

Overview: Children's Health and the Law

Restrictions on Nursing Care for Children: A Policy That Saves No Dollars and Makes No Sense

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In 1981, three and a half-year old Katie Beckett caught the attention of President Ronald Reagan.¹ Katie had contracted viral encephalitis as an infant and as a result required a mechanical ventilator to help her breathe. Her parents wanted to take her home from the hospital where she had lived since infancy, but Medicaid would fund her care only if she remained in the institution.² Therefore Katie remained in the hospital, which cost the public approximately \$10,000 more per month than home care.³

Katie's situation seemed ridiculous, the product of an inefficient bureaucracy. Since President Reagan had campaigned against a growing federal bureaucracy, Katie's plight presented a perfect issue. The President's concern led to implementation of so-called "Katie Beckett waivers,"⁴ which, after a case-specific determination of cost effectiveness, allowed a child with severe disabilities to receive care at home while remaining eligible for Medicaid services.⁵ The Katie Beckett waiver program has evolved over the years⁶ and

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1. Des Moines Register, Mar. 17, 1991, at 1B.

2. Katie could receive Medicaid funding only while hospitalized because of the Supplemental Security Income "deeming regulations," under which the income and resources of parents living in the same household as a child are deemed available to the child. 42 C.F.R. § 416.821(a) (1990). Katie was not categorically eligible for Medicaid while living in her parents' home because their income was above the Medicaid eligibility level. After thirty days of institutionalization, the regulation considers the child a separate household and Medicaid funding becomes available. 42 C.F.R. § 435.724(c) (1990).

3. 2 TASK FORCE ON TECHNOLOGY-DEPENDENT CHILDREN, FOSTERING HOME AND COMMUNITY-BASED CARE FOR TECHNOLOGY-DEPENDENT CHILDREN 92 (1988) [hereinafter TASK FORCE].

4. HHS Specific Services Requirements and Limitations, 42 C.F.R. § 441 (1990).

5. TASK FORCE, *supra* note 3, at 92.

6. The Omnibus Budget Reconciliation Act of 1981, § 2176, Pub. L. No. 97-35, 95 Stat. 812 (1982) (codified at 42 U.S.C. § 1396n(c) (1990)), permitted states, at their option, to expand medical coverage to "medically needy" persons who were not previously covered by Medicaid. This group includes those who would otherwise require care in a long term facility. In late 1982, the Health Care Financing Administration (HCFA) developed a model waiver program to allow states to offer selected groups home and community-based services. Each state is free to devise a set of services as long as it can show that its proposed program is not more costly than institutionalization. See 42 C.F.R. § 441 (1990). The individual "Katie Beckett" waivers were phased out after 1984. TASK FORCE, *supra* note 3, at 93.

has proven to be a significant step toward community-based care for children with disabilities.⁷

A decade after Katie's story made the front pages, however, equally senseless policies continue to harm children with severe disabilities. Children like Katie Beckett use life-sustaining medical equipment and often require constant monitoring by nurses. In 1988, the Department of Health and Human Services (HHS) interpreted the two Medicaid regulations that govern nursing services to limit such nurses to the recipient's home; the nurses could not accompany the children to school, religious services, or any other location beyond the confines of the family residence.⁸ Both private duty nursing services⁹ and home health services¹⁰ were originally subject to such place restrictions.¹¹

The 'at home' limitation on private duty nursing services was challenged successfully by litigation. Congress has recently amended the home health services provision and added a new category, personal care services, for which the place restriction was lifted explicitly. The implications of this amendment on skilled nursing services currently provided under the home health services regulation are unclear and the amendment does not become effective until 1994.¹² To date, HHS has not lifted the restrictions on home health nursing services in accordance with this recent expression of Congressional intent to expand home health care outside of the home. We believe that the Department should immediately lift the restrictions on all home health services and rewrite the regulations accordingly.

7. Community-based care refers to more than simply living in a residence in the community. As used in this Article, community-based care for children with disabilities means integrated programs and services that foster interaction with people without disabilities and address the developmental needs of the children. See Nisbet, Clark, & Covert, *Living It Up! An Analysis of Research on Community Living*, in CRITICAL ISSUES IN THE LIVES OF PEOPLE WITH SEVERE DISABILITIES 115, 117 (L. Meyer, C. Peck & L. Brown 1991).

8. Under the authority of the Medicaid Act, 42 U.S.C. § 1396d(a), the Department of Health and Human Services has promulgated regulations defining private duty nursing services and home health services. See 42 C.F.R. § 440.80 and 42 C.F.R. § 440.70 (1990). See *infra* notes 33 & 35 for the text of the regulations. In relevant part, the regulations provide for services in the recipient's "home" (§440.80) or "place of residence" (§440.70). The Secretary has interpreted this language to mean that nursing services will be provided only within the four walls of the family home. For a full discussion of the Secretary's interpretation, see *infra* notes 33-38 and accompanying text.

9. Private duty nursing services are nursing services provided by a registered nurse or licensed practical nurse. Private duty nursing services are more continuous services than those that can be provided by a visiting nurse. 42 C.F.R. § 440.80 (1990). See *infra* note 33 and accompanying text for the complete regulation and a discussion of private duty nursing.

10. Home health nursing services are nursing services provided by a home health agency on a part-time or intermittent basis. 42 C.F.R. § 440.70 (b)(1) (1990). See *infra* note 35 and accompanying text for a discussion of the regulation.

11. It is difficult to discern a difference between the two services, except that the regulations suggest that home health nursing may be a more intermittent service. See *infra* notes 37-38 and accompanying text.

12. The case challenging private duty nursing is *Detsel v. Sullivan*, 895 F.2d 58 (2d Cir. 1990). The amended statute is found at Omnibus Reconciliation Act of 1990, Pub. L. No. 101-508, § 4721, 104 Stat. 1388 (1990).

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The Jerome N. Frank Clinical Program at Yale Law School (Yale Legal Services) filed an amicus curiae brief in the case that reversed the limitation on private duty nursing, and it recently has initiated a suit challenging similar place restrictions on home health services.¹³ As members of the litigation team on the new case, we find no rational basis for distinguishing between the two types of nursing services or for applying a place restriction to services for people with disabilities. Simply put, the government's restrictive policy regarding home health services "saves no dollars and makes no sense."¹⁴ It saves no dollars because Medicaid already pays for a set number of hours of nursing care prescribed by the child's physician;¹⁵ it makes no sense because it prevents children from receiving the benefits of attending school, religious services and community events. The children's severe disabilities make it impossible for them to leave their homes without nursing assistance. Before President Reagan's intervention, children like Katie Beckett were needlessly institutionalized in a hospital; now they are needlessly institutionalized in their homes.

Why do such restrictive policies exist? Two broad paradigms in disability law are useful analytical tools for explaining the current policy and working toward new solutions. The first paradigm is premised on the physical differences of people with disabilities.¹⁶ This paradigm asserts that the physical differences of people with disabilities justify policies that disparately affect them.¹⁷ It assumes that discrimination against those with disabilities is premised on physical difference and thus stems from ignorance and indifference,

13. Complaint for Declaratory and Injunctive Relief, *Skubel v. Sullivan*, No. N-90-279 (D. Conn. filed June 4, 1990). The litigation team includes Yale Law School professors Stephen Wizner and Carroll L. Lucht and students Andrew S. Golub, Mary Giliberti, Edward Bennett, Sumy Daeufer, and Alissa Reiner.

14. Lewis Golinker Esq., the attorney who argued against the place restrictions on private duty nursing services in *Detsel*, coined this phrase. The financial implications of the 'at-home restrictions' are discussed at length in Section III, *infra* notes 86-110 and accompanying text.

15. See 42 C.F.R. § 440.70(a)(2) (1990).

16. *Alexander v. Choate*, 469 U.S. 287, 298 (1985) (state Medicaid policy reducing number of hospital days covered was not discrimination against people with disabilities under section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794); Wegner, *The Antidiscrimination Model Reconsidered: Ensuring Equal Opportunity Without Respect to Handicap Under Section 504 of the Rehabilitation Act of 1973*, 69 CORNELL L. REV. 401, 429 (1984) (comparing discrimination on the basis of disability to other forms of discrimination); Rebell, *Structural Discrimination and the Rights of the Disabled*, 74 GEO. L.J. 1435, 1437 (arguing that the very notion of "disability" implies limitations); Note, *Employment Discrimination Against the Handicapped and Section 504 of the Rehabilitation Act: An Essay on Legal Evasiveness*, 97 HARV. L. REV. 997 (1984) (proposing an explicit definition of employment discrimination against people with disabilities).

17. In *Cleburne Living Center v. City of Cleburne*, 473 U.S. 432 (1985), the Supreme Court held that mental retardation did not require heightened judicial scrutiny because the immutability of this characteristic justified differential treatment. The Court stated that those with mental retardation "are thus different, immutably so, in relevant respects, and the States' interest in dealing with and providing for them is plainly a legitimate one." *Id.* at 442. The Court has not ruled directly on whether physically handicapped individuals are entitled to heightened judicial scrutiny. Courts could logically extend the reasoning in *Cleburne*, however, to deny such scrutiny based on physical differences.

not animus.¹⁸ Consequently, the legal framework for analyzing discrimination against people with disabilities is distinct from that applied to discrimination against other minorities, who are not presumptively different.¹⁹

The "difference" paradigm treats policies that improve the lives of people with disabilities as accommodations of their physical needs.²⁰ Since accommodations are fundamentally benefits, not rights, the paradigm argues that benefits should be weighed against their costs; subject to resource constraints, policy-makers may set priorities and make rational choices that only partially accommodate the needs of those with disabilities.²¹ The language and methodology of cost-benefit analysis is thus at the heart of the difference paradigm. Since agencies and courts frequently use cost-benefit analysis, it will be the primary focus of this article.²²

Insights from a second paradigm in disability policy, however, are useful in critiquing and improving cost-benefit analysis. This second paradigm begins with the premise that the central problem faced by people with disabilities is prejudice, which leads to a misperception that the needs of people with disabilities are different from those of people without disabilities.²³ The paradigm of prejudice draws parallels between the obstacles faced by people with disabilities and the obstacles, including segregation, animus and stereotyping, faced by other disadvantaged groups. The fundamental policy issue raised by this paradigm is how to combat these prejudices and misperceptions in order to grant people with disabilities equal access to education, programs, transportation and other services. Thus, the language and methodology of this paradigm is that of civil rights, not privileges.²⁴

18. *Alexander v. Choate*, 469 U.S. at 298 (quoting legislative history of section 504 of the Rehabilitation Act to support contention that discrimination is not caused by animus and ill will); *Rebell*, *supra* note 16, at 1437-38.

19. *Alexander v. Choate*, 469 U.S. at 298; *Rebell*, *supra* note 16, at 1436-1441; *Note*, *supra* note 16, at 1001.

20. Michael Rebell proposes a sophisticated version of cost-benefit analysis that he calls "structural discrimination." This model develops substantive criteria for balancing the competing claims of people with disabilities against the demands of the public fisc. Rebell proposes that if policy makers determined priority areas for structural change, policies within these areas could then be subject to a "manageable decision process." *Rebell*, *supra* note 16, at 1455.

21. *Rebell*, *supra* note 16, at 1454-55.

22. See *Southern Community College v. Davis*, 442 U.S. 397, 410 (1979) (balancing the costs to the integrity of a nursing program against the benefits to a deaf woman if she gains access to the program); *Alexander v. Choate*, 469 U.S. at 308 (weighing the administrative costs of analyzing the harms to people with disabilities); *Detsel v. Sullivan*, 895 F.2d 58 (2d Cir. 1990) (agency claims that cost of providing nursing care in the community is a reasonable basis for denying such services).

23. *Note*, *Rethinking Equality and Difference: Disability Discrimination in Public Transportation*, 97 YALE L.J. 863, 864 (1988) (arguing that "prejudice is central to the problems faced by people with disabilities"); M. EISENBERG, C. GRIGGINS, & R. DUVAL, *DISABLED PEOPLE AS SECOND-CLASS CITIZENS* xiii (1982) (arguing that the study of people with disabilities must be more than a study of physical disabilities).

24. See *Cook*, *The Scope of the Right to Meaningful Access and the Defense of Undue Burdens Under Disabilities Civil Rights Laws*, 20 LOY. L.A. L. REV. 1471 (1987); R. SCOTCH, *FROM GOOD WILL TO CIVIL RIGHTS* (1984); *Note*, *Abroad in the Land: Legal Strategies to Effectuate the Rights of the Physically*

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In analyzing the way Medicaid defines children with disabilities, the “difference” paradigm explains the government’s focus on medical treatment and cost. The “prejudice” paradigm, however, reminds us that a child with a disability is more than a number or a case: she is a person with developmental needs. In assessing the costs of the ‘at home’ restriction, the prejudice model cautions against an ‘able bodied bias’ that creates an irrebuttable presumption that providing effective services for people with disabilities is always costly.²⁵ This prejudice model also emphasizes benefits, particularly developmental benefits and the potential for reducing prejudice by integrating children with disabilities into the larger community.

We believe that indifference and ignorance ultimately explain the inertia that has maintained the place restrictions on nursing services. A civil rights perspective could correct these problems by introducing an appreciation of the liberties and freedoms at stake, including the rights to travel freely, to speak and associate, and to practice religion. We do not advocate discarding the cost-benefit model, but rather including on the benefits side of the equation a valuation of the numerous rights that can be exercised only if the place restrictions are lifted.

Section I of this article describes the statutory and regulatory framework of nursing care. This section also defines and estimates the population of children affected by the ‘at-home’ limitation on their nursing services. Section II discusses the controlling case law and litigation efforts to challenge the restrictive policy regarding home health nursing services. Section III analyzes the costs and then the benefits of a non-restrictive policy. Finally, Section IV proposes ways to lift the ‘at-home’ restrictions and improve service provision for people with disabilities.

I. STATUTORY AND REGULATORY FRAMEWORK

A. *The Medicaid Act and Implementing Regulations*

The Medicaid Act,²⁶ a joint federal-state program that helps states provide medical assistance to “needy” individuals, provides the majority of services to children with severe disabilities. “Needy” individuals include those persons below a specified income who are also aged, blind, disabled or who receive Aid to Families with Dependent Children.²⁷ At their discretion, states may also extend coverage to “medically needy” people, including children whose

Disabled, 61 GEO. L.J. 1501 (1973) (arguing for a rights-based legal framework for education, physical access and employment).

25. See Note, *supra* note 23, at 877.

26. 42 U.S.C. § 1396 (1988).

27. 42 U.S.C. § 1396a(a)(10)(A)(i) (1988).

parents' income is too high to qualify categorically for Medicaid,²⁸ but who would otherwise be cared for in a hospital or intermediary care facility.²⁹

Under the Medicaid program, states retain considerable discretion over service provision. States voluntarily choose to participate by submitting a "state plan" that must comply with the federal statutory guidelines and the regulations of the Department of Health and Human Services.³⁰ Once a state elects to participate in the program, it must provide a menu of services mandated by the Medicaid statute. All states, for example, must provide home health services for any individual who is otherwise entitled to skilled nursing facility services under the state plan.³¹ A state may then choose to provide optional services, including private duty nursing and home health services for additional individuals.³²

Each of these services is defined by regulations. The important regulations for the purposes of this Article are those governing private duty nursing and home health care nursing. The implementing regulations describe private duty nursing as professional nursing services provided in the recipient's own home, a hospital, or a skilled nursing facility.³³ The Department of Health and Human Services interpreted this regulation to limit the provision of services to the confines of a recipient's home.³⁴ The "home health services" regulation states that these services, which include nursing services, home health aide services, and medical supplies and therapy, will be provided to a recipient "at his place of residence," which does not include a hospital, skilled nursing

28. 42 U.S.C. §§ 1396a(a)(10)(C)(ii)(I) & (a)(17)(D) (1988).

29. 29 U.S.C. § 1396a(a)(10)(A)(ii)(VI) (1988). Although the child *may* receive services if she qualifies as medically needy, the state must apply for a waiver in order for the child to actually receive services.

30. 42 U.S.C. § 1396a(a) (1988); 42 C.F.R. § 430.30 (1990).

31. 42 U.S.C. § 1396a(a)(10)(A)(ii)(VI) (1988).

32. 42 U.S.C. § 1396d(a)(6),(7) (1988). The statute originally read "home health care services." It has been amended to read "home health care services including personal care services (A) prescribed by a physician for an individual in accordance with a plan of treatment, (B) provided by an individual who is qualified to provide such services and who is not a member of the individual's family, (C) supervised by a registered nurse, and (D) furnished in a home or other location; but not including such services furnished to an inpatient or resident of a nursing facility." Omnibus Budget Reconciliation Act of 1990, P.L. 101-508, 104 Stat. 1388. Personal care services are designed to assist people with disabilities with tasks of daily living, including grooming, eating, and toileting.

33. 42 C.F.R. § 440.80 provides:

Private duty nursing services means nursing services for recipients who require more individual and continuous care than is available from a visiting nurse or routinely provided by the nursing staff of the hospital or skilled nursing facility. These services are provided—

- (a) By a registered nurse or a licensed practical nurse;
- (b) Under the direction of the recipient's physician; and
- (c) To a recipient in one or more of the following locations at the option of the State—
 - (1) His or her own home;
 - (2) A hospital; or
 - (3) A skilled nursing facility.

34. See *Detsel v. Sullivan*, 895 F.2d 58, 59 (2d Cir. 1990). The Secretary's interpretation will hereinafter be referred to as the "interpretation" or the "at-home restriction."

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facility, or intermediate care facility.³⁵ Again, the Secretary of Health and Human Services ("HHS") interpreted the regulation to restrict such services to the physical confines of the recipient's home.³⁶

The differences between home health and private duty nursing services are difficult to discern because the language in the regulations is vague. Nonetheless, there is some textual support for the proposition that private duty nursing services are more continuous than home health services.³⁷ Also, the physician's role in prescribing home health services is more detailed. These differences, however, do not support a restriction on home health services that is not applicable to private duty nursing. Moreover, the agency's interpretation of the home health services regulation is now inconsistent with the recent amendment to the Medicaid statute that will take effect in 1994.³⁸

B. Defining and Estimating the Number of Children Affected

The children eligible for home health care nursing services are those with serious medical conditions that require the supervision of a nurse or aide. These children are commonly referred to as "technology-dependent,"³⁹ which

35. 42 C.F.R. § 440.70 states:

(a) "Home health services" means the services in paragraph (b) of this section that are provided to a recipient—

(1) At his place of residence, as specified in paragraph (c) of this section; and

(2) On his physician's orders as part of a written plan of care that the physician reviews every 60 days.

(b) Home Health Services include the following services and items. Those listed in paragraphs (b)(1), (2) and (3) of this section are required services; those in paragraph (b)(4) of this section are optional.

(1) Nursing Service . . . that is provided on a part-time or intermittent basis by a home health agency . . .

(2) Home health aide service provided by a home health agency,

(3) Medical supplies, equipment, and appliances suitable for use in the home, and

(4) Physical therapy, occupational therapy, or speech pathology and audiology services,

(c) A recipient's place of residence, for home health services, does not include a hospital, skilled nursing facility, or intermediate care facility

This regulation may be changed in light of a recent amendment to the Medicaid statute governing home health services. *See supra* note 32.

36. Letter from Alfred Fuoroli, Associate Regional Administrator, Health Care Financing Administration, to Stephen Heintz, Commissioner of the Department of Income Maintenance (Nov. 15, 1988) (stating that home health as well as private duty nursing services would be restricted to the physical confines of the home) (copy on file at Yale Legal Services).

37. *See supra* notes 33 & 35 for the text of the regulations.

38. *See supra* note 32. Congress has explicitly stated that the place restrictions on a subset of home health services do not apply; therefore, the restrictions that currently govern the entire category of home health services must be invalid. In addition, the statutory language can be construed as lifting place restrictions for all home health services. The agency has not corrected the inconsistencies between the amended Medicaid statute and the current interpretation of the regulation.

39. The term "technology-dependence" