action. *See id.* at 883-85. Their analysis also conflicts with my own experience advising health care professionals developing policies and procedures for counseling patients undergoing prenatal testing, representing families of children with genetic disorders, and observing the highly personal and complex factors that contribute to the decision to terminate a pregnancy diagnosed with Down syndrome or another genetic disorder. In Professors Fox and Griffin’s own words, “[a] skeptical reader might even accept [or at least find them carefully developed and well-argued] our statistical findings but still not agree with our narrative premise.” *Id.* at 871. I also disagree with their emphasis on supplementing the passage of certain civil rights laws with public education campaigns on behalf of the protected group in question as a way of securing the promise of civil rights and self-respect for those in need of the law’s protection. *See id.* at 893. While public education campaigns are a worthy endeavor, the externality that would result in measurable differences in the life experience of children and adults with disabilities is the allocation of public resources and health, education, and social services.

V. THE ILLUSION OF SPECIAL EDUCATION:
THE PRIVATIZATION OF RESOURCES AND CHOICE

A. *Public Special Education and the IDEA*

Public special education provides an opportunity to consider how the privatization of responsibility for children with disabilities affects access to the choices that may ultimately determine the outcome of these children's lives.¹⁵¹ This section will provide a brief overview of the Individuals with Disabilities Education Act (IDEA) and discuss the increasing transfer of responsibility for the education of children with disabilities to the private sector. This shift has resulted in the contraction—not expansion—of choices available to parents of children with disabilities.

For parents of children with disabilities, educational issues are often a primary concern.¹⁵² This concern arises from personal responsibilities and the more global reality that the public school system is the government institution that families of children with disabilities are most likely to interact with.¹⁵³ Concerns about education also relate to the tremendous responsibilities parents shoulder under the IDEA.¹⁵⁴ The IDEA is based on the expectation that parents serve as private “attorneys general” that enforce the law, protect their children's rights, and ensure access to services.¹⁵⁵

American public school districts provide special education services to children with a diverse range of disabilities. The IDEA mandates that a child receive special education if he has at least one of fourteen

-
151. Wendy F. Hensel, *Vouchers for Students with Disabilities: The Future of Special Education?*, 39 J.L. & EDUC. 291, 327 (2010).
152. See Teresa Scruton, *Bardet Biedel Syndrome (BBS)*, ORPHAN DISEASE NETWORK, <http://www.orphandiseasenetworg/ciliopathies-bbs-meckel-gruber-joubert-jeune-lca-nphp/bardet-biedl-syndrome-bbs/> (last visited Feb. 17, 2013) (“[T]he issue that worried caregivers the most was . . . management and nutrition, with 66% reporting this concern. Closely following weight management were concerns for their child's education (53%) . . .”).
153. See Cohen & Petrescu-Parhova, *supra* note 131, at 630-31.
154. See *generally* Individuals with Disabilities Education Act, 20 U.S.C. § 1400 *et seq.* (2006).
155. See Erin Phillips, *When Parents Aren't Enough: External Advocacy in Special Education*, 117 YALE L.J. 1802, 1828 n.127 (2008) (“[T]he IDEA assumes that parents are willing to make the extra effort to participate in the special education process. There are certainly families in which, for whatever reason, the parent will not be sufficiently motivated to fight for a FAPE for his child.”). There are also certainly families in which, for reasons including lack of personal motivation and external forces such as poverty, parental disability, illiteracy, that the parent will not be able to marshal the resources necessary to advocate for their child.

enumerated impairments¹⁵⁶ and thus requires special education and related services.¹⁵⁷ The IDEA provides educational services to eligible children until age twenty-one and has grown to include over 9 percent of students ages six through twenty-one.¹⁵⁸

The number of children qualifying for special education under the IDEA is growing. This is for several reasons, including: greater acknowledgment of the needs of children with disabilities;¹⁵⁹ improvements in technology that shift mortality to chronic morbidity;¹⁶⁰ federal policy guidance that expanded eligibility to include children with attention deficit disorder and attention deficit hyperactivity disorder under the category “Otherwise Health Impaired”; and the significant increase in the number of children diagnosed with autism.¹⁶¹ Another explanation focuses on the expansive use of the term “specific learning disability.” This may be exacerbated by the efforts of school districts serving low-income populations to obtain funds for students who previously would have been considered non-disabled low-achievers.¹⁶²

156. Individuals with Disabilities Education Act (IDEA), 20 U.S.C. § 1401(3)(A)(i), (B)(i) (2006).

157. 20 U.S.C. § 1400(d)(1)(A) (2006); 34 C.F.R. § 300.8(a) (2012).

158. “In 2006, a total of 6,081,890 students ages six through twenty-one were served under *IDEA*, Part B.” DEPARTMENT OF EDUCATION, 30TH ANNUAL REPORT TO CONGRESS ON THE IMPLEMENTATION OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT, at xx (2008). “Of these students, 5,986,644 were served in the 50 states, the District of Columbia and Bureau of Indian Education schools.” *Id.* This number represented 9.1 percent of the general population ages six through twenty-one. *Id.*

159. The fact that the number of children considered disabled by public schools systems has increased despite increasing use of prenatal genetic testing has not yet entered the debates over prenatal genetic testing and reproductive choice. A discussion of this important topic and the potential consequences for the development of legislation affecting both pregnant women and children with disabilities enrolled in public schools is beyond the scope of this Article but should receive future attention from legal scholars, geneticists and genetic counselors, and other academic disciplines.

160. See Paul H. Wise, *Emerging Technologies and Their Impact on Disability*, 169 FUTURE OF CHILDREN 169, 174 (2012).

161. See Laudan Aron & Pamela Loprest, *Disability and the Education System*, 22 FUTURE OF CHILDREN 97, 102 (2012).

162. By contrast, another cynical explanation, popular among conservative social critics, is that social changes have resulted in destigmatizing disability among affluent parents. These parents now purposely have their children diagnosed with learning disabilities to obtain advantages such as extended time on college admissions tests. See Wade F. Horn & Douglas Tynan, *Time to Make Special Education “Special” Again*, in RETHINKING SPECIAL EDUCATION FOR A NEW CENTURY 23, 28-31 (Chester E. Finn et al. eds., 2001).

The growing acceptance of disability and efforts to address the needs of children with disabilities represents a significant evolution in social attitudes and public policy about the right to a public education. Beginning with *Brown v. Board of Education* in 1954, the practice of ending the unequal treatment of children by public schools became a defining issue for civil rights movements. Building upon *Brown*, advocates for children with disabilities began to argue that children with disabilities were entitled to access to public schools, either by integration into the regular classroom or by the provision of special programs that may have been separate but at least equal.

Until the 1970s, it was common for many children with severe intellectual and physical disabilities to languish in institutions even if their families had resources. This was because of the stigma surrounding disability—particularly intellectual disabilities.¹⁶³ Laws in most states allowed school districts to refuse to enroll students they considered “uneducable,” which local school district officials could define as they chose.¹⁶⁴ Although there were nascent efforts by the federal government in the 1950s and 1960s to provide resources to address the educational needs of children with disabilities, no state served all of these children.¹⁶⁵ The few programs that did offer help were often misguided, sometimes placing all children together, regardless of need, simply because they were “handicapped.”¹⁶⁶

The IDEA requires that states identify, locate, and evaluate “[a]ll children with disabilities residing in the State . . . who are in need of special education and related services.”¹⁶⁷ An essential principle of the IDEA is “zero exclusion,” the proposition that severity of disability cannot be used to exclude a child from school or receiving educational

163. See § 20 U.S.C. 1400(c)(2)(A)-(D) (2006) (providing a brief overview of the history of the exclusion of children with disabilities from public schools).

164. MARK C. WEBER, SPECIAL EDUCATION LAW AND LITIGATION TREATISE 1:2 (3d ed. Supp. 2010) (summarizing court decisions allowing for the exclusion of children with disabilities from the public schools); see also *Watson v. City of Cambridge*, 132 N.E. 864, 864-865 (Mass. 1893) (upholding the expulsion from public school of a child considered “weak minded”); *State ex rel. Beattie v. Board of Educ.*, 172 N.W. 153, 154-55 (Wis. 1919) (approving the exclusion from public schools a boy who had drooled uncontrollably, displayed facial contortions, and had a speech impairment); *Dep’t of Pub. Welfare v. Haas*, 154 N.E.2d 265, 270 (Ill. 1958) (finding that existing state laws requiring compulsory schooling did not require that children with disabilities receive a free public education).

165. Edwin W. Martin et al., *The Legislative and Litigation History of Special Education*, 6 FUTURE OF CHILDREN 25, 25-27 (1996) (discussing the historical background of the Individuals with Disabilities Education Act).

166. Cf. *id.* at 26-27.

167. 20 U.S.C. § 1412 (a)(3)(A) (2006).

services from the responsible local educational authority.¹⁶⁸ These requirements represent a hard-won change over the systemic exclusion of children with disabilities from public schools before access to public education become a right recognized by the courts and enshrined in federal statutes.¹⁶⁹

In 1972, the United States District Court for the Eastern District of Pennsylvania held in *Pennsylvania Association for Retarded Children v. Pennsylvania*¹⁷⁰ that depriving disabled students who were deemed not to have had attained a mental age of five years from entering school violated the Equal Protection Clause and thus enjoined the Commonwealth of Pennsylvania from applying the statute to disabled students.¹⁷¹ The same year, in *Mills v. Board of Education*,¹⁷² the US District Court for the District of Columbia held that the Constitution required the District of Columbia to provide a publicly supported education for disabled children.¹⁷³ The court found that if sufficient funds are not available to finance all of the necessary services, then available funds must be expended equitably and “cannot be permitted to bear more heavily on the ‘exceptional’ or handicapped child than on the normal child.”¹⁷⁴ *PARC* and *Mills* directed attention to the ideas that the constitutional principles of equal protection and due process entitled children with disabilities to publicly supported education suited to their needs and that children with disabilities could and should be educated in public schools.¹⁷⁵ Congress was spurred to action by the increased focus on the needs and educational rights of disabled children reflected and reinforced in these cases and a growing lobbying effort undertaken by parents and organizations focused on addressing the needs of children with disabilities and advocating for their greater inclusion in American society.¹⁷⁶

168. *Timothy W. v. Rochester Sch. Dist.*, 875 F.2d 954, 960 (1st Cir. 1989); *Thomas v. Cincinnati Bd. of Educ.*, 918 F.2d 618, 620 (6th Cir. 1990).

