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Health Law Symposium Articles

Health Care Access for Children with Disabilities

Linda C. Fentiman*

I. Introduction

In the last twenty-five years, we have seen a remarkable evolution in attitudes and practice toward the treatment of children with disabilities.¹ Children born with severe physical and mental anomalies are no longer routinely allowed to die. Many such children, along with those who become disabled later in childhood through illness or injury, receive aggressive life-saving medical treatment as well as continuing medical and habilitative care. Some children, particularly those whose families are affluent, receive substantial therapeutic and other supportive services that permit them to overcome their disabilities and function effectively in school and, later, at work.²

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1. Studies indicate that nearly 7% of all American children have some form of mental or physical disability, including physical disabilities like cerebral palsy, chronic illnesses like AIDS, birth defects like spina bifida, cognitive disorders like mental retardation, behavioral disorders like autism and attention deficit hyperactivity disorder, and mental illnesses like schizophrenia. See Dorothy K. Doolittle, *Welfare Reform: Loss of Supplemental Security Income SSI for Children with Disabilities*, 3 J. OF THE SOC'Y OF PEDIATRIC NURSES 33 (Jan. 12, 1998).

2. Schools are also becoming more adept at integrating disabled children into the classroom and providing supportive services for them, acting under the man-

Even though the approaches to treatment of disabled children have changed significantly during the last quarter century, the fundamental legal, ethical, and resource allocation issues remain constant. These are the complex and intertwined issues of authority, autonomy, and advocacy. Authority is the legal and moral power of parents, physicians, and the government to make decisions about disabled children's access to health care. Autonomy involves the practical ability of parents, physicians, and others, to make such decisions alone, free from outside interference. Advocacy, of course, is giving voice to a particular child, or a group of disabled children, who seek access to high quality health care.

Problems of access arise in two major contexts: access to acute medical treatment, including urgent and emergent care, and access to continuing medical, habilitative and supportive services. The paradigmatic acute care cases are those involving severely disabled newborns - Baby Doe in Indiana,³ Baby Jane Doe in the *University Hospital* case,⁴ Baby "K" in Virginia,⁵ and Baby Terry in Michigan.⁶ In these cases, the primary focus of analysis has been on parents' capacity and power to make appropriate health care decisions for their children, when their authority to do so has been challenged by physicians, hospitals, or the government. Other notable cases have arisen when chil-

dates of the Individuals with Disabilities in Education Act (IDEA), 20 U.S.C. §§ 1400-1491 (1996), and § 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 701 *et seq.* (1998). Detailed exploration of this subject is beyond the scope of this article. However, it is noteworthy that the Supreme Court has recently granted certiorari in *Cedar Rapids Community School District v. Garrett*, 106 F.3d 822 (8th Cir. 1997), *cert. granted*, 118 S. Ct. 1793 (1998), a case holding that the IDEA requires school districts to pay for full-time nursing services at school which are "required to assist a child with a disability to benefit from special education." *Id.* at 824 (quoting 20 U.S.C. § 1401(a)(17) (1996)).

3. See JEFF LYON, *PLAYING GOD IN THE NURSERY* 21-58 (1985).

4. *United States v. Univ. Hosp., State Univ. of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984).

5. In the Matter of Baby "K," 16 F.3d 590 (4th Cir. 1994), *affg and modifying* In the Matter of Baby "K," 832 F. Supp. 1022 (E.D. Va. 1993).

6. *In re Achtabowski*, No. G93-142173-GD (Mich. P.Ct. July 30, 1993), No. 93-1247-AV (Mich. Cir. Ct. Aug. 12, 1993), *leave to appeal denied*, 548 N.W.2d 628 (Mich. 1995), *discussed in* James Bopp Jr. & Richard E. Coleson, *Child Abuse by Whom? Parental Rights and Judicial Competency Determinations: The Baby K and Baby Terry Cases*, 20 OHIO N.U. L. REV. 821, 825 (1994).

dren become candidates for aggressive medical care, and their parents do not want to pursue it.⁷

The second cluster of cases involves access to care on a continuing or chronic basis: gaining access to appropriate medical specialty care and appropriate habilitation services, and integrating medical and other services in order to maximize a child's opportunities for effective functioning. Chronic disability cases are much more numerous than the headline-grabbing acute care cases, and usually do not involve dramatic "life and death" decisions. Instead, disputes usually raise two types of issues: (1) whether services are related to a medical condition, and thus are *medically necessary*, and (2) whether a child's disabilities are sufficiently severe to meet government criteria for financial assistance.⁸

Eligibility for federal Supplemental Security Income (SSI)⁹ benefits for poor, disabled children is particularly valuable because it guarantees its recipients access to Medicaid, the federal-state partnership that pays for medical services for certain categories of low income individuals.¹⁰ In addition, SSI provides a cash benefit to families of disabled children, which is critical in permitting poor families to buy necessary supportive products and services, such as state of the art wheelchairs, nutritional supplements, and other items not covered by Medicaid. The cash benefit also allows parents of disabled children to purchase child care services that permit them to work more

7. See, e.g., *In re Hudson*, 126 P.2d 765 (Wash. 1942) (holding that there was no basis for overruling parental refusal to consent to medically recommended amputation of deformed arm, absent demonstration that parent was unfit to make decision); *In re Custody of a Minor*, 393 N.E.2d 836 (Mass. 1979) (finding that three year old child suffering from leukemia was in need of state care and protection where, against medical advice, his parents discontinued chemotherapy and substituted treatment with laetrile); *Walker v. Superior Court*, 763 P.2d 852 (Cal. 1988), *cert. denied*, 491 U.S. 905 (1989) (holding that mother could be prosecuted for involuntary manslaughter and felony child endangerment after she treated her child with prayer rather than Western medicine, despite a faith healing exemption in the misdemeanor child neglect statute).

8. See, e.g., *Nelson v. Apfel*, 131 F.3d 1228 (7th Cir. 1997).

9. The Supplemental Security Income Program guarantees minimal cash assistance and access to medical care to disabled adults and children. See 42 U.S.C. § 1381 *et seq.*

10. See *Overview of the Medicare and Medicaid Programs: Medicare and Medicaid Statistical Supplement, 1997*, 18 HEALTH CARE FIN. REV. 1 (1997), available in 1997 WL 18242940.

hours, and thus, try to bring the family out of poverty.¹¹ By 1995, nearly one million poor American children received cash assistance through the SSI program because they were disabled.¹² This number has been drastically reduced since Congress enacted the Personal Responsibility and Work Opportunity Reconciliation Act of 1996.¹³ As part of a broad overhaul of American social welfare law, this Act altered both the criteria and the process for determining eligibility for SSI benefits due to childhood disability, excluding many children with moderate disabilities from the SSI program, particularly if their disabilities were behavioral or emotional.¹⁴ Exclusion also threatened to deny these children benefits under the Medicaid Act,¹⁵ but Congress reversed itself in the Balanced Budget Act of 1997,¹⁶ which restored Medicaid eligibility for disabled children who had been cut from SSI by the 1996 law.¹⁷

Disability cases also shine a spotlight on the medical versus habilitative distinction that pervades the United States health care system, which generally provides and pays for care within the framework of the medical model. The medical model is predicated on treatment for an injury or illness, designed to lead to restoration and recovery to a previously existing "normal" status. In contrast, the disabilities model is organized around a child's "condition," for which treatment and services are provided focusing on developmental progression and attainment. Medical necessity disputes arise out of the health care reimbursement system's historical reliance on physicians as gatekeepers, who, in this role, designate patients as ill or injured and in need of acute or chronic health care. This focus on medically oriented definitions of impairment frequently leads to the drawing of arbitrary distinctions between "medical" care,

11. See Adam Piori, *Losing a Lifeline: Disability Cutbacks Imperil Children's Health*, BERGEN COUNTY RECORD, Feb. 15, 1998, at A1.

12. See Lenna Kennedy, *SSA Programs that Benefit Children (Social Security Administration)*, 59 SOC. SEC. BULL. 64 (Sept. 1996), available in 1996 WL 11547698; see also Doolittle, *supra* note 1, at 38.

13. Pub. L. No. 104-193, 110 Stat. 2105 (1996).

14. See *id.* § 211.

15. 42 U.S.C. § 1396a *et seq.* (1998).

16. Pub. L. No. 105-33, 111 Stat. 251 (1998) (codified as amended in scattered sections of 42 U.S.C.).

17. See Doolittle, *supra* note 1, at 40; see also Balanced Budget Act of 1997, Pub. L. No. 105-33, 111 Stat. 251 (1997).

which is covered by a government or private payor, and "habilitative" or "custodial" care, which is not.¹⁸ Disputes about eligibility for government payment for habilitative and other services for disabled children are often an outgrowth of this medically based approach to providing services. They also reflect a profound lack of understanding of, and skepticism about, the nature of disabilities, particularly where children are concerned.

II. Autonomy, Authority, and Advocacy

What links these two groups of children's access cases are the concepts of autonomy, authority, and advocacy. The autonomy principle raises the question: Under what circumstances should parents be left alone, free from interference from health care professionals, the government, and third-party payors, to make decisions about what treatment is most appropriate for their child? For most lawyers, and many parents, autonomy is the preeminent principle, trumping all other considerations.

The authority principle asks: Who is legally authorized to make decisions on behalf of a disabled child, and under what circumstances should it be someone other than the child's parents - the government, physicians, or other health care providers - who has the final say? Authority issues arise in a wide range of circumstances, including decisions about proposed medical treatments,¹⁹ and access to habilitative services and other resources necessary to maximize a disabled child's functioning.

The concept of advocacy cuts across the principles of autonomy and authority. Here we are asking: Who speaks for the

18. See, e.g., RAND E. ROSENBLATT ET AL., LAW AND THE AMERICAN HEALTH CARE SYSTEM 1151 (1997) (discussing long term care).

19. These cases raise not only the question of *what* medical treatment is necessary, but *where* it should be provided, and *who* should pay for it. See, e.g., *In re Baby "K,"* 16 F.3d 590 (4th Cir. 1994), *affg and modifying In re Baby "K,"* 832 F. Supp. 1022 (E.D. Va. 1993) (upholding the right of a mother of an anencephalic baby to insist that it receive life-saving respirator treatment when brought to a hospital emergency room); *Parham v. J.R.*, 442 U.S. 584 (1979) (upholding parents' rights to commit their mentally ill children to a state mental hospital without judicial review of the commitment decision); *Detsel v. Sullivan*, 895 F.2d 58 (2d Cir. 1990) (holding that Medicaid must pay for skilled nursing care necessary to permit a severely disabled child to attend public school).

child – the parents or other legal representative, health care professionals, or the government, either individually or in combination?

III. Access to Acute Care

A review of acute care treatment decisions for disabled children shows a remarkable swing of the pendulum in the last twenty-five years. Treatment has moved from deliberate non-action, to aggressive medical intervention, to a more recent re-examination of the appropriateness of deploying high technology solutions in all cases.

In 1973, Raymond Duff and A.G.M. Campbell launched a firestorm of controversy with an article that acknowledged publicly what was commonly known among pediatricians: that in some cases, physicians and families considered it appropriate, and indeed superior, to withdraw or withhold medical treatment from disabled newborns, rather than insisting on aggressive treatment which would likely be painful, might ultimately prove futile, and would in any case permit a child to live who was expected to have a very poor quality of life.²⁰ In 1979, Robert and Peggy Stinson published an agonizing account of the tragic life of their extremely premature son, which vividly dramatized the consequences of denigration of parental autonomy and authority and its replacement with untrammelled physician authority and a commitment to pushing the outside of the envelope.²¹ The Stinson's son, "Baby Andrew," was treated over their objections in a neonatal intensive care unit for six months, until physicians finally decided that his case was indeed hopeless, and permitted him to die.²²

IV. The "Baby Doe" Cases

"Baby Doe" was a highly publicized case which made visible the conflict between parents who sought to make a "quality of

20. See Raymond Duff & A.G.M. Campbell, *Moral and Ethical Issues in the Special Care Nursery*, 289 NEW ENG. J. MED. 890 (1973), reprinted in JUDITH AREEN ET AL., *LAW, SCIENCE AND MEDICINE* 1169 (1984).

21. See Robert Stinson & Peggy Stinson, *On the Death of a Baby*, 244 THE ATLANTIC 64 (July 1979); see also ROBERT STINSON & PEGGY STINSON, *THE LONG DYING OF BABY ANDREW* (1983).

22. See *id.*

life” decision for their disabled child and a physician who tried to insist on aggressive medical intervention.²³ “Baby Doe” was born in Bloomington, Indiana, in 1982 suffering from Down Syndrome (a condition that always involves mild to severe mental retardation), apparent circulatory and neurological impairments, and esophageal atresia (a gap between the esophagus and stomach that prevents ingested food from reaching the stomach).²⁴ If the esophageal atresia was not surgically corrected, the baby would have starved to death.²⁵ The parents decided, after consulting with their obstetrician and pediatrician, that their child would have such a poor quality of life due to Down Syndrome and his other disabilities, that it would be wrong for him, his parents, and his older siblings to agree to the necessary surgery.²⁶ The parents’ decision was challenged by another pediatrician and the local prosecutor, but the parents’ right to decide what was best for their child, given conflicting medical opinions, was upheld first by a lower court, and then by the Indiana Supreme Court.²⁷ Baby Doe died six days after birth.²⁸

The enormous publicity surrounding this case caused an outcry by disability rights and “right to life” advocates. In 1983, in response to this case, the “Baby Doe” regulations were promulgated on an “interim final” basis by the Reagan Administration, under the authority of § 504 of the Rehabilitation Act of 1973.²⁹ These regulations prohibited hospitals from discriminating on the basis of a handicap in providing medical treatment to seriously ill newborns (i.e., not treating children with disabilities when they would have treated a non-disabled child).³⁰ The regulations focused primarily on the process by which potential cases of medical neglect should be handled by state child abuse authorities, but they also significantly expanded the federal government’s role in overseeing and investigating medical treatment decisions for severely disabled

23. See LYON, *supra* note 3, at 24-25.

24. See *id.*

25. See *id.*

26. See *id.*

27. See *id.*

28. See LYON, *supra* note 3, at 28-38.

29. See 45 C.F.R. pt. 84, App. C. (1998).

30. See *id.*

newborns.³¹ The regulations established a "Handicapped Infant Hotline," and required hospitals receiving federal funds to post signs in all infant care settings, warning "Discriminatory Failure to Feed and Care for Handicapped Infants in this Facility is Prohibited by Federal Law."³² So called "Baby Doe Squads" would descend upon hospitals where discriminatory denial of treatment was suspected, often based upon the report of a nurse or relative of a seriously ill newborn, and launch an inquiry into the child's case.³³ On occasion, the federal investigative process worked so quickly that federal authorities arrived at a hospital even before a treatment decision had been made.³⁴

Ultimately, the "Baby Doe" regulations were struck down as having exceeded the Congressional grant of authority in § 504 of the Rehabilitation Act of 1973.³⁵ The regulations were first invalidated in *American Academy of Pediatrics v. Heckler*,³⁶ in which the Federal District Court for the District of Columbia agreed with a facial challenge to the hastily published regulations, and held that the regulations were adopted in violation of the Administrative Procedure Act.³⁷

In 1984, in *United States v. University Hospital*,³⁸ the Second Circuit Court of Appeals found that the Rehabilitation Act did not authorize the government to compel access to the Medicaid records of a handicapped infant.³⁹ This case involved the federal government's attempt to intervene in the medical decision-making process in the case of a particular child, Baby Jane Doe, who was born with multiple congenital anomalies, includ-

31. *See id.*

32. *Id.* at 9631. In pertinent part, § 504 of the Rehabilitation Act of 1973 provides that, "No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance." 29 U.S.C. § 794 (1973).

33. *See LYON, supra* note 3, at 42-43; *see also* *United States v. Univ. Hospital, State Univ. of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984).

34. *See* *Bowen v. The Am. Hosp. Ass'n*, 476 U.S. 610, 635-636 (1986).

35. *See* *Am. Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983) (citing Administrative Procedure Act, 5 U.S.C. § 553 *et seq.* (1996)).

36. 561 F. Supp. 395.

37. *See id.* at 400-03.

38. 729 F.2d 144 (2d Cir. 1984).

39. *Id.* at 160-61.

ing spina bifida,⁴⁰ microcephaly,⁴¹ and hydrocephalus.⁴² Because of these conditions, it was expected that she would be mentally retarded, and might have a short life.⁴³ After consulting with physicians at University Hospital in Stony Brook, New York, the parents elected to forego surgery to correct the spina bifida and hydrocephalus, and instead chose to undertake more conservative, comfort-based treatment, which was less likely to prolong her life.⁴⁴

The *University Hospital* case was widely publicized when a Vermont attorney, who was unknown to the family, initiated an action in New York State court to compel the hospital to undertake the more aggressive course of treatment.⁴⁵ Although he succeeded at the trial court level, that decision was reversed on appeal.⁴⁶ The New York Court of Appeals held that an unrelated person had no authority to seek judicial intervention in a private medical decision.⁴⁷

Concurrently, the United States Department of Health and Human Services (HHS) sought to review Baby Jane Doe's medical records, in order to determine if the decision to pursue less aggressive medical care violated the "Baby Doe" regulations,⁴⁸ and thus, § 504 of the Rehabilitation Act.⁴⁹ When the hospital refused the HHS request, the United States brought suit in the Federal District Court for the Eastern District of New York.

The district court found that University Hospital had not discriminatorily failed to treat Baby Jane Doe, because it was the parents, and not the hospital, who decided not to conduct the surgery.⁵⁰ Furthermore, the court emphasized the reasona-

40. Spina bifida is a "congenital defect in which part of the meninges or spinal cord protrudes through the spinal column, often resulting in neurological impairment." RANDOM HOUSE UNABRIDGED DICTIONARY 1838 (1993).

41. Microcephaly is a condition in which the child's skull is unusually small. *See id.* at 1214.

42. Hydrocephalus is an accumulation of fluid within the skull which often causes great enlargement of the head. *See id.* at 937.

43. *See Univ. Hosp.*, 729 F.2d at 146.

44. *See id.*

45. *See Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63 (1983).

46. *See id.*

47. *See id.*

48. *See University Hospital*, 729 F.2d at 147-48.

49. 29 U.S.C. § 794 (1973).

50. *See Univ. Hosp.*, 729 F.2d at 149.

bleness of the parents' decision in light of "'due consideration of the medical options available and on a genuine concern for the best interests of the child.'"⁵¹ On appeal, the Second Circuit Court of Appeals held that § 504 of the Rehabilitation Act was never intended to involve the federal government in medical treatment decisions for seriously ill newborns.⁵²

The case of *Bowen v. The American Hospital Association*⁵³ involved a facial challenge to the "Baby Doe" regulations.⁵⁴ In *Bowen*, a plurality of the Supreme Court agreed with the Second Circuit's view that the "Baby Doe" regulations were promulgated in excess of the authority granted by § 504 of the Rehabilitation Act.⁵⁵ The Supreme Court reviewed the history of the "Baby Doe" regulations, and found no evidence that hospitals were discriminating against disabled newborns by withholding treatment, because whenever treatment was not provided, it was because the parents had not consented.⁵⁶ The Supreme Court concluded that there was no basis for the Secretary of Health and Human Services' decision to invoke § 504's prohibition against federally funded facilities discriminating on the basis of handicap.⁵⁷ Instead, the Court found that state child abuse agencies were providing ample protection against the medical neglect of disabled newborns and had intervened to seek judicial authorization of medical treatment when necessary.⁵⁸

What are the lessons of the *Baby Doe* cases? An initial examination of these cases reveals that the courts affirmed the ability of parents to decide what was appropriate medical care for their children, so long as the parents had consulted with medical professionals, and had gained some medical support for their decision. These decisions, from *Baby Doe* in Bloomington, Indiana, to *Baby Jane Doe* in Stony Brook, New York, to *Bowen*'s invalidation of the "Baby Doe" regulations in their en-

51. *Id.* (quoting *United States v. Univ. Hosp.*, 575 F. Supp. 607, 615 (E.D.N.Y. 1983)).

52. *See id.* at 161.

53. 476 U.S. 610 (1986).

54. *See id.* at 613.

55. *See id.* at 647.

56. *See id.* at 610.

57. *See id.* at 646.

58. *See Bowen*, 476 U.S. at 639.

tirety, can be seen as affirming parental autonomy and authority. The decisions also uphold the authority of physicians and other health care providers to guide parents through difficult health care decisions, free from outside interference. The government was permitted to intervene only in extreme cases of medical neglect and child abuse (where, presumably, physicians disagreed with parents about the appropriate treatment approach), and then it was the state, not federal government that was held to have authority to second guess the parents' decision.

On a deeper level, however, the apparent recognition of parental autonomy and authority in the *Baby Doe* cases may be illusory. In reality, only in cases where the doctors agreed with the parents were the parents' choices affirmed.⁵⁹ In other cases, where the physicians believed that treatment should be given, the parents' authority was overruled, and they were either ignored, as were the Stinsons in the case of Baby Andrew,⁶⁰ or reported to state child abuse authorities as noted in *Bowen*.⁶¹ Thus, in truth, the *Baby Doe* decisions vindicated physician, not parental autonomy and authority.

V. The Child Abuse Prevention and Treatment and Adoption Reform Act

Even as challenges to the "Baby Doe" regulations were wending their way through the federal courts, Congress was acting to provide the authority for federal involvement in medical decision-making for seriously ill newborns which was alleged to be lacking in § 504 of the Rehabilitation Act. As part of a broad concern with child abuse and adoption and the lack of adequate resources to investigate and prosecute cases of abuse, Congress sought to ensure that uniform federal standards would be used in cases of medical neglect. Congress offered a carrot-and-stick approach: a promise to supply more financial resources to state child abuse programs if states would adopt sweeping definitions of medical neglect, which were directly focused at disabled newborns. Under the 1984 amendments to

59. See, e.g., LYON, *supra* note 3, at 21-58; *United States v. Univ. Hosp.*, 729 F.2d 144 (2d Cir. 1984).

60. See sources cited *supra* note 21.

61. See *Bowen*, 476 U.S. at 635.

the Child Abuse Prevention and Treatment and Adoption Reform Act ("the Child Abuse Prevention Act"),⁶² and the regulations promulgated under it in 1985,⁶³ "medical neglect" was defined as:

The withholding of medically indicated treatment unless:

- i) the infant is chronically and irreversibly comatose;
- ii) the provision of such services would merely prolong dying and not be effective in ameliorating all of the infant's life threatening conditions, or otherwise be futile in the survival of the infant; or
- iii) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.⁶⁴

The regulations further mandated that nutrition, hydration, and medication always be provided.⁶⁵ This directly addressed the situation frequently at issue in the *Baby Doe* cases, where the medical treatment involved the provision of corrective surgery to permit nutrition and hydration, and a decision not to treat often included the withholding of food and fluids. The Child Abuse Prevention Act was a delicately crafted political compromise. It involved negotiations among representatives of the American Academy of Pediatrics, right to life and disability advocacy groups, and HHS, who sought to identify common ground on which there was agreement that no medical treatment should be provided.

The common ground, however, was extremely sparse, and the inherent ambiguity and subjectivity in such terms as "merely prolong dying," "futile," and "inhumane" have had a significant impact on the practice of medicine in hospital delivery rooms and neonatal intensive care units. Several studies have indicated that in the wake of the "Baby Doe" regulations and the 1985 Child Abuse regulations, physicians and other health care professionals have become much more aggressive in their treatment of extremely premature, low birth weight infants, or other infants born with severe and multiple anomalies, fearing

62. Pub. L. No. 98-457, 98 Stat. 1749 (1984).

63. 45 C.F.R. §§ 1340.1 - 1340.20 (1998).

64. 45 C.F.R. § 1340.15(b)(2).

65. *See id.*

that to do otherwise would provoke federal or state intervention.⁶⁶

Thus, Congress succeeded where HHS did not, in imposing federal substantive standards for the medical treatment of children born with severe disabilities.⁶⁷ These standards froze medical standards in the mid-1980's, unable to evolve with medical and scientific advances in the last fifteen years. They also directly limit physician autonomy and authority to make medical treatment decisions for seriously ill newborns, and indirectly constrain parental autonomy and authority as well, by limiting the options that physicians can provide to parents in discussing their child's condition and prognosis.

VI. *Baby K and Baby Terry*

In two cases in the 1990's, courts have again been called upon to decide whether parents or physicians have the authority to decide the course of a disabled child's medical treatment. The results have been inconsistent. In one case, courts upheld the right of a mother of a severely disabled infant to insist on medical treatment, while in the other, courts found that parents who insisted on treatment over the objections of the baby's doctors were incompetent to make medical treatment decisions. In *In re Baby "K,"*⁶⁸ two federal courts addressed the question of whether the mother of an anencephalic child could insist on medical treatment that a hospital's physicians believed to be futile, and therefore inappropriate.⁶⁹ After Baby "K" was born, she was diagnosed as anencephalic (lacking major portions of her brain, skull, and scalp, and as a result, permanently unconscious).⁷⁰ Believing that she would soon die, hospital physicians recommended that Baby "K" be provided only comfort care: nutrition, hydration, and warmth, but urged that she not be

66. See L.M. Kopelman et al., *Neonatologists Judge the "Baby Doe" Regulations*, 318 NEW ENG. J. MED. 677, 683 (1988); J.J. Pomerance & T.C. Yu et al., *Changing Attitudes of Neonatologists Toward Ventilator Support*, 8 J. PERINATOLOGY 232, 237 (1988); cf. JEANNE GUILLEMIN & LYNDY HOLMSTROM, MIXED BLESSINGS: INTENSIVE CARE FOR NEWBORNS 281-82 (1982).

67. See 45 C.F.R. 1340.1 – 1340.20.

68. 16 F.3d 590 (4th Cir. 1994), *aff'd and modifying In re Baby "K,"* 832 F. Supp. 1022 (E.D. Va. 1993).

69. See *id.* at 590.

70. See *id.* at 592.

placed on a respirator if she began to experience difficulty in breathing, which was a normal outgrowth of her anencephalic condition.⁷¹ Baby "K"'s mother rejected the physicians' proposal, and refused to agree to a "Do Not Resuscitate Order."⁷² Instead, she insisted that Baby "K" receive mechanical respiratory support when necessary.⁷³

As a result of this impasse, the hospital sought to transfer Baby "K" to another hospital with a pediatric intensive care unit, but none was willing to accept her.⁷⁴ However, Baby "K" progressed, miraculously, to the point that she no longer needed acute hospital care, and she was moved to a nursing home.⁷⁵ Thereafter, she occasionally suffered severe respiratory distress necessitating mechanical respiratory support, which the nursing home could not provide.⁷⁶ Baby "K" would then be brought to the original hospital's emergency room, where her mother would request respiratory support to stabilize her breathing, which was provided under protest.⁷⁷

After Baby "K"'s second emergency room visit, the hospital brought suit in the Federal District Court for the Eastern District of Virginia, seeking a declaratory judgment that it was not obligated, under Virginia or federal law, to provide treatment that it believed to be futile and therefore ethically inappropriate.⁷⁸ The district court ruled in favor of the mother, concluding that under § 504 of the Rehabilitation Act,⁷⁹ the Americans with Disabilities Act (ADA),⁸⁰ and the Emergency Medical Treatment and Active Labor Act (EMTALA),⁸¹ the hospital was compelled to furnish care to Baby "K."⁸²

The Fourth Circuit Court of Appeals affirmed the decision of the district court, but relied solely on EMTALA for its deci-

71. *See id.* at 592-93.

72. *See id.* at 593.

73. *See Baby "K,"* 16 F.3d at 593.

74. *See id.*

75. *See id.*

76. *See id.*

77. *See id.*

78. *See Baby "K,"* 16 F.3d at 593.

79. 29 U.S.C. § 794.

80. 42 U.S.C. § 12101 *et seq.* (1998).

81. 42 U.S.C. § 1395dd (1998).

82. *See Baby "K,"* 16 F.3d at 592.

sion.⁸³ Thus, the court was able to avoid two trickier questions: 1) whether under § 504 of the Rehabilitation Act, an anencephalic child was “otherwise qualified” despite her anencephaly to receive medical treatment from a federally supported hospital, and 2) whether such a child was being discriminated against because of her disability, in violation of the ADA, when the hospital refused to provide respiratory support, which would have been provided to a non-anencephalic child who was having difficulty breathing.

The court construed EMTALA in what it deemed a “straightforward” manner, holding that EMTALA reflected a Congressional mandate that all persons who presented themselves at hospital emergency rooms with a potential emergency health condition be given an appropriate medical screening examination to determine if a medical emergency existed, and receive appropriate stabilizing treatment before admission to the hospital or transfer to another institution for appropriate care.⁸⁴ Under this view of EMTALA, once Baby “K” arrived at the hospital in respiratory distress, the hospital had no alternative but to examine her and provide stabilizing treatment for her breathing difficulties. The court found that EMTALA preempted all state law to the contrary, including medical malpractice and professional ethics laws.⁸⁵

In his dissent, Judge Sprouse expressly voiced concern that federal involvement in individual medical treatment decisions was inappropriate,⁸⁶ sounding remarkably like Justice Stevens’ plurality opinion in *Bowen v. The American Hospital Association*.⁸⁷ Judge Sprouse voiced disbelief “that Congress, in enacting EMTALA, meant for the judiciary to superintend the sensitive decision-making process between family and physicians at the bedside of a helpless and terminally ill patient.”⁸⁸ He observed, “[t]ragic end-of-life hospital dramas such as this one do not represent phenomena susceptible of uniform legal control. . . . Congress, even in its weakest moments, would not

83. *See id.*

84. *See id.* at 594-95.

85. *See id.* at 597.

86. *See Baby “K,”* 16 F.3d at 598 (Sprouse, S.J., dissenting).

87. 476 U.S. 610 (1986).

88. *Baby “K,”* 16 F.3d at 598 (Sprouse, S.J., dissenting).

have attempted to impose federal control in this sensitive, private area.”⁸⁹

At first glance, *In re Baby “K”*⁹⁰ appears to be a victory for parents, and a defeat for physicians and other health care providers, because the court held that a parent *can* insist on provision of medical care for a disabled child, even if physicians do not wish to provide it. However, other Fourth Circuit EMTALA decisions make clear the limited nature of this holding because seriously disabled newborns rarely receive treatment in an emergency room,⁹¹ and because EMTALA demands treatment only when a physician actually determines that a patient is in the midst of medical emergency.⁹² In *Baber v. Hospital Corporation of America*,⁹³ the Fourth Circuit declined to find a violation of EMTALA when an emergency room physician refused to perform an x-ray or other radiological procedure for an emergency room patient who hit her head when she fell in the emergency room, despite her brother’s repeated requests.⁹⁴ The patient subsequently died due to an undiagnosed brain injury.⁹⁵ Determining that the physician had no reason to believe that the patient had suffered a serious injury, nor that there was a medical emergency, the court found that EMTALA’s emergency screening requirement was not triggered, and thus EMTALA had not been violated.⁹⁶

In *Bryan v. The Rectors and Visitors of the University of Virginia*,⁹⁷ the court held that the duty imposed by EMTALA, to stabilize and provide appropriate medical care, did not extend beyond the emergency room.⁹⁸ In a situation akin to that of Baby “K,” but at the other end of life, physicians who had provided respiratory support to an elderly patient upon her admission to the hospital from its emergency room, declined to

89. *Id.*

90. *Id.* at 590.

91. *See, e.g., Bryan v. The Rectors and Visitors of the Univ. of Virginia*, 95 F.3d 349, 352 (4th Cir. 1996) (holding that EMTALA did not impose a continuing duty to treat after the patient was admitted to the hospital).

92. *See Baber v. Hosp. Corp. of Am.*, 977 F.2d 872 (4th Cir. 1992).

93. *Id.*

94. *See id.* at 874.

95. *See id.* at 875.

96. *See id.* at 885.

97. 95 F.3d 349 (4th Cir. 1996).

98. *See id.* at 349.

continue that support when they concluded that further treatment would be futile, despite the family's wishes to the contrary.⁹⁹ The court rejected the plaintiff's argument that EMTALA imposed a continuing duty to provide medical care whenever a patient's life was at stake, and declared instead that EMTALA's focus was limited to the emergency room.¹⁰⁰

Thus, the significance of *In re Baby "K"* appears to be quite limited. *In re Baby "K"* should not be considered a ringing endorsement of parental rights to insist on treatment of handicapped children. Rather, it reflects the limited, patchwork nature of federal regulation of medical treatment decisions, and the isolated and sometimes arbitrary impact of federal laws on physician autonomy in making treatment decisions.

The case of *Baby Terry*¹⁰¹ provides a strikingly different view of parental autonomy in making medical decisions for seriously ill newborns. Baby Terry was born in Michigan in 1993 at twenty-three weeks gestational age, suffering from respiratory distress and a number of other complications that frequently accompany extreme prematurity.¹⁰² He was placed on a respirator to assist him in breathing, but defied his physicians' predictions that he would soon die.¹⁰³ Because his physicians believed that the respirator treatment was merely prolonging death, and did not provide a meaningful chance to recover from his many illnesses, they tried to persuade his parents to discontinue the respirator.¹⁰⁴

After the parents refused to stop treatment, the Genesee County Department of Social Services sought a judicial declaration that the parents were incompetent decision-makers and that another person should be substituted as Terry's guardian.¹⁰⁵ Ultimately, the Genesee County Probate Court declared

99. *See id.* at 350.

100. *See id.* at 353.

101. The facts of Baby Terry's case are taken from the Appellant's Brief, *In re Achtabowski*, No. 93-1247-AV (Mich. Cir. Ct. Aug. 12, 1993), cited in James Bopp Jr. & Richard E. Coleson, *Child Abuse by Whom? Parental Rights and Judicial Competency Determinations: The Baby K and Baby Terry Cases*, 20 Ohio N.U. L. REV. 821, 825 (1994). The author was unable to independently verify these facts either through a court opinion or trial transcripts.

102. *See id.*

103. *See id.*

104. *See id.*

105. *See id.* at 826, 828.

the parents to be specifically incompetent to make medical treatment decisions for Baby Terry.¹⁰⁶ Although no psychological or psychiatric evaluation of the parents was conducted, the court apparently believed that because the parents refused to accept the doctors' grim prognosis for their son, their judgment was so impaired that they could not be considered competent decision-makers. The court appointed another relative as Baby Terry's guardian.¹⁰⁷ The guardian declared that it was in Baby Terry's best interest to withdraw the respiratory treatment, and let him die.¹⁰⁸

Baby Terry is a troubling example of judicial and physician usurpation of parental authority to make decisions about the medical treatment of their children. In this case, the Genesee County Probate Court totally ignored the usual presumption that parents act in their children's best interest,¹⁰⁹ which requires judicial deference, unless the parents' decision is clearly erroneous.¹¹⁰ In failing to distinguish between the question of competency (capacity) to make a decision and the merits of that decision, the probate court overlooked the presumption that parents *are* the most appropriate decision-makers for their child,¹¹¹ and exalted physician judgment to a pinnacle from which it could not be overthrown. At the very least, procedural due process demands both that a decision to supersede parental authority be based upon a thorough examination of the parents' psychiatric and psychological functioning and that other medical opinions on the appropriateness of continuing medical treatment for a particular child be presented. Further, because of the irrevocable nature of the probate court's decision to effectively terminate parental rights and select a guardian whose sole function would be to declare that it was in Baby Terry's

106. See Bopp & Coleson, *supra* note 101, at 826.

107. See *id.*

108. See *id.* at 827. After Baby Terry's death, his mother sought review in the Michigan Supreme Court, asserting that this was a classic case capable of repetition but evading review. See *id.* The court declined to accept review. See *In re Achtabowski*, 548 N.W.2d 628 (Mich. 1995).

109. See, e.g., *Pierce v. Society of Sisters*, 268 U.S. 510 (1925); *Parham v. J.R.*, 442 U.S. 584 (1979).

110. See *Parham v. J.R.*, 442 U.S. 584, 602-03 (1979).

111. See *id.*

interest to die, it was incumbent upon the court to stay its decision to provide the opportunity for appellate review.

Baby Terry is clearly aberrational when compared with most other cases in which parental authority to make difficult medical decisions for their children has been challenged. It is significant that in the *Baby Doe* and *University Hospital* cases, the parents' judgment was supported by at least some physicians, so that reviewing courts could find the parents' decision to be reasonable and decide that federal courts should stay out of this type of medical decision-making.¹¹² In contrast, in *Baby Terry* and *Baby Andrew*, the parents' views were rejected by all of the physicians involved.¹¹³ In each of these cases, the parents, who, ironically, were at opposite ends of the pro- and anti-treatment spectrum, were powerless to have their treatment decisions respected and implemented.¹¹⁴ Baby "K" appears to be unique because even though her mother stood alone in her opinion that continuing medical treatment was appropriate, Baby "K" happened to need that treatment in a situation in which EMTALA provided essential protection. These cases suggest that our laws provide insufficient support for parental autonomy and authority in making medical decisions on behalf of their disabled children. The general rule under our federal and state laws, as applied in the last twenty years, is that parents are permitted the autonomy and authority to act on behalf of their children only when they can find a physician who supports their decision, a physician who is in turn constrained by the authority of the federal government as embodied in the Child Abuse Regulations.¹¹⁵ Thus, in reality, American law and American courts actually denigrate parental autonomy and authority in favor of medical and governmental authority.

VII. Access to Chronic or Outpatient Care

In addition to receiving acute health care, usually in the hospital setting, children with disabilities frequently face obstacles in obtaining continuing care, particularly in the least re-

112. See LYON, *supra* note 3, at 32, 35; *United States v. Univ. Hosp.*, 729 F.2d 144, 146 (2d Cir. 1984).

113. See *supra* text accompanying notes 21-22, 101-108.

114. See *id.*

115. 45 C.F.R. § 1340.1 - 1340.20.

strictive setting possible. Four recent cases may change this: two interpreting the Americans with Disabilities Act¹¹⁶ and two reviewing challenges to regulations promulgated under the Medicaid Act.¹¹⁷ The ADA was enacted to expand the reach of the Rehabilitation Act of 1973, in order to more fully integrate disabled Americans into the mainstream of social and economic life.¹¹⁸ Title II of the ADA imposes a prohibition against discrimination on the basis of disability on all arms of state government, including state funded programs for health services.¹¹⁹ Title III of the ADA imposes a requirement of non-discrimination on all places of public accommodation, including hospitals and physicians' offices.¹²⁰

In *Helen L. v. DiDario*,¹²¹ the Third Circuit Court of Appeals held that the ADA required the Pennsylvania Department of Public Welfare to provide supportive services to a disabled woman in a non-institutionalized setting.¹²² The plaintiff, Idell S., was a forty-three-year-old woman who was paralyzed from the waist down.¹²³ She required some assistance with the activities of daily living, and was eligible for assistance from the Department of Public Welfare because she was indigent.¹²⁴ The Department provided such services in two programs: a nursing home residence program, funded through Medicaid at an annual cost of \$45,000, and an attendant care program, which provided the same services to people in their own homes, at an annual cost of \$10,500.¹²⁵ Due to the way the Pennsylvania legislature had organized and funded these two programs, there was space for Ms. S. only in the more expensive nursing home program.¹²⁶ In the nursing home, Ms. S. was surrounded by dis-

116. See *Bragdon v. Abbott*, 118 S. Ct. 2196 (1998); *Helen L. v. DiDario*, 46 F.3d 325 (3d Cir. 1995). Americans with Disabilities Act, 42 U.S.C. § 12101 *et seq.* (1998).

117. See *Detsel v. Sullivan*, 895 F.2d 58 (2d Cir. 1990); *Skubel v. Fuoroli*, 113 F.3d 330 (2d Cir. 1997). Medicaid Act, 42 U.S.C. § 1396a *et seq.* (1998).

118. See *Helen L.*, 46 F.3d at 331 (citing S. REP. NO. 116, 101st Cong., 1st Sess. 20 (1989), H.R. REP. NO. 485 II, 101st Cong., 2d Sess. 50 (1990)).

119. See 42 U.S.C. §§ 12131-12134 (1997).

120. See 42 U.S.C. §§ 12181 - 12189 (1995).

121. 46 F.3d 325.

122. See *id.* at 325.

123. See *id.* at 328.

124. See *id.*

125. See *id.* at 329.

126. See *Helen L.*, 46 F.3d at 329.

abled individuals, isolated from friends in the community, and unable to care for her two adolescent children.¹²⁷ She sued the Department of Public Welfare, arguing that its failure to provide the services for which she was eligible in the less restrictive setting of her home violated the ADA, because it prevented her from being integrated into the mainstream of society to the fullest extent possible.¹²⁸

The Third Circuit agreed, ruling that “the unnecessary segregation of individuals with disabilities in the provision of public services is itself a form of discrimination within the meaning of ” the ADA and § 504 of the Rehabilitation Act.¹²⁹ The court further held that under these statutes, “a public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.”¹³⁰ In this case, the court found that it was entirely reasonable for the Department of Public Welfare to modify its programs for persons with disabilities who needed assistance with the activities of daily living to provide more spaces in its attendant care program.¹³¹ Since the program’s avowed goal was to “enable [adults]. . . to live in their own homes and communities,” requiring the Department to provide health care services for additional people would not alter the fundamental nature of the program, and it would cost less to enroll more people like Ms. Idell S. in the attendant care program.¹³²

The reasoning of *Helen L. v. DiDario*,¹³³ if widely accepted,¹³⁴ would have far-reaching implications for the provision of services for disabled children. No longer could states and the federal government, the primary payors for services for

127. *See id.* at 329.

128. *See id.*

129. *Id.* at 33.

130. *Id.* at 336-37 (citing 28 C.F.R. § 35.130(b)(7)).

131. *See Helen L.* 46 F.3d at 337.

132. *Id.* at 337-38.

133. 46 F.3d 325.

134. The wide reach of Title II of the ADA was recently recognized by the Supreme Court in *Pennsylvania Dep’t of Corrections v. Yeskey*, 118 S. Ct. 1952 (1998) (holding, on appeal from the Third Circuit, that Title II of the ADA applies to a state’s department of corrections).

disabled children, insist that the price for receiving a broad package of services is living in an institution. Instead, authority to decide where services are to be provided would be shifted from the government to the parents, who are in a better position to know their children's needs as well as their strengths. Giving parents the authority and autonomy to decide that such services are required to be provided in the children's home or in an out-patient setting, would greatly enhance disabled children's ability to be fully integrated into the life of their family, school, and community.

Two cases from the Second Circuit Court of Appeals have a similar potential for expanding disabled children's integration into the community, through avoiding the Procrustean bed of Medicaid Regulations. *Detsel v. Sullivan*¹³⁵ and *Skubel v. Sullivan*¹³⁶ invalidated HHS regulations under the Medicaid Act,¹³⁷ which effectively confined disabled children to their homes as the price of receiving nursing services under the Medicaid Act. In *Detsel*, the Second Circuit held that the Secretary's interpretation of the Medicaid regulations as denying coverage for private duty nursing for a severely disabled child while she was attending school, while covering identical services if they were provided while the child was receiving private tutoring at home,¹³⁸ was an unreasonable construction of congressional intent in regard to Medicaid.¹³⁹ The court stressed that Congress had "created the Medicaid program in part to assist states in providing 'rehabilitation and other services to help [recipients] attain or retain capability for independence or self-care.'"¹⁴⁰ In later amendments to the Medicaid Act, Congress was particularly concerned about identifying and removing "barriers that prevent the provision of appropriate care in a home or community setting to meet the special needs of technology-dependent children."¹⁴¹ Congress was also concerned about "recommend[ing] changes in private and public health care programs

135. 895 F.2d 58 (2d Cir. 1990).

136. 113 F.3d 330 (2d Cir. 1997).

137. 42 U.S.C. § 1396a *et seq.* (1998).

138. *See* 42 C.F.R. § 440.80 (1997).

139. *See Detsel*, 895 F.2d at 63-64.

140. *Id.* at 62 (quoting 42 U.S.C. § 1396(a)(19)).

141. *Id.* (quoting Pub. L. No. 99-272, § 952D (1986) (current version at 42 U.S.C. § 1396a, note (1998))).

so as to provide home and community-based alternatives to the institutionalization of technology-based children.”¹⁴² While at the time that the Medicaid Act was adopted, few, if any technology dependent children *could* live at home, the court found that that was no reason to enshrine an outdated medical perspective in regulations.¹⁴³

In *Skubel v. Sullivan*,¹⁴⁴ the Second Circuit applied similar reasoning to Medicaid home health nursing regulations.¹⁴⁵ These regulations required that home health nursing services be provided only in a Medicaid recipient’s home, and not in an alternative setting, such as a school.¹⁴⁶ The effect of these regulations was to keep children out of public school and in their homes. As in *Detsel*, the court in *Skubel* invalidated these regulations as an unreasonable interpretation of the Medicaid Act.¹⁴⁷

Taken together, *Detsel* and *Skubel* demonstrate the importance of dedicated and persistent advocacy on the part of parents of disabled children, to challenge arbitrary and rigid interpretations of laws which are supposed to expand access to health care services, but in fact frustrate efforts to provide these services in a way which enhances disabled children’s independence and integration into the wider community. These cases also transfer authority from the government to parents to decide what is in a particular child’s best interest.

*Bragdon v. Abbott*¹⁴⁸ is a Supreme Court case with broad implications for access to care for people with disabilities. The specific issue in *Bragdon* was whether asymptomatic HIV infection was a disability within the meaning of the ADA, which outlaws discriminatory treatment by places of public accommodation, including hospitals and physicians’ offices.¹⁴⁹ Sidney Abbott visited a dentist, Dr. Bragdon, for a routine filling of a cavity.¹⁵⁰ When Dr. Bragdon learned that Ms. Abbott

142. *Id.*

143. *See Detsel*, 895 F.2d at 65.

144. 113 F.3d 330 (2d Cir. 1997).

145. *See id.* at 336-37.

146. *See* 42 C.F.R. § 440.70 (a)(1) (1997).

147. *See Skubel*, 113 F.3d at 337.

148. 118 S. Ct. 2196 (1998).

149. *See id.* at 2200.

150. *See id.* at 2201.

was HIV positive, he refused to treat her, except in a hospital, where the costs of treatment would be higher.¹⁵¹ Abbott declined, and instead sued Bragdon under Maine antidiscrimination law and the ADA.¹⁵²

The United States District Court for the District of Maine,¹⁵³ the First Circuit Court of Appeals,¹⁵⁴ and the Supreme Court¹⁵⁵ all agreed that asymptomatic HIV infection was a physical impairment of the reproductive system that limited Ms. Abbott in a major life activity, to wit, reproduction. The Supreme Court expressly rejected the argument that the only life activities which merit protection under the ADA are those which have a "public, economic, or daily character."¹⁵⁶ Since Ms. Abbott might reasonably choose not to risk infecting a sexual partner or a fetus in utero, her reproductive capacity was substantially limited. The Court found that the ADA definition of disability does "not turn on personal choice."¹⁵⁷ As long as Ms. Abbott's HIV infection substantially limited her ability to reproduce, she was disabled within the meaning of the ADA.¹⁵⁸ The Court remanded the case to the Court of Appeals for further determination of whether her disability could be reasonably accommodated, in light of the significant risk of transmission of HIV to Dr. Bragdon, which could not be eliminated through the use of appropriate precautions.¹⁵⁹

The significance of *Bragdon* for children with disabilities is profound. By holding that persons with disabilities must be afforded equal access to necessary medical care, the Supreme Court effectuates the ADA's goal of ensuring full integration of persons with disabilities into the mainstream of American life, and potentially enhances parental authority to seek services for their disabled children as they see fit. No longer can children with HIV and other physical and mental disabilities be steered routinely into specialty practices and clinics for those with par-

151. *See id.*

152. *See id.*

153. *See Abbott v. Bragdon*, 912 F. Supp. 580 (D. Me. 1995).

154. *See Abbott v. Bragdon*, 107 F.3d 934 (1st Cir. 1996).

155. *See Bragdon*, 118 S. Ct. 2196.

156. *Id.* at 2205.

157. *Id.* at 2206.

158. *See id.* at 2207.

159. *See id.* at 2213.

ticular disabilities.¹⁶⁰ Instead, they must be given access to treatment by mainstream providers, who must reasonably accommodate a child's particular disability.¹⁶¹ Necessary accommodations include wheelchair accessibility, sign language interpretation, and the use of universal precautions to prevent the spread of infectious diseases.¹⁶²

VIII. The Supplemental Security Income Program: Access to Medicaid and Money

A crucial part of access to health care services for many children with disabilities is their ability to receive cash assistance and their eligibility for Medicaid services under the Supplemental Security Income Program.¹⁶³ Under this program, many children living at or below the poverty level can receive cash for habilitative devices and services which they might not be able to receive under a narrow definition of "medically necessary," and which they could not otherwise afford.¹⁶⁴ In addition, if children are determined to be disabled for the purposes of the SSI program, they automatically become eligible to receive Medicaid, which guarantees them access to medical care.¹⁶⁵

The landmark Supreme Court case of *Sullivan v. Zebley*¹⁶⁶ provides critical background to the current controversy about children's eligibility for SSI benefits cases. Brian Zebley, a dis-

160. Although, many times, children with disabilities will not seek care from specialized providers who are experts at treating their particular illness or condition. However, it does suggest, particularly when viewed in conjunction with *Helen L. v. DiDario*, 46 F.3d 325 (3d Cir. 1995) and *Pennsylvania Department of Corrections v. Yeskey*, 118 U.S. 1952 (1998), that neither private health care professionals nor state funded medical and habilitative service providers can *insist* that disabled children visit only "high risk" practitioners or disability specialists, if that is not what the children or their parents want.

161. Indeed, safeguards to secure access to health care for persons with disabilities is mandated as part of the effort to move more indigent individuals into Medicaid managed care plans. In New York, for example, health plans must demonstrate how they will comply with the ADA as a condition of acceptance as a Medicaid managed care provider. See New York State Dep't of Health, *Guidelines for Medicaid MCO Compliance with the Americans with Disabilities Act (ADA)*, Oct. 27, 1997.

162. See *id.*

163. 42 U.S.C. § 1381 *et seq.* (1998).

164. See Piori, *supra* note 11, at A1.

165. See *supra* notes 9-17 and accompanying text.

166. 493 U.S. 521 (1990).

abled child, brought a class action suit against Louis Sullivan, the Secretary of HHS, challenging Social Security regulations. The regulations treated disabled adults and children differently in terms of their ability to qualify for the SSI program.¹⁶⁷ The Social Security Administration (SSA) required adult claimants to show that they were unable to find substantial gainful employment due to a disability.¹⁶⁸ Adults were presumed disabled if they suffered from a listed medical condition that was severe enough to prevent them from obtaining substantial gainful employment.¹⁶⁹ In addition, adults who did not meet the enumerated medical conditions could still be found disabled if an individualized assessment showed that they were unable to do their own past work or any other work available in the national economy.¹⁷⁰ Approximately one quarter of all adults who qualified for SSI benefits were found eligible under this individualized review process.¹⁷¹

In contrast, the SSI regulations for children with disabilities failed to implement the statutory mandate that children should be deemed disabled if they had a condition comparable in severity to those that would prevent an adult from working, since the regulations failed to provide a similar, individualized opportunity for children to demonstrate a disability of "comparable severity."¹⁷² The Supreme Court struck down these regulations as inconsistent with the statute, which in effect required the Secretary of HHS to promulgate new regulations that provided for an individualized functional assessment of a child-claimant's physical or mental impairments, and would evaluate the impact of those impairments on the normal activities of a child the claimant's age.¹⁷³

The new regulations required a child to show either a disability that met enumerated medical criteria, or, pursuant to an

167. *See id.* at 526.

168. *See id.* at 533.

169. Indeed, the list of medical conditions in the regulations was deliberately designed to require a higher level of severity than mandated by the statute. The regulations were so stringent that a person whose disabilities matched one of the listed conditions would not be able to work at all. *See id.* at 532-33.

170. *See id.* at 534-35.

171. *See Sullivan*, 493 U.S. at 535, n. 15.

172. *Id.*, 493 U.S. at 535-36.

173. *See id.* at 541.

individualized functional assessment, that he or she was severely impaired in one area of functioning, markedly impaired in two areas of functioning, or moderately impaired in three areas of functioning.¹⁷⁴ In practice, these regulations resulted in a huge increase in the number of children who were receiving SSI and Medicaid because of their disabilities, and greatly increased the costs of the SSI and Medicaid programs.

In the mid-1990's, Congress was besieged with media stories suggesting that some children were feigning disabilities, as well as concerns that the regulations defined disability so broadly that many children without serious disabilities were receiving benefits.¹⁷⁵ As part of a broad program of "welfare reform," Congress enacted the Personal Responsibility and Work Opportunity Reconciliation Act of 1996.¹⁷⁶ The Act eliminated the parallel treatment of disabled children and adults.¹⁷⁷ Rather than defining disability for children to encompass those children whose impairments were of "comparable severity" to adults whose disability precluded them from attaining substantial gainful employment, the Act redefined disability to include only those children whose mental or physical impairments resulted in "marked and severe functional limitations," which could be expected to last at least one year.¹⁷⁸ In addition, the Act mandated two major changes in implementing regulations which also excluded many children who had previously been classified as disabled.¹⁷⁹ The first was to rewrite the medical criteria for mental and emotional disorders "to eliminate references to maladaptive behavior in the domain of personal/behavioral function,"¹⁸⁰ which would preclude a finding of disability for many children with Attention Deficit Hyperactivity Disorder and other mental illnesses. The second change was even more sweeping, as Congress eliminated individualized functional as-

174. *Cf.* Supplemental Security Income; Determining Disability for a Child Under Age 18; Interim Final Rules With Request for Comments, 62 Fed. Reg. 6408, 6409 (1997) (to be codified at 20 C.F.R. pts. 404 and 416).

175. *See Doolittle, supra* note 1, at 39.

176. Pub. L. No. 104-193, 110 Stat. 2105 (1996).

177. *See id.* § 211(a)(4)(I).

178. *Id.* § 211(a)(4)(i).

179. *See id.* § 211(b)(1) and (2).

180. *Id.* § 211(b)(1).

sessments for children who did not meet the listed medical conditions,¹⁸¹ as had been required by *Zebley*.¹⁸²

These changes in the disability program for children were expected to save nearly \$5 billion in the SSI program over a six year period, and \$1.2 billion in federal and state Medicaid costs over the same time frame.¹⁸³ As a result of this drastic rewriting of federal disability law,¹⁸⁴ it was estimated that as many as 315,000 children, many of whom were significantly impaired, would either lose their current SSI and Medicaid benefits or be declared ineligible to receive them if they applied.¹⁸⁵

In January 1997, the SSA began its redetermination process, mailing letters to the parents of more than 270,000 children informing them that the SSA would review their child's eligibility for SSI.¹⁸⁶ This review process focused on those children who had been deemed eligible for SSI benefits based on an individualized functional assessment, and began with children whose disability had in part been expressed in maladaptive behavior.¹⁸⁷

In the first few months of this review, more than half the children whose eligibility was reconsidered had their benefits denied.¹⁸⁸ Preliminary data showed wide variations among states in the proportion of children removed from SSI rolls.¹⁸⁹ Many children's advocacy groups identified significant numbers of severely disabled children who had been cut from the SSI

181. See Pub. L. No. 104-193, 211(b)(2).

182. See *Sullivan v. Zebley*, 493 U.S. 521 (1990).

183. See Supplemental Security Income; Determining Disability for a Child Under Age 18; Interim Final Rules With Request for Comments, 62 Fed. Reg. 6408, 6417 (1997) (to be codified at 20 CFR pts. 404 and 416).

184. Under the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, the new definition of disability and new evaluation process for children with disabilities was to apply to all claims filed on or after August 22, 1996, and to all claims not yet finally adjudicated by that date, including all cases in various stages of appeal. See 104 Pub. L. No. 193, 211(d), 110 Stat. 2105, 2190 (1996); see also Social Security Administration (SSA): Statement of Regulatory Priorities, 62 Fed. Reg. 57189, 57193 (1997).

185. See Doolittle, *supra* note 1, at 35. However, the Balanced Budget Act of 1997 restored Medicaid entitlement for children who had previously received it by virtue of their SSI eligibility. See *id.* at 40.

186. See *id.* at 39.

187. See *id.*

188. See *id.*

189. See Doolittle, *supra* note 1, at 37.

rolls. When these cases received media attention, there was a huge public and legislative outcry. In order to assist parents whose children's eligibility for SSI would have to be redetermined under the new law, in 1996 the American Bar Association launched a pro bono advocacy program, the SSI Children's Project, to connect families with lawyers who represent them in the redetermination process.¹⁹⁰ The ABA has also provided an important voice insisting that children receive a full and fair hearing.¹⁹¹

In response, the Social Security Administration ordered a "top to bottom" review of its procedures. In February 1998, 78,000 children (and their families), whose appeals had been denied, were given notice of their ability to appeal these denials and were specifically advised that they could petition for benefits pending appeal.¹⁹² Nonetheless, there continue to be disparities among the states in their rates of removing children from SSI eligibility and many advocates for disabled children are still concerned that children are improperly being denied SSI benefits.¹⁹³ More than 147,000 children were cut from the SSI by March of 1998, with 82% of them suffering from mental retardation or mental disorders.¹⁹⁴ Whether many of these children will have their SSI benefits restored after their case is reheard remains to be seen. The ultimate societal impact of leaving a large number of mentally disabled children without necessary treatment and supportive services is problematic, and the decision to remove these children from the SSI program, while fiscally attractive in the short-run, appears extremely unsound over the long term.

190. See *ABA Urges the Social Security Administration to Correct Continuing Problems in SSI Cutoff for Disabled Children*, (last modified Jan. 5, 1999) <http://www.abanet.org/media/news.html>.

191. See *id.*

192. See Bazelon Center for Mental Health Law (hereinafter Bazelon), *Children's SSI Update* (visited June 22, 1998) <<http://www.bazelon.org/ssiupdat.html>>.

193. See *ABA Urges the Social Security Administration to Correct Continuing Problems in SSI Cutoff for Disabled Children* (visited July 24, 1998) <<http://www.abanet.org/media/news.html>>.

194. See Bazelon, *supra* note 192.

IX. Conclusion

Children with disabilities continue in an uphill battle to gain access to necessary health care. Their parents' ability to advocate effectively on their behalf is frequently constrained by poverty, as well as by narrow and medically based criteria for eligibility for supportive services. Further, in both chronic and acute care settings, twenty-five years of judicial precedent, statutes, and regulations have diminished the authority of all parents to make treatment choices which they believe are in their child's best interest, and denied parents a zone of autonomy in which to make those choices. The right of parents to make medical decisions for their children, a staple of our common law heritage, has become a vestigial illusion, with parents having the authority to decide what is necessary treatment for their children only if physicians and the federal government concur. Although cases of medical neglect and abuse do occur, it is important that a parent not be charged with child abuse or being an unfit parent simply because physicians disagree with the parent's reasoning. As medicine and technology continue to expand opportunities for disabled children to reach their full potential, it is critical that parents be given the authority and autonomy to chart the course for their children that appears wisest to them.