169. *See generally* WEBER, *supra* note 164, at 1:1-1:5 (summarizing court decisions allowing for the exclusion of children with disabilities from the public schools).

170. 343 F. Supp. 279, 279 (E.D. Pa. 1972).

171. *Id.*

172. 348 F. Supp. 866, 866 (D.D.C. 1972).

173. *Id.* at 876.

174. *Id.*

175. Jon Romberg, *The Means Justify the Ends: Structural Due Process in Special Education Law*, 48 HARV. J. ON LEGIS. 415, 423 (2011) (quoting *Board of Educ. v. Rowley*, 458 U.S. 176, 193-94 (1982)).

176. Martin et al., *supra* note 165, at 28-29 (discussing the historical background of the Individuals with Disabilities Education Act).

In 1975, Congress passed the Education for All Handicapped Children Act (EAHCA).¹⁷⁷ The law was not without its critics. President Gerald Ford believed the bill would be too costly, interfere with state responsibilities, and “upset the balance of relationships between parents and local schools.”¹⁷⁸ While Congress sought to open the door of public education to disabled students by mandating that children in states accepting EAHCA funds receive a free public program of education and training appropriate to their capacities, the Act did not necessarily guarantee any particular level of education to children with disabilities once they were inside the schoolhouse doors.¹⁷⁹

Despite these limitations, the IDEA represents a significant evolution in society’s attitudes toward children with disabilities and the recognition of the need to confront the discrimination, exclusion, and abuse experienced by these children. While acknowledging this hard-won transformation, “[m]any voices over the last decade have called for reform in special education in American public schools.”¹⁸⁰

As the number of students receiving services under the IDEA has grown, scholars, pundits, parents, attorneys, and others have increasingly criticized the educational system for failing to meet the needs of many children and even harming others.¹⁸¹ For example, minority children, especially African-American boys, are over-identified as disabled.¹⁸² African-American boys are also disproportionately identified as mentally

177. Education for All Handicapped Children Act of 1975, Pub. L. No. 94-142, 89 Stat. 773 (1975); *see also* Education of the Handicapped Act Amendments of 1990, Pub. L. No. 101-476, 104 Stat. 1103, 1141-42 (1990) (renaming the EAHCA as the Individuals with Disabilities Education Act (IDEA)).

178. Martin et al., *supra* note 165, at 30 (citing President Gerald R. Ford, Statement on Signing the Education for All Handicapped Children Act of 1975 (Dec. 2, 1975)).

179. *Id.* at 29.

180. Hensel, *supra* note 151, at 291.

181. *Id.*

182. 20 U.S.C. § 1400(c)(12)(B) (2006). Although 15 percent of students nationwide are African-American, African-American children comprise 20 percent of the special education population. Rebecca Vallas, *The Disproportionality Problem: The Overrepresentation of Black Students in Special Education and Recommendations for Reform*, 17 VA. J. SOC. POL’Y & L. 181, 184 (2009). *But see* Jonathan Feldman, *Racial Perspectives on Eligibility for Special Education: For Students of Color Who Are Struggling, Is Special Education a Potential Evil or a Potential Good?* 20 AM. U. J. GENDER SOC. POL’Y & L. 183, 186-87, 190 (2011). Professor Feldman argues that the disproportionality perspective is of limited utility and reflects a critique of institutionalized racism that was horrific and historically significant but not currently relevant to the needs of students, particularly in urban districts, where the vast majority of students are often students of color.

retarded or emotionally disturbed compared to their white counterparts.¹⁸³ In sharp contrast, there is a parallel argument that in more affluent communities with majority white populations, special education is being inappropriately used to obtain academic advantages, especially for competitive college entrance examinations for those with milder disabilities like ADHD.¹⁸⁴

Another source of criticism is the emphasis that states and school districts place on procedural compliance to measure the success of special-needs children rather than looking to outcomes such as graduation, employment, and the level of independence in adult living situations.¹⁸⁵ Another overarching challenge results from the continuing, and arguably unresolvable, tensions over what level of impairment justifies eligibility under the IDEA¹⁸⁶ and whether inclusion versus access to specialized services should drive the design and implementation of special education policies.¹⁸⁷

183. 20 U.S.C. § 1400(c)(12)(C) (2006).

184. See Chester E. Finn et al., *Conclusions and Principles for Reform*, in RETHINKING SPECIAL EDUCATION FOR A NEW CENTURY 30-31 (Chester E. Finn et al. eds., 2001).

185. See generally Patrick J. Wolf & Bryan C. Hassel, *Effectiveness and Accountability (Part 1): The Compliance Model*, in RETHINKING SPECIAL EDUCATION FOR A NEW CENTURY 53, 53 (Chester E. Finn et al. eds., 2001) (discussing the existing model of compliance accountability in assessing the effectiveness of special education); Bryan C. Hassel & Patrick J. Wolf, *Effectiveness and Accountability (Part 2): Alternatives to the Compliance Model*, in RETHINKING SPECIAL EDUCATION FOR A NEW CENTURY 309, 309 (Chester E. Finn et al. eds., 2001) (proposing alternative ways to measure effectiveness of special education programs and incentive programs with a market-oriented focus intended to improve special education outcomes).

186. See generally Mark C. Weber, *The IDEA Eligibility Mess*, 57 BUFF. L. REV. 83, 102-22 (2009) (discussing the confusion over recent court cases that reached conflicting conclusions about how much adverse education impact the child's disability must have and when children with emotional disabilities are eligible).

187. See Ruth Colker, *The Disability Integration Presumption: Thirty Years Later*, 154 U. PA. L. REV. 789, 796 (2006) (challenging the integration presumption by arguing for some children the empirical literature demonstrates that it hinders the development of an appropriate individualized educational program as required by the IDEA). But see Mark C. Weber, *A Nuanced Approach to the Disability Integration Presumption*, 156 U. PA. L. REV. PENNUMBRA 174, 174-75 (2007) (contending that the integration presumption should be the rule in absence of other evidence based on which party is arguing for or against the presumption; that separate classes should be used only when supplemental services cannot make general education work for a given child; and that services should be broadly defined to include such things as co-teaching by special education professionals, aide services, assistive technology, behavior intervention, and initiatives to prevent harassment and mistreatment by teachers and peers).

The more practical concern of funding the IDEA's mandates has sparked considerable public and political discussion because of the extra costs for special education programs compared to regular education programs.¹⁸⁸ When IDEA was enacted, the intent was to help states provide special education by funding a portion of the additional, or "excess," costs of special education over the costs of general education programs.¹⁸⁹ The original legislation set the maximum federal contribution at 40 percent of the estimated excess cost of educating children with disabilities. Despite this enactment, federal funding has historically provided only a small share of total expenditures on special education.¹⁹⁰ Most recently, the federal funding levels for special education have remained relatively flat since 2004, with the exception of a significant infusion of funds under the American Recovery and Reinvestment Act of 2009.¹⁹¹ Although politicians are usually careful to avoid seeming opposed to the interests of schoolchildren with disabilities, Congress has never authorized full funding for the IDEA.¹⁹²

While full funding remains a central component of the political discourse on federal special education policies, debates increasingly reflect themes over the need to reform all sectors of public education.¹⁹³ These include arguments over the need to increase economic efficiencies, accountability, improve post-secondary school outcomes, and enhance

188. The cost of special education compared to regular education is the subject of significant controversy and is extremely difficult to quantify. Costs and spending are dependent on many variables due to regional differences and differences in needs across disabilities. Moreover, states are not obligated to give detailed state and local breakdowns of special education spending to the federal government. See Laudan Aron & Pamela Loprest, *Disability and the Education System*, 22 FUTURE OF CHILDREN 97, 109-11 (2012) (providing an overview of the funding mechanism for IDEA and the controversies surrounding federal and state funding structures for special education programs). One of the most respected studies found that in the 1999-2000 school year, schools spent 90 percent more on the average school-age special education student (including general and special education funding) than on the average general education student. See J.G. Chambers et al., *Special Education Spending Estimates from 1969-2000*, 18 J. SPECIAL EDUCATION LEADERSHIP 5, 5-13 (2005).

189. *Id.*

190. *Id.*

191. *Id.* (noting that the ARRA provided an additional \$11.3 billion in grants to states under IDEA Part B in 2009).

192. *Id.*

193. *Id.* at 100 ("Significant influences include the standards-based reform movement, which led to and was then accelerated by the federal No Child Left Behind law of 2002; the school choice and public charter school movement; and the growing need for "alternative" schools and programs for students who for a variety of reasons are not succeeding in regular public schools.").

parental choice.¹⁹⁴ Privatization and deregulation are key tenets of neoliberal educational policies that have been embraced across the political spectrum.¹⁹⁵ The argument that privatization of public education will result in systemic improvements for all children is premised on claims that the efficiencies of the marketplace will provide more effective services by removing unnecessary regulatory requirements and empowering parents by enhancing or guaranteeing choice.¹⁹⁶ The use of choice as the primary justification for the privatization of special education becomes even more significant because of the role parents play in ensuring their children receive the benefits to which they are entitled under the IDEA, and the resulting limitations on access. Parents of children with disabilities, legal scholars, and attorneys have long recognized the double-edged consequences of private enforcement: while it has granted some parents greater choice, control, and power over their child's education, private enforcement is unnecessarily adversarial and has created some of the greatest systemic inequities limiting access to educational benefits for many other children with disabilities.¹⁹⁷

B. Parents as Enforcers: The Privatization of "Rights" and the Illusion of Parents as Equal Members of the "Team"

The stated purpose of the IDEA is to ensure that children with disabilities have available to them "a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living."¹⁹⁸ The IDEA mandates that states' local educational agencies (i.e., school districts)¹⁹⁹ provide a free appropriate

194. *Id.*

195. *See, e.g.,* ROMNEY: BELIEVE IN AMERICA, A CHANCE FOR EVERY CHILD: MITT ROMNEY'S PLAN FOR RESTORING THE PROMISE OF AMERICAN EDUCATION 3-4, 5-9, 19-28 (2012) (delineating a federal K-12 education policy that emphasizes parental choice, charter schools, voucher/scholarships, and local control); *see also* David Stout, *Obama Outlines Plan for Education Overhaul*, N.Y. TIMES, Mar. 11, 2009, at A14.

196. *See* Harrison, *supra* note 28 (providing an overview of the market approach to organizing elementary and secondary education systems).

197. *See* Martin A. Kotler, *The Individuals with Disabilities Education Act: A Parent's Perspective and Proposal for Change*, 27 U. MICH. J.L. REFORM 331, 341 (1994); Phillips, *supra* note 155, at 1828; *see also* Miriam Kurtzig Freedman, *Special Education: Its Ethical Dilemmas, Entitlement Status, and Suggested Systemic Reforms*, U. CHI. L. REV., 1, 7, 16-17, 20, https://lawreview.uchicago.edu/sites/lawreview.uchicago.edu/files/uploads/79_1/Freedman.pdf (last visited Feb. 15, 2013).

198. 20 U.S.C. § 1400(d)(1)(A) (2006).

199. The statutory text references local education agencies (LEAs), which are defined to include school boards. § 1401(19)(A).

public education²⁰⁰ “tailored to the unique needs of the handicapped child by means of an ‘individualized educational program (IEP).’”²⁰¹ An IEP must be a written document containing a specific statement of the child’s current performance levels, the child’s short-term and long-term goals, the proposed educational services, and criteria for evaluating the child’s progress.²⁰² The school district must review the IEP annually to make necessary adjustments and revisions.²⁰³ Under IDEA, children with disabilities must be educated to the maximum extent appropriate with children without disabilities, and supplementary aids and services must be provided to prevent removal from regular classes.²⁰⁴ School districts must maintain and provide a continuum of placements ranging from placement in regular classes to restrictive placements such as home and hospital settings.²⁰⁵

The Supreme Court’s analysis of “appropriate” in *Board of Education v. Rowley*²⁰⁶ continues to inform how that term and other key elements of the IDEA are understood. *Rowley* views special education law as procedural, not substantive, in nature and arguably dictates that the process by which the IEP is created is far more important than its content.²⁰⁷ In the words of dissenting Justice White, the *Rowley* court set a “basic floor of opportunity” for children “intended to eliminate the effects of the handicap, at least to the extent that the child will be given an equal opportunity to learn if that is reasonably possible.”²⁰⁸ Educational progress, however, “must be ‘meaningful’ and not trivial or de minimis.”²⁰⁹ *Rowley*’s central holding was its establishment of a two-part

200. § 1401(9) (“The term ‘free appropriate public education’ means special education and related services that (A) have been provided at public expense, under public supervision and direction, and without charge, (B) meet the standards of the State educational agency, (C) include an appropriate preschool, elementary school, or secondary school education in the State involved, and (D) are provided in conformity with the individualized education program required under section 1414(d) of this title.”).

201. § 1414(d)(i)(A).

202. § 1414(d)(1)(A)(i).

203. § 1414(d)(4)(A).

204. § 1412(a)(5)(A).

205. § 1412(a)(5).

206. 458 U.S. 176 (1982).

207. *Id.* at 206.

208. *Id.* at 215 (1982) (White, J., dissenting).

209. *Id.* *Rowley* remains the Supreme Court’s sole pronouncement on the meaning of the public schools’ duty to provide appropriate education to children with disabilities as mandated by the Individuals with Disabilities Education Act (IDEA) and its predecessors. Although the Court cautioned

test for assessing when a school district has violated the IDEA and a student and parents are entitled to redress.²¹⁰ A reviewing court must ask two questions: “First, has the State complied with the procedures set forth in the Act [in developing the IEP]? And second, is the individualized educational program developed through the Act’s procedures reasonably calculated to enable the child to receive educational benefits?”²¹¹

The IDEA is unusual among education programs created under the framework of cooperative federalism and statutory provisions designed to facilitate the inclusion of people with disability in that it creates an individually enforceable entitlement right to services.²¹² The *Rowley* court remarked that “[p]arents and guardians will not lack ardor in seeking to ensure that handicapped children receive all of the benefits to which they are entitled under the Act.”²¹³ Thus, the IDEA creates a host of private enforcement mechanisms that parents may use when seeking to challenge a substantive decision about their child’s IEP or the process by which it was developed, ranging from administrative hearings to lawsuits, as well as a system of public enforcement through federal and state agencies.²¹⁴ The IDEA is not a means-tested program.²¹⁵ Although states with higher numbers of poor children receive greater funding, resources under the statute are to be distributed equitably.²¹⁶

Despite its origins in disability rights advocacy and jurisprudence and the language of equality, the IDEA is less a civil rights statute and more a funding mechanism in the guise of a civil rights statute with the provision of a “guaranteed” entitlement for certain children. While it would never be acknowledged publicly, school districts have been able to

that its decision was limited to facts similar to those before it, lower courts have applied *Rowley*’s interpretation of the law to almost all other special education disputes. Over thirty years after the decision, what was meant by “basic access” and “meaningful benefit” remains in dispute, and *Rowley*’s continued relevance for determining policy and guiding decisions made by lower courts is being questioned. See generally Andrea Kayne Kaufman & Evan Blewett, *When Good Enough is No Longer Good Enough: How the High Stakes Nature of the No Child Left Behind Act Supplemented the Rowley Definition of a Free Appropriate Public Education*, 41 J.L. & EDUC. 5 (2012).

210. *Id.* at 206-07.

211. *Id.*

212. Eloise Pasachoff, *Special Education, Poverty, and the Limits of Private Enforcement*, 86 NOTRE DAME L. REV. 1413, 1422 (2011) (describing the structural components of the IDEA and the Act’s private enforcement system).

213. *Rowley*, 458 U.S. at 713-14.

214. Pasachoff, *supra* note 212, at 1417.

215. *Id.*

216. *Id.*

exploit parents' role as a fiscal gatekeeper and may base decisions about the allocation of resources on the socio-economic status of parents.²¹⁷ The entitlement to public services is only guaranteed for children with parents able to access their own private resources to compete on behalf of their child for the limited public resources;²¹⁸ indeed, the evidence suggests that children from wealthier families enforce their rights under the statute at higher rates than do children in poverty and with much greater ease and success.²¹⁹ More importantly, this enforcement disparity has a negative effect on the ability of parents to exercise their procedural rights and also the amount and quality of services children in poverty actually receive.²²⁰ Beside difficulties securing and paying for counsel, parents also face additional challenges in seeking private enforcement under the IDEA. Not only do school districts have ready access to legal counsel, they have a stable of potential witnesses in the form of teachers, related service providers, and administrators. Moreover, in *Arlington Central School District v. Murphy*, the Supreme Court ruled that parents do not have the right to recover the costs of experts, witnesses or non-lawyer consultants hired in the course of litigation.²²¹ These costs potentially compound other incurred costs for parents regardless of the merits or outcome of the case.

Although enforcement of the IDEA is the source of compelling cases before the federal courts, litigation at both the administrative and federal court level is a very small part of the experience most parents

217. Charles P. Fox, a Chicago area special education attorney and former director of the DePaul College of Law Special Education Advocacy Clinic, terms these practices "educational advocacy redlining." Mr. Fox has observed that special education directors often use parents' addresses and property tax rates to assess whether they have resources to mount a legal challenge against a school district. See Charles Fox, *School District's Gathering Information on Parents*, SPECIAL EDUC. L. BLOG (Feb. 9, 2011, 12:01 AM), <http://blog.foxspecialledlaw.com/2011/02/page/2/>; see also Valerie Leiter & Marty Wyngaarden Krauss, *Claims, Barriers, and Satisfaction: Parents' Requests for Additional Special Education Services*, 15 J. DISABILITY POL'Y STUD. 135, 143 (2004) (hypothesizing that families living in poverty could be more likely to report barriers to additional special education services because school personnel perceive them as not having the financial or time resources to contest schools' refusals of additional services or reflect the limitations on funding in school districts with high poverty rates).

218. Pasachoff, *supra* note 212, at 1424-34.

219. *Id.* at 1426; see also Margaret M. Wakelin, *Challenging Disparities in Special Education: Moving Parents from Disempowered Team Members to Ardent Advocates*, 3 NW. J.L. & SOC. POL'Y 263, 277 (2008) (describing the difficulties parents face obtaining affordable legal representation in special education matters).

220. Pasachoff, *supra* note 212, at 1426-28.

221. 548 U.S. 291, 300 (2006).

have exercising their rights under the IDEA.²²² The IEP process is the locus for the vast majority of interactions between public school district officials and parents of children with disabilities.²²³ While it is intended to be collaborative and “parent friendly,”²²⁴ the IEP process is a daunting and occasionally contentious process even for the most empowered parents with ready access to traditional avenues of power and legal representation.²²⁵ Professor Daniela Caruso has described IEPs as being “as close to contracts as it gets in the realm of public services governed by federal law”²²⁶ and compares the IEP drafting process to the bargaining process involved in private party contractual dealings.²²⁷ Additionally, limitations on resources force families to compete for special education services just as qualified corporate entities may compete for affirmative action entitlements.²²⁸

Olga Pribyl, Managing Attorney of the Special Education Clinic for Equip for Equality, Illinois’ Protection and Advocacy System, provides a telling description of the illusory nature of parental equality in the IEP process:

Ask any attorney who has a child with special education needs what it is like to attend their own child’s Individualized Education Program (IEP) meeting. Most likely, they will reply that they had knots in their stomach, were nervous, felt out-numbered, and were completely intimidated. Yes, even your fellow experienced attorneys can be intimidated by a process that is intended to be “parent-friendly.”²²⁹

222. See Perry A. Zirkel & Gina Scala, *Due Process Hearing Systems Under the IDEA: A State-by-State Survey*, 21 J. DISABILITY POL’Y STUD. 3, 4-5 (2010) (reporting 2,033 adjudicated hearings in 2008-2009 with four states (New York, California, New Jersey, Pennsylvania) and the District of Columbia accounting for 85 percent of the total adjudicated hearings).

223. Cf. Muller, *supra* note 94, at 512.

224. Olga Pribyl, *Leveling the Playing Field: Helping Children with Special Education Needs*, 23 CBA REC. 42, 42 (2009).

225. Professor David Engel analyzed a 1988-1989 study that found that parents feel inadequate and unqualified in special education situations across socioeconomic and other demographic classes. The study is now over twenty years old, but these descriptions closely match the current culture and climate surrounding the IEP process. See David M. Engel, *Law, Culture, and Children with Disabilities: Educational Rights and the Construction of Difference*, DUKE L.J. 166, 188 (1991).

226. Daniela Caruso, *Bargaining and Distribution in Special Education*, 14 CORNELL J.L. & PUB. POL’Y 171, 177 (2005).

227. *Id.* at 177.

228. *Id.*

229. Pribyl, *supra* note 224, at 42.

School districts may use tactics that depend on intimidation and discrepancies in power to shift responsibility to the family and force the use of private resources. Even parents who have a lengthy history of thoughtful involvement in their child's education and school community are characterized as hostile or emotionally disturbed and seeking outlandish, unreasonable, and unnecessary services and placements at "taxpayer" expense. These arguments typically reflect both aggressive legal tactics and an effort to objectify the child with a disability into a commodity. School districts often appear to fail to—or sometimes consciously refuse to—consider that the IDEA expects parents to advocate for their children and also that parents of children with disabilities are most often taxpayers. School districts argue that the parents have taken a frivolous position and their attorneys should be sanctioned through fee-shifting provisions.²³⁰ Another tactic is to argue that parents are seeking a particular service or placement for their child because of their own pathology, denial, or guilt over their failure to act, which has caused or worsened their child's condition²³¹ or that the parent may even be causing their child harm by seeking services for a child who is actually flourishing.²³² These arguments are used to diminish the power of a family's legitimate claims that their child has been denied educational opportunities or to refute arguments that public responsibil-

-
230. Since the 2004 revision of the IDEA, school districts and states that prevail at due process hearings are able to recover attorneys' fees against parents when the complaints are "frivolous, unreasonable, or without foundation." See Jessica Butler-Arkow, *The Individuals with Disabilities Education Improvement Act of 2004: Shifting School Districts' Attorney's Fees to Parents of Children with Disabilities and Counsel*, 42 WILLIAMETTE L. REV. 527, 527-28 (2006) (providing an overview of the IDEA provisions involving fee shifting to parents and their counsel). Some commentators have argued that this addition to the provision may further discourage attorneys' representation of parents in possibly worthy challenges under the IDEA. See, e.g., Wakelin, *supra* note 219, at 282.
231. Cf. Charles Fox, *Retaliation Against Parents for Advocating: An Emerging Trend*, SPECIAL EDUC. L. BLOG (July 5, 2012, 12:45 PM), <http://blog.foxspecialdew.com/2012/07/index.html> (discussing the misperceptions of school districts when they equate parents who are anxious, exhausted, and very frightened as being difficult and angry); see generally *Retaliation: A Primer and The Retaliation Triangle*, WRIGHTSLAW (last updated Aug. 24, 2012), <http://www.wrightslaw.com/info/retal.primer.htm> (providing an overview of retaliatory practices engaged in by some school districts to scare parents and reduce their advocacy).
232. See Jennifer Laviano, *The Sudden Blossoming of the Represented Child*, CONN. SPECIAL EDUC. LAW. (July 31, 2009), <http://www.connecticutspedaleducationlawyer.com/blog/occasional-rants/the-sudden-blossoming-of-the-represented-child> (describing how school districts will present documentary evidence during IEP meetings that a child has "blossomed" and made significant educational and behavioral progress after a parent retains an attorney).

ity for a necessary and appropriate research-based educational intervention for the child is a reasonable expectation.

C. *Private Remedies: The Real Focus of the IDEA and the Illusion of Public Responsibility for Children with Disabilities*

The preference for inclusion of children with disabilities in public schools is not an absolute mandate but a Congressional preference.²³³ The more exclusionary placements include separate classes and therapeutic schools, many of which are privately operated. When a public school district fails to provide a child with a disability an appropriate education, a parent may obtain tuition payment for the child to attend a private school under the IDEA as a remedy through an impartial hearing and/or judicial proceeding.²³⁴ Without doubt, placement of some children with disabilities in such schools is often a necessary intervention and the only way to address complex educational needs.²³⁵ Students placed in private schools represent a small fraction of special education students but have been scapegoated as the primary cause of escalating special education costs.²³⁶ Not only is this depiction unfair, it has allowed discussion to shift away from examining what the emphasis on these placements means in the provision of equitable public education services for children with disabilities. The emphasis in IDEA scholarship and jurisprudence on placements in privately run therapeutic programs reflects the ever-deepening wealth inequities in the education of children with disabilities, and the shifting responsibility for children with disabilities from the public sector to the private realms of family and marketplace.²³⁷

233. Roncker *ex rel.* Roncker v. Walter, 700 F.2d 1058, 1063 (6th Cir. 1983) (“The [IDEA] does not require mainstreaming in every case but its requirement that mainstreaming be provided to the *maximum* extent appropriate indicates a very strong congressional preference.”).

234. 20 U.S.C. § 1412(a)(10)(C)(i-ii) (2006).

235. See Ruth Colker, *The Disability Integration Presumption: Thirty Years Later*, 154 U. PA. L. REV. 789, 825 (2006).

236. See Jay P. Greene & Marcus A. Winters, *Debunking a Special Education Myth: Don’t Blame Private Options for Rising Costs*, 67 EDUC. NEXT 67, 68, 70 (2007). A review of US Department of Education data suggests that Professor Greene and Mr. Winters’ statements regarding the numbers and percentages of students in private placements has remained constant. See *Data Tables for OSEP State Reported Data: Part B Educational Environment (2009)*, DATA ACCOUNTABILITY CTR., http://www.idea.data.org/arc_toc11.asp#partBLRE (last visited Feb. 15, 2013).

237. The importance of the private tuition remedy is evidenced by the fact that even in cases before the Supreme Court that address procedural issues under the IDEA, the underlying issue is most often placement of the child in a private therapeutic school and parents’ rights reimbursement under the IDEA. See, e.g., Winkelman *ex rel.* Winkelman v. Parma City Sch. Dist., 550 U.S. 518, 533 (2007) (holding that “IDEA grants parents independent, enforceable rights. These rights, which are not limited to certain procedural and reimbursement-related matters, encompass the

Despite the underlying purpose of the IDEA, the language of the statute and the decisions are framed in terms of “reimbursement.”²³⁸ This raises the question whether families who cannot afford to pay tuition and the legal fees necessary to seek reimbursement can really avail themselves of this remedy.²³⁹ Along with high tuition fees and costs for transportation (or in the case of residential placements, room and board), private schools may require application fee deposits, long-term contracts, or have exclusionary admissions.²⁴⁰ This remedy results in a tacit creation of a means test for a statute that is explicitly intended to provide for an entitlement to all considered qualified through disability. Those who have the private resources to provide for a child with a disability can, but others are excluded from exercising a fundamental right, thus reinforcing inequities.²⁴¹

In *School Committee of Burlington v. Department of Education*,²⁴² the Supreme Court, while finding that this was part of the IDEA’s procedural safeguards, explicitly acknowledged that this remedy was available to parents of “adequate means:”

[T]he parents who disagree with the proposed IEP are faced with a choice: go along with the IEP to the detriment of their child if it turns out to be inappropriate or pay for what they consider to be the appropriate placement. If they choose the latter course, *which conscientious parents who have adequate means* and who are reasonably confident of their assessment normally would, it would be an empty victory to tell them several years later that they were right but that these expenditures could not in a proper case be reimbursed by the school officials. If that were the case, the child’s right to a *free* appropriate public education, the parents’ right to

entitlement to a free appropriate public education for the parents’ child.”). Although this is an expansive reading of the statute and clearly indicates the importance of the entire bundle of procedural rights, the importance of reimbursement is inescapable. *See also* Schaffer v. Weast, 546 U.S. 49, 62 (2005).

238. Elisa Hyman et al., *How IDEA Fails Families Without Means: Causes and Corrections from the Frontlines of Special Education Lawyering*, 20 AM. U. J. GENDER SOC. POL’Y & L. 107, 122 (2011).

239. *Id.* *See* Lorraine Forte, *Ensuring Equity for Children Who Have Special Needs*, CATALYST IN DEPTH, Spring 2012, at 2, 2.

240. Hyman et al., *supra* note 238, at 112, 121, 126 (discussing how the IDEA’s private school tuition remedy constitutes an inherent structural bias that disproportionately benefits wealthy families).

241. *Id.*

242. 471 U.S. 359, 370 (1985).

participate fully in developing the proper IEP, and all of the procedural safeguards would be less than complete.²⁴³

In 1997, the IDEA was amended and the right to tuition reimbursement for private placements was expressly codified in the statute entitled “Payment for education of children enrolled in private schools without consent of or referral by the public agency.”²⁴⁴ Ten years later, the Court again considered issues related to private placements in *Board of Education v. Tom F.*,²⁴⁵ which raised the question of whether the IDEA entitles parents to reimbursement for their child’s private school education if the child has never received special education services provided by a public school.²⁴⁶ The Court considered the question again in 2009 in *Forest Grove School District v. T.A.*,²⁴⁷ holding that *Burlington* and *Carter* authorized reimbursement where a free appropriate public education was not provided, “without regard to the child’s prior receipt of services.”²⁴⁸ Despite this finding, courts and impartial hearing officers/administrative law judges often still seek evidence that a child has made progress in the private placement before finding that placement is appropriate.²⁴⁹ “[N]o circuit court has ruled on the specific question of tuition relief for poor families; and, if decisions in other contexts can be read as barometers, the circuits would likely be split on this question.”²⁵⁰ Arguably, reimbursement of private school tuition under the IDEA is available to parents that manage to place their child in a private school that does not require tuition payments because the school has concluded that the parents’ likelihood of success on the merits

243. *Id.* at 370 (emphasis added).

244. 20 U.S.C. § 1412(a)(10)(C)(ii) (2006).

245. 552 U.S. 1 (2007).

246. The case resulted in a 4-4, two-sentence *per curiam* non-precedential decision affirming the Second Circuit’s grant of reimbursement to parents. The original administrative matter involved payment of \$21,819 for a student’s private school tuition. The parent had recently resigned as the President and Chief Executive Officer of Viacom Inc., and was awarded an \$85 million severance package. He told interviewers he insisted on appearing as an anonymous litigant to avoid publicity for both himself and his son but that he litigated the case for potential precedential value and to address an unfairness for other parents who could not afford the costs of private education for their child with special needs. See John Sullivan, *New York City Loses Special Education Appeal*, CITY ROOM, N.Y. TIMES (Oct. 10, 2007, 12:48 PM), <http://cityroom.blogs.nytimes.com/2007/10/10/new-york-city-loses-special-education-appeal/>.

247. *Forest Grove Sch. Dist. v. T.A.*, 557 U.S. 230, 233 (2009).

248. *Id.* at 243.

249. Hyman et al., *supra* note 238, at 123-25.

250. *Id.* at 124.

is high.²⁵¹ Some parents have been granted this relief in administrative hearings and by a court.²⁵² But there is no current uniform approach among the circuits regarding this issue, and whether it is possible for all families with limited financial resources to have equal access to the remedy of private school tuition remains uncertain.²⁵³

As the Supreme Court stated in *Winkelman v. Parma City School District*, “we find nothing in the statute to indicate that when Congress required States to provide adequate instruction to a child ‘at no cost to parents,’ it intended that only some parents would be able to enforce that mandate.”²⁵⁴ Arguably, denial of the right of tuition to low-income parents may be construed as a violation of the Equal Protection Clause because it denies access to an appropriate education for one class of eligible individuals while providing the right to another class. Sustaining this argument is highly improbable either under a strict scrutiny or rational basis standard.²⁵⁵ Changing the inequality will likely require an amendment to the IDEA or an almost revolutionary rejection of the Supreme Court’s formulation that parents who unilaterally place their child with a disability in a private therapeutic school do so “at their own financial risk.”²⁵⁶ This is unlikely in the current political climate, with its increasing emphasis on private responsibilities and resources in addressing the educational needs of children with disabilities.²⁵⁷

D. Vouchers and Charter Schools: The Illusion of Choice and the Ultimate Privatization of Public Education

The involvement of the private sector in public K-12 education is not new.²⁵⁸ Entire industries have long served public schools through textbook and supply companies, bus and custodial services, and food

251. *Id.* at 126.

252. *Id.*

253. *Winkelman ex rel. Winkelman v. Parma City Sch. Dist.*, 550 U.S. 516, 533 (2007) (quoting Individuals with Disabilities Education Act, 20 U.S.C. § 1400(d)(1)(B) (2006)).

254. *Id.* at 533.

255. See Katie Harrison, *Direct Tuition Payments Under the Individuals with Disabilities Education Act: Equal Remedies for Equal Harm*, 25 J. CIV. RTS. & ECON. DEV. 873, 895-902 (2011) (analyzing the constitutional implications of precluding low-income parents from the unilateral placement remedy).

256. *Sch. Comm. of Burlington v. Dep’t of Educ.*, 471 U.S. 359, 373-74 (1985).

257. See Harrison, *supra* note 255, at 902-07.

258. WILLIAM J. MATHIS & LORNA JIMERSON, A GUIDE TO CONTRACTING OUT SCHOOL SUPPORT SERVICES: GOOD FOR THE SCHOOL? GOOD FOR THE COMMUNITY? 7-8 (2008).

service providers.²⁵⁹ An extensive number of private day and residential schools have educated children with disabilities after receiving tuition payments from public school systems or other public agencies.²⁶⁰ Outsourcing has grown to include contracts with companies to provide services like speech, language, occupational, and physical therapies and nursing services within public schools—activities traditionally conducted by professionals working directly for the school district.²⁶¹ This change has made true privatization of public education for all children, including children with disabilities, more acceptable. There are long-standing concerns about the lack of quality control and evidence of the potential for abuse and even criminal corruption when school systems vest control of special education to the private sector.²⁶² Yet it is unlikely that the trend toward privatization of the education of children with disabilities will be slowed.²⁶³

1. Vouchers

Privatization has resulted from two-interrelated movements gathered under the banner of “choice:” the voucher movement and the charter school movement.²⁶⁴ The concept of special education vouchers is simple: they are taxpayer-funded payments made to a parent or an educational institution for any eligible child who obtains a voucher that can be used to pay for the tuition at a private school.²⁶⁵ Since the Supreme Court’s

259. Stephanie Simon, *Privatizing Public Schools: Big Firms Eyeing Profits From U.S. K-12 Market*, HUFFINGTON POST (Aug. 2, 2012, 10:16 AM), http://www.huffingtonpost.com/2012/08/02/private-firms-eyeing-prof_n_1732856.html.

260. MATHIS & JIMERSON, *supra* note 258, at 8; *see also Association Policies & Procedures*, NAT’L ASS’N OF PRIVATE SPECIAL EDUC. CENTERS, <http://www.napsec.org/strategicplan.html#WhatIs> (last visited Feb. 21, 2013).

261. Ron Schachter, *Seeking Savings in Special Ed: Accelerating Costs Are Driving Some Districts to Outsource These Services*, DIST. ADMIN., Jan. 1, 2012, at 35.

262. *See e.g.*, David M. Halbfinger, *Companies Shortchanged Preschool Special Education, State Audits Find*, N.Y. TIMES, June 25, 2012, at A14; David M. Halbfinger, *Preschool Special Education Trade Group Calls for More Audits and Penalties*, N.Y. TIMES, Aug. 23, 2012, at A20.

263. *Cf.* Martha Minow, *Confronting the Seduction of Choice: Law, Education, and American Pluralism*, 120 YALE L.J. 814, 847 (2011) (“Our laws have made school choice a force, thus influencing the worlds of families, nations, cultures, religions, genders, sexualities, disabilities, and even the narratives we tell about what we want for the next generation.”).

264. Martha Minow, *Reforming School Reform*, 68 FORDHAM L. REV. 257, 258 (1999).

265. Hensel, *supra* note 151, at 292. *See also* Curt Dudley-Marling & Diana Baker, *The Effects of Market-Based School Reforms on Students with Disabilities*, DISABILITY STUDIES Q., Vol. 32, No. 2 (2012).

decisions in *Zelman v. Simmons-Harris*²⁶⁶ and *Arizona Christian School Tuition Organization v. Winn*²⁶⁷ that rejected challenges to voucher programs as violating the Establishment Clause, the role of the voucher movement as a significant part of the debate over educational reform has been assured.

As of August 2012, there were thirty-two “private school choice programs” in the United States.²⁶⁸ Sixteen of these programs are school voucher programs, and fourteen are scholarship tax programs.²⁶⁹ It is estimated that about 30,000 students with disabilities use vouchers to attend private schools, although it is unclear whether the vouchers are being used primarily for therapeutic schools or private schools where students may be integrated with those without disabilities.²⁷⁰ There is no question that the provision of private school vouchers is controversial; many politicians even use the term “scholarship” to describe voucher programs.²⁷¹ There is no clear consensus among disability and parent groups regarding special needs tuition vouchers. The debate continues over whether such programs enhance parental choice over children’s educations and provide a step forward for children with disabilities, or whether vouchers represent a renunciation of the public’s obligation to provide a free appropriate public education and will ultimately result in the return of the widespread exclusion of children with disabilities from public schools.

266. 536 U.S. 639, 662-63 (2002) (holding that the Cleveland Pilot Project Scholarship program did not violate the Establishment Clause because it is “entirely neutral with respect to religion” and “provides benefits [] to a wide spectrum of individuals, defined only by financial need and residence in a particular school district” and therefore is a “program of true private choice”).

267. 131 S. Ct. 1436, 1440 (2011) (holding that a group of Arizona taxpayers did not have standing to challenge a state law that provides tax credits to people who donate to school tuition organizations that in turn provide scholarships to students who want to attend private or religious schools because any damages or harm claimed by the taxpayers by virtue of simply being a taxpayer would be pure speculation because the issue at hand was a tax credit and not a government expenditure).

268. *See School Choice Programs in America: The Facts*, ALLIANCE FOR SCHOOL CHOICE, <http://www.allianceforschoolchoice.org/school-choice-programs-in-america-the-facts> (last visited Mar. 6, 2013).

269. *Id.*

270. Nirvi Shah, *30,000 Students with Disabilities Use Private School Vouchers*, EDUCATION WEEK (Apr. 5, 2012, 9:08 AM), http://blogs.edweek.org/edweek/speced/2012/04/30000_students_with_disabiliti.html.

271. Sarah Carr, *School Vouchers Make a Comeback, Stir Concerns About Quality*, THE HECHINGER REPORT (Aug. 21, 2012, 11:07 AM), http://hechingerreport.org/content/school-vouchers-make-a-comeback-stir-concerns-about-quality_9285/.

The application of free market models to contemporary school reform originated with economist Milton Friedman over a half-century ago. Professor Friedman advocated for a publicly financed, free-market school choice model that provided parents with cash vouchers to select among schools operated by for-profit or non-profit companies.²⁷² During the 1980s and early 1990s, interest in neo-liberal, free-market-oriented school reform resurfaced as a means to address failing schools in urban areas.²⁷³ The general argument for school voucher programs was “that a graduated or calibrated voucher system, diverting funds complementary to the income needs of the family, would create an incentive for private schools and high-quality suburban public schools to recruit low-income students.”²⁷⁴

Advocates of voucher programs for children with disabilities argue that they will cure most of the systemic inadequacies and inequities that plague public schools’ provision of special education under the IDEA. They claim that the increased competition for students with disabilities resulting from the involvement of the private sector offers a superior approach to traditional reform efforts to address the limited resources, indifference, and lack of meaningful progress that children with disabilities experience in the public schools, and that competition ultimately will benefit students who remain in public schools.²⁷⁵ Voucher advocates have also asserted that market forces create incentives for school districts to avoid the unnecessary over-identification of students with disabilities and thereby save taxpayers money.²⁷⁶

Proponents of vouchers also claim that they eliminate the disparities between parents’ abilities to access private therapeutic school placements by eliminating the inherent uncertainty of litigation and the financial

272. *See generally* Milton Friedman, *The Role of Government in Education*, in *ECONOMICS AND THE PUBLIC INTEREST* 123, 143-44 (Robert A. Solo ed., 1955) (arguing the most effective means of reforming American education is to expose schools to the competitive forces of the free market and limiting the state’s role in education to ensure that schools meet minimum standards).

273. *See generally* JOHN E. CHUBB & TERRY M. MOE, *POLITICS, MARKETS, & AMERICA’S SCHOOLS* 10-11 (1990) (arguing that opening up educational markets to competition was a necessary and sufficient condition for reforming American schools and that the notion of choice is a panacea).

274. William N. Myhill, *No FAPE for Children with Disabilities in the Milwaukee Parental Choice Program: Time to Redefine a Free Appropriate Public Education*, 89 IOWA L. REV. 1051, 1062 (2004).

275. Hensel, *supra* note 151, at 292, 294.

276. Jay P. Greene & Stuart Buck, *The Case for Special Education Vouchers*, *EDUCATION NEXT*, Winter 2010, at 36, 41. It is important to note that this argument fails to consider the multifactorial social, public policy and scientific reasons that have likely contributed to the increase in students identified with disabilities.

and psychological toll of suing the same people charged with teaching their children.²⁷⁷ More dramatically, supporters contend voucher programs remove the inequities caused by the IDEA's reliance on private enforcement and democratize access to private placements by reducing legal and financial barriers created by the hearing process when parents are seeking a private therapeutic placement.²⁷⁸ Supporters argue that the rights of parents are seemingly identical under IDEA and under special education voucher laws, but the ease with which parents can exercise those rights is profoundly different because of the power of market forces and the inadequacy of the legal system.²⁷⁹

The claim of greater accountability for outcomes and identical protection or even greater rights is made despite acknowledging that parents have no legal right to specific services from private schools²⁸⁰ and the fact that the U.S. Department of Education's Office of Civil Rights (OCR) has repeatedly opined that students with disabilities who voluntarily participate in voucher programs waive most of their rights under the IDEA.²⁸¹ The only enforceable individual right that remains is the right to complain about the local school district's failure to identify, locate and evaluate students with disabilities—not to complain about the failure to provide appropriate related services.

The OCR has determined that private schools participating in voucher programs do not become state contractors when they accept state funds because parents are the decision-makers and local educational authorities are not involved in the decision to place children.²⁸² More importantly, nothing in Section 504 or the ADA mandates that children in private schools be provided with an IEP or the other entitlements designed to ensure meaningful educational benefit or receive differentiated programming and related services.²⁸³ Therefore, when parents of children

277. *Id.* at 41.

278. *Id.*

279. *Id.* But see Hensel, *supra* note 151, at 331 (discussing the limited value of the threat of transferring a child back to public school).

280. Hensel, *supra* note 151, at 321.

281. Richard D. Komer, *OCR Staff Memorandum*, 22 INDIVIDUALS WITH DISABILITIES EDUC. L. REP. 669, 669 (1990); Letter from Susan Bowers, Acting Deputy Assistant Secretary for Civil Rights, & Patricia J. Guard, Acting Director, U.S. Dep't of Ed., to John W. Bowen, School Board Attorney, Pinellas County School Board (Mar. 30, 2001), *available at* <http://www2.ed.gov/policy/speced/guid/idea/letters/2001-1/bowen3302001fape.pdf> (stating that students placed through Florida's Opportunity Scholarship Program are considered "private school children with disabilities" with no individual entitlement to FAPE or related services under the IDEA).

282. Komer, *supra* note 281, at 670, 672.

283. See Hensel, *supra* note 151, at 321-330.

with disabilities choose to accept a voucher and place the child in a private school, they have effectively waived meaningful protection under federal civil law of their child's rights to access an education.²⁸⁴

"From the viewpoint of parents stuck in incompetent districts, financially unable to pay tuition, and faced with the awful prospect of seeing their children doomed to poor functioning for lack of early intervention, school choice may be the only hope and is a sacrosanct advocacy goal. But from a broader societal perspective, developing publicly funded, state-of-the-art special education programs remains a far more desirable option—one that vouchers and scholarships inevitably undermine."²⁸⁵ The argument that vouchers provide choices that result in meaningful educational benefits for individual children and hold the promise to resolve the systemic inequities that have plagued special education necessitates consideration of whether these choices are real, or merely illusory promises designed to promote free-market school reform ideology. The essential question is whether the educational outcomes of children with disabilities educated in private schools paid for by vouchers justify the waiver of the rights guaranteed by the IDEA.²⁸⁶

While there is evidence that voucher programs can benefit children with less severe disabilities,²⁸⁷ the evidence points to overall negative implications for the development and provisions of special education programs for children most in need of specialized instruction and related services. Students with mild disabilities such as learning disabilities, attention deficit disorder, and mild speech and language disorders may only require a small learning environment or interventions that can be provided by any reasonably competent educator with adequate instructional resources, the opportunity to respond to differentiate instruction, and administrative support.²⁸⁸ The exodus of students with milder disabilities from the public school system may also result in the redistribution of funds to the private sector and lessen collaboration among parents of children with disabilities. This is because parents of students with varying levels of impairment would be forced to compete for

284. See NAT'L COUNCIL ON DISABILITY LIVING, *SCHOOL VOUCHERS AND STUDENTS WITH DISABILITIES* (2003).

285. Caruso, *supra* note 84, at 523.

286. See NAT'L COUNCIL ON DISABILITY LIVING, *supra* note 284 ("The principle of school choice, and voucher programs in particular, have not been adequately shown to be internally consistent and mutually reinforcing with regard to the other three principles of IDEA reauthorization (accountability for results, increasing local flexibility, and a focus on what works) outlined by the U.S. Department of Education . . .").

287. Hensel, *supra* note 151, at 337.

288. Cf. *id.* at 323, 336 (discussing the needs of children with mild learning disabilities, comparing the demands created by students with mild, moderate, and severe impairments and the potential impact of diminished public resources to educate children with severe disabilities).

the increasingly scarce resources designated for the actual provision of direct therapeutic services.²⁸⁹

The effectiveness of voucher programs in addressing the needs of children with more severe disabilities has not been demonstrated by a study of objective measures of student progress in academic subjects or basic skill development.²⁹⁰ Such students require highly specialized instruction and services necessitating the involvement of specially trained and certified therapists and nursing services or the availability of assistive technology for communication, mobility, and other needs. Paradoxically, they are the same students who are most often depicted as the “poster children” for the voucher movement because it is politically treacherous to argue for a position that may be construed as antithetical to the interests of children with disabilities.²⁹¹ The lack of persuasive evidence that voucher programs result in meaningful educational outcomes and indications that they may actually disadvantage children with severe disabilities raises questions about the continued availability of appropriate public resources to provide for these children’s educational needs. As Professor Hensel has argued,

289. The IDEA requires school districts to apportion IDEA Part-B dollars to provide for special education and related services to private school students with disabilities with the amount proportionate to the number of children with disabilities enrolled in private schools in the districts. 20 U.S.C § 1412(a)(3)(A) (2006); 34 C.F.R. § 300.131(a) (2012). This is not an individual entitlement for services but the delineation of the local educational authority to identify, locate and evaluate students with disabilities and to engage in meaningful consultation. “There is no individual entitlement to services at all There are no hearing rights to challenge decisions to give or withhold services.” Mark C. Weber, *Services for Private School Students Under the Individuals with Disabilities Education Improvement Act: Issues for Statutory Entitlement, Religious Liberty, and Procedural Regularity*, 36 J.L. & EDUC. 163, 205 (2007).

290. Compare Hensel, *supra* note 151, at 328-30 (discussing lack of objective outcome measures to assess voucher programs and criticizing the research by the Manhattan Institute on the Florida McKay scholarship program as hopeful but not sufficient to make up for the lack of public data on the superiority of a private education for students with disabilities), with JAY P. GREENE & MARCUS WINTERS, MANHATTAN INSTITUTE FOR POLICY RESEARCH, *THE EFFECT OF SPECIAL EDUCATION VOUCHERS ON PUBLIC SCHOOL ACHIEVEMENT: EVIDENCE FROM FLORIDA’S MCKAY SCHOLARSHIP PROGRAM* (2008). See also Dudey-Marling & Baker, *supra* note 265 (“[S]ince the private schools accepting the vouchers are exempt from state and federal accountability requirements, data on the academic achievement of special education students who attend voucher schools in Florida are unavailable; therefore, the quality of education for students with disabilities who use vouchers to attend private schools in the state is largely unknown.” (citation omitted)).

291. Hensel, *supra* note 151, at 296.

[t]he wide-spread dissatisfaction with the status quo for students with disabilities is not a simple result of the public schools' inability to meet the needs of these children. Instead, to a large extent, it is a product of the public's unwillingness to make meeting the needs of such students a priority. Legislators would be better served by looking to programs that help all students with disabilities achieve their academic potential rather than focusing on benefits for only a few.²⁹²

Supporters of vouchers may also wish to consider the inherent contradiction of predicating access to the marketplace of such reforms and "choices" on the waiver of the basic protections for children with disabilities under the IDEA.

2. Charter Schools

While vouchers are a perennial favorite cause among conservative critics of public schools, the charter school movement has been embraced by many parents, politicians, social critics, philanthropists, business leaders, and other self-styled education reformers from an array of political persuasions. Charter schools are frequently at the epicenter of the debates over American public school reform, with new controversies emerging almost every day.²⁹³

"Charter schools are the 'kudzu of school choice' and their spread is inevitable."²⁹⁴ Their proliferation has also been facilitated by the dominant place they are given in federal education legislation and grant programs.²⁹⁵ In some cities, charter schools have become the cornerstone of school reform. In post-Katrina New Orleans, for example, charter schools are the foundation for the entire school system.²⁹⁶ Despite their spread and prominence in educational reform efforts, there is little evidence that charter schools have resulted in improvements in public schools or equitable educational choices. The evidence suggests that the proliferation of charter schools is actually *constricting* the choices

292. Hensel, *supra* note 151, at 349.

293. At the time this Article was being prepared for publication, school reform and the expansion of charter schools were a frequent topic of debate in the presidential election and an issue in the strike by the Chicago Teachers Union against the Chicago Public Schools. *See, e.g.*, Monica Davey, *Teachers' Strike in Chicago Tests Mayor and Union*, N.Y. TIMES, Sept. 11, 2012, at A1.

294. Robert A. Garda, Jr., *Culture Clash: Special Education in Charter Schools*, 90 N.C. L. REV. 655, 657 (2012).

295. *Id.* at 658. *See also* KATHLEEN B. BOUNDY, COUNCIL OF PARENT ATTORNEYS AND ADVOCATES, CHARTER SCHOOLS AND STUDENTS WITH DISABILITIES: PRELIMINARY ANALYSIS OF THE LEGAL ISSUES AND AREAS OF CONCERN 6-7 (2012).

296. Robert A. Garda, Jr., *The Politics of Education Reform: Lessons from New Orleans*, 40 J.L. & EDUC. 57 (2011).

available to families of children with disabilities and may ultimately result in widespread limitations on services and do little to improve outcomes. There is clear evidence demonstrating that charter schools seek to limit the enrollment of children who require expensive or time-consuming special education interventions. More importantly, evidence demonstrates that even those children enrolled in charter schools are being denied adequate services and that services for the children with disabilities left in traditional public schools may be placed at risk by the diversion of funding resources to charter schools.

Charter schools function as quasi-market schools and are distinguished from traditional public schools by their autonomy from state and local educational authorities in governance, teacher hiring, budget, curriculum, and a range of school policies pertaining to administration and operations.²⁹⁷ The management and operational structures of charters vary from for-profit educational management organizations to nonprofit entities including universities, religious organizations, and community groups.²⁹⁸ Because they are publicly funded schools, they must comply with federal laws concerning the rights of students with disabilities under the IDEA, Section 504, and the ADA.²⁹⁹

The National Alliance for Public Charter Schools reported that in 2011-2012, 4.2 percent of America's public school children attended charter schools.³⁰⁰ The Government Accounting Office found that in 2009-2010, the most recent data available at the time of its review, approximately eleven percent of students enrolled in traditional public schools were students with disabilities, compared to about 8 percent of

297. See generally BOUNDY, *supra* note 295, at 8-12 (describing the various structures of charters and the legal relationships between charters and local and state education authorities).

298. A discussion of the complexities of the law surrounding charter school organization, management, and relationship with local and state educational authorities is beyond the scope of this Article, which seeks to discuss the philosophical implications of charter schools on choices available for families of children with disabilities for this information. See generally Kathleen Conn, *For-Profit School Management Corporations: Serving the Wrong Master*, 31 J.L. & EDUC. 129, 137-142 (2002) (providing an overview of for-profit and nonprofit organizations of charter schools); Alexandria Barkmeier, *Special Education Compliance and Charter Schools: A Study of National, State, and Local Policy in Denver Public Schools*, 19 GEO. J. ON POVERTY L. & POL'Y 283, 285-87 (2012).

299. Robert A. Garda, Jr., *Disabled Students' Rights of Access to Charter Schools Under the IDEA, Section 504 and the ADA 2* (June 1, 2012) (unpublished manuscript) available at http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2072498.

300. *The Public Charter School Dashboard*, NAT'L ALLIANCE FOR PUB. CHARTER SCHS., <http://dashboard.publiccharters.org/dashboard/students/page/overview/year/2012> (last visited Feb. 15, 2013).

students enrolled in charter schools.³⁰¹ With regard to the effectiveness of charter schools, the evidence is inconclusive as to whether both regular education and special education charter students truly obtain meaningful measurable levels of academic achievement compared to students at traditionally organized public schools. The evidence suggests that the quality and performance of charter schools varies significantly from state to state.³⁰² While the same can be said of American education in general, charter schools' expansion into forty states, the District of Columbia, and Puerto Rico and their favored political position makes nationwide outcomes fair game for determining the validity of the claims that charter school supporters frequently make about both general and special education students and the importance of school choice for their families.³⁰³

A longstanding criticism of charters schools is their lack of inclusion of racial minorities and students with disabilities. Critics argue that rather than improving the overall quality of public education, charters create a two-tiered balkanized education system with different resources that cater to different populations. The concern regarding students with disabilities is that large urban school systems will become increasingly segregated, with more disabled students left in traditional public schools with dwindling resources due to shrinking student populations and students with less complex disabilities attending charter schools.³⁰⁴ While the issues of funding disparities are beyond the scope of this Article, the resulting limitations on the educational choices available to families of children with disabilities and the expectation that families assume responsibility for services that were previously the province of the public schools must be considered in this discussion of school choice and students with disabilities.

A recent RAND Corporation study found that students in public schools have achievement levels that are comparable to their peers who *enter* charter schools. This finding refutes a frequent criticism that the proliferation of charter schools in urban and minority communities

301. U.S. GOVERNMENT ACCOUNTABILITY OFFICE, CHARTER SCHOOLS: ADDITIONAL FEDERAL ATTENTION NEEDED TO HELP PROTECT ACCESS FOR STUDENTS WITH DISABILITIES 7 (2012) [hereinafter GAO REPORT].

302. See RON ZIMMER ET AL., CHARTER SCHOOLS IN EIGHT STATES: EFFECTS ON ACHIEVEMENT, ATTAINMENT, INTEGRATION, AND COMPETITION 87 (2009) (stating that across locations there is little evidence that charter schools are producing, on average, achievement impacts that differ substantially from those of traditional public schools); ANNA NICOTERA, NAT'L ALLIANCE FOR PUB. CHARTER SCHS., MEASURING CHARTER PERFORMANCE 2-6 (6th ed. 2010) (concluding that charter school student achievement demonstrate mixed results).

303. BOUNDY, *supra* note 295, at 4-5.

304. See Derek W. Black, *Education's Elusive Future, Storied Past, and the Fundamental Inequities Between*, 46 GA. L. REV. 557, 590-593 (2012).

results in the exodus of the best students from traditional public schools. However, other studies demonstrate that school choice tends to advantage students who may not necessarily have stronger academic histories but come from families better equipped to participate in the application process to exercise school “choice.”³⁰⁵ Research suggests that families’ access to the “educational marketplace” is unequally constrained by such factors as connection with social media or other influential networks through which knowledge about particular school choices and the process is shared. The same research also suggests that language barriers, socioeconomic status, and the ability of parents to arrange transportation for their school-age children contributes to the ability of a family to access charter schools.³⁰⁶ This data may also indicate that families of children with disabilities are more easily excluded from the charter schools because of intensified challenges families face while advocating for a change in a child’s placement in the IEP process.

A study of charter schools in thirteen states by the Government Accounting Office (GAO) released in June 2012 found that charter schools enrolled a lower percentage of students with disabilities than traditional public schools in both school years 2008-2009 and 2009-2010.³⁰⁷ The GAO documented that in six states, charter schools enrolled a higher proportion of disabled students than traditional public schools. But this may not reflect equal access: schools where more than 20 percent of the students had disabilities were more likely to be charter schools, in part because those schools cater specifically to students with special needs like autism.³⁰⁸ Charter schools struggle to enroll and appropriately serve students with disabilities such as mental retardation; serious emotional disturbance; autism; and hearing, speech, language, or orthopedic or visual impairments.³⁰⁹ The charter schools in large urban districts tend to enroll disproportionately greater numbers of students with high-incidence disabilities such as specific learning disabilities and lower numbers of students with low-incidence, more significant disabilities (e.g., intellectual disabilities and autism) and more educationally intensive and costly needs.³¹⁰ “For example, during the 2005-2006 school year, there were only three children with intellectual disabilities in all

305. *Cf. id.* at 589.

306. *See id.* at 582.

307. GAO REPORT, *supra* note 301, at 6.

308. *Id.* at 8. The numbers of disability focused charter schools is very small, making up only 2 percent of all charter schools nationwide. BOUNDY, *supra* note 295, at 35.

309. Garda, *supra* note 294, at 659.

310. BOUNDY, *supra* note 295, at 27.

San Diego non-conversion charter schools combined.”³¹¹ In comparison, traditional schools in the same district educated almost one thousand students with intellectual disabilities.³¹²

The GAO suggested several possible reasons for the overall disparity. Some parents choose public schools that have more established programs for students with disabilities, while some charter schools do not have the resources or teaching staff to support individual students’ needs.³¹³ But in some cases, school administrators tacitly acknowledged that some charter schools may be discouraging students with disabilities from enrolling and denying admission to students with more severe disabilities to prevent lowering overall test scores or to avoid the costs associated with educating these students.³¹⁴ Other accounts indicate that charter schools “push out” students with disabilities who cannot conform to the charter school’s strategies or rigid disciplinary code for reasons related to their disability and not willful misconduct.³¹⁵

The GAO also found a variety of other factors that resulted in lower enrollment, including some that result from efforts to circumvent the procedural requirements and protections of the IDEA.³¹⁶ A survey evaluating special education programs and services of twenty-three charter schools in New Orleans found “an astonishing number of 504 plans.”³¹⁷ “[S]everal of the surveyed special education coordinators acknowledged that the Section 504 plans were developed to avoid referring students for special education evaluations.”³¹⁸ The findings of the GAO study regarding systemic exclusion of students with disabilities and violations of the IDEA are echoed in the allegations made in a pending complaint filed by the Bazelon Center with the DOJ alleging that charter schools in Washington, D.C., illegally require parents to disclose information about students’ disabilities to screen out applicants with serious disabilities, advise parents that the school cannot or will not meet a student’s needs, and segregate students with disabilities in two overly restrictive schools. A federal class action suit on behalf of all New Orleans students with special needs is also currently pending against the Louisiana Department of Education, the Board of Elementary and Secondary Education, and state superintendent Paul Pastorek.³¹⁹ The

311. *Id.* at 29.

312. *Id.*

313. GAO REPORT, *supra* note 301, at 14, 17.

314. *Id.* at 15. *See also* Barkmeier, *supra* note 298, at 284-85.

315. Forte, *supra* note 239, at 2.

316. GAO REPORT, *supra* note 301, at 19-20.

317. BOUNDY, *supra* note 295, at 28.

318. *See id.*

319. P.B. v. Pastorek, No. 2:10-cv-04049, (E.D. La. Apr. 26, 2011).

suit alleges that the defendants have (1) denied students with disabilities the same variety of educational programs and services available to non-disabled students in violation of Section 504; (2) failed to locate, identify, and evaluate students in need of special education services in a timely fashion; (3) failed to provide a free and appropriate public education; and (4) unlawfully disciplined and excluded students with disabilities from educational programs in contravention of the IDEA.³²⁰

The reasons for failure to serve students reflect both the continuing struggles all schools face educating students with complex disabilities and also issues unique to charter schools. Because of their autonomous structures, charter schools may be isolated or fail to develop systems that allow for the “economies of scale” for the recruitment of teachers and the development of resources necessary to serve students with disabilities.³²¹ These arrangements result in the same kind of delays and lack of quality assurance that have fueled dissatisfaction with the public school system. They also reflect the systemic inequities in school funding that affect the provision of K-12 public education throughout the United States.³²² Some states provide a higher level of funding for special education based on the severity of a student’s disability, making it more feasible financially for charter schools in those states to serve students with more severe disabilities.³²³ In contrast, other states do not take such factors into consideration when providing funding for special education. This shifts the responsibility of school districts and places financial burden on individual charter schools. The resulting limitation on service may ultimately create an expectation that parents of children with disabilities turn to private resources to ensure their child receives the educational services that under the IDEA should be provided by the public schools.³²⁴

Although several thoughtful proposals have been made about how to address these problems, too little attention is being given to finding actual solutions.³²⁵ The wide-scale avoidance of responsibility resulting in

320. See Complaint, P.B. v. Pastorek, No. 2:10-cv-04049 (E.D. La. Oct. 26, 2010), *available at* <http://www.lawyerscommittee.org/admin/education/documents/files/FILED-COMPLAINT-P-B-v-Pastorek.pdf>.

321. Barkmeier, *supra* note 298, at 284.

322. See *id.* at 304.

323. See generally Mark C. Weber, *Special Education from the (Damp) Ground Up: Children with Disabilities in a Charter School-Dependent Educational System*, 11 LOY. J. PUB. INT. L. 217, 241-45 (2010).

324. Cf. *id.* at 244-45.

325. These proposals include one that Professor Mark Weber advocated for in considering the limitations on access and the provision of services that are already apparent in the reconstituted post-Katrina New Orleans school system. Professor Weber suggests that six principles should guide reforms in reconstructing a program of special education in the reconstructed city. *Id.* at 221-22 (concluding that “outcomes will not be improved, children

“pushing out” of students with disabilities from charter schools or the failure to provide services for the students left in them will likely result in pressure on families to obtain resources outside of the school system. Such a result represents merely a shifting of problems from the public to private sector without addressing the fundamental issues of ensuring meaningful educational outcomes for children with disabilities.

When the IDEA was reauthorized in 2004, increasing parental choice was one of the hallmarks of what was touted as a new era of accountability and improved educational outcomes for children with disabilities through the promise of reforms made possible by the involvement of the private sector in public education. “If a significant fraction of students—those with disabilities—are kept from having adequate choices, no one will ever know if a choice system can work when all students are included. Most important, critical opportunities to improve education for children with disabilities are at risk of being lost.”³²⁶ Most importantly, it appears that the choices afforded to families of children with disabilities may be another illusion of choice created by the privatization of responsibilities for children with disabilities.

CONCLUSION

This Article began by discussing debates about the rights of women to exercise rational choice in the use of prenatal genetic testing technologies and the responsibilities of a just society in the care and education of children with disabilities. The connection between the choice to use prenatal testing and issues of access and choice in special education is not readily apparent but demonstrates the complex challenges and choices that confront women and their partners about nurturing, rearing, and educating children.

One solution to the decades-long, highly-charged political, legal, and cultural battles over prenatal testing and abortion has been efforts designed to provide pregnant women with information about the possible life course of a child with disabilities, including educational outcomes, through the Prenatally and Postnatally Diagnosed Conditions Awareness Act. Proponents of this approach have emphasized that great strides

with disabilities will not be treated as equals, and rights will be violated unless the school system takes seriously the job of guaranteeing high quality supportive services for children who need special education.”). Professor Robert Garda advocates that there should be amendments to IDEA that compel charter schools to link with other charter schools, existing local educational authorities, or larger service organizations for the provision of special education, the utilization of uniform enrollment procedures, requiring detailed special education plans in charter applications, and implementing specific accountability measures that must be met for authorization and reauthorization of charters. *See generally* Garda, *supra* note 294.

326. Weber, *supra* note 323, at 220.

have been made in improving the lives of people with disabilities through legislation addressing entitlement to public benefits and access to services and public accommodations. The access to public education for children with disabilities guaranteed by the Individuals with Disabilities Education Act is often cited as one of the most successful examples of these efforts. Yet, the success of the system in providing meaningful benefit to children with disabilities is being questioned by stakeholders across the political spectrum. As argued above, access to public education services is dependent on a parent's ability to navigate the increasingly fragmented system of public resources or reliance on the private resources of family and marketplace, if available. Access to private resources may also require the willingness to waive meaningful legal protections under the IDEA and other civil rights statutes.

The competing agendas and tensions that structure relationships between school districts and parents and the growing role the market plays in the provision of special education in American public schools illustrates an encroaching movement back to private, familial responsibility for children with disabilities. Parents of children with disabilities are increasingly limited in the choices they have for their children despite the political rhetoric emphasizing the right to choice for these families. The available evidence regarding the effects of the increasing privatization of responsibility for the education of children through the use of vouchers and charter schools indicates that children with disabilities are not well served by market-based reforms and are being further marginalized by them. Free-market reforms may be fundamentally incompatible with the educational needs of children with disabilities and the overarching goals of promoting the dignity and inclusion of people with disabilities. We must acknowledge the paradox created when there is concerted effort to encourage women and their partners to choose to have a child with a prenatally diagnosed disability while government policies emphasize private responsibility for the care and education of children with disabilities and mandate restrictions on public expenditures for them.

The emphasis on private responsibility and restrictions on public expenditures for children with disabilities are often justified by claims that such strictures are designed out of respect for the sanctity of family life and to encourage the overarching moral and legal duty of parents to care for their children. This is not to suggest that parents do not owe a duty to care for their children, disabled or not, but it is a recognition that society plays an essential role in caring for vulnerable citizens and promoting the healthy development of its citizenry. Pregnant women and their partners often use prenatal genetic diagnosis to achieve a sense of reassurance and to assert control over their reproductive choices. Prenatal testing, when chosen in an informed and conscious manner, increases reproductive choice, and it also provides hope, information, control, and autonomy. The practices of genetic screening and prenatal genetic diagnosis can be inherently pro-natal. By supporting parental hopes for reasonably healthy children—not perfect offspring—the use of

prenatal diagnosis encourages at-risk women to undertake a pregnancy and to have children. Within the boundaries of the law and rational regulation, pregnant women and their partners should be able to make use of prenatal testing and related technologies, if they choose.³²⁷

There is a continuing struggle to understand that allowing the choice to use prenatal genetic technologies can be incorporated into a political and legal agenda designed to protect the rights of children and families affected by disabilities and to promote the development of all children.³²⁸ We must recognize the importance of empowering both pregnant women and parents of children with disabilities to exercise choice as a cornerstone of ensuring the continuation of a just society. An obvious way to subjugate people is to make them feel powerless over their own lives so that they will not challenge the dominant paradigm. This can be done by constricting choices over childbearing and restricting access to the resources necessary to address the demands and limitations that such choices may create for women, families, children, and society.

In recognition that reproductive choice in a just society encompasses all options, refusing prenatal testing is as accepted as choosing to undergo prenatal testing. More importantly, when addressing all results of that choice, we must avoid encouraging legal or social mandates that demand pregnant women and their partners reduce the likelihood that their future children will have a serious disability. Instead, we must endeavor to develop procedures for the equitable use of prenatal testing by all who choose to use it, on a voluntary basis—the very essence of choice.

In doing so, we must also recognize that prenatal screening and diagnosis, even with increasingly sophisticated technologies, cannot eliminate all of the uncertainties about the health of a fetus. But they can dramatically reduce them, and that is the aim of the technologies. We must acknowledge that children with genetic and other disabilities will continue to be born even with the availability of these technologies, as no technology dependent on the human involvement in its application is infallible and the expression of many genetic conditions is multifactorial in nature.

Professor Abby Lippman, in 1994, asked a series of questions concerning society's responsibility to mothers and children in the present and future generations with regard to prenatal testing and disability. "The question is how to provide support for women in a way that does no harm, that does not measure its effectiveness by the short-term profit from

327. Abby Lippman, *The Genetic Construction of Prenatal Testing: Choice, Consent, or Conformity?*, in *WOMEN & PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY* 9, 30 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994) ("Women's desire for children without disability warrants complete public and private support.").

328. *Id.*

money saved when the lives of those with present or future disabilities are prevented, that does not view the birth of a child with a disability as a technological failure.”³²⁹ These questions obviously persist and must be answered by considering how a just society must ensure both the right to choose to use prenatal technologies and the rights of children and adults with disabilities.

The rights and needs of children and adults with disabilities cannot be subjected because of the existence of technologies that can be used to prevent those disabilities. The just society does not simply provide the illusion of choice by ignoring all consequences of those choices, including the responsibility to ensure the inclusion and acceptance of those members with greater and more challenging needs. Such a society promotes meaningful inclusion by ensuring all members are educated to maximize their potential for independent functioning (at whatever level possible) while at the same time making resources to support those who are dependent readily available.

Most importantly, a just society recognizes that women are capable of choices and entitled to support in confronting all of the potential consequences of those choices. It is both logically inconsistent and fundamentally unfair to burden women by denying them the right to make decisions that result in that private responsibility. They should not be punished for making demands on the state to care for and educate children with disabilities that result from the reproductive choices and uncertainties that are an inherent part of the human condition.

329. *Id.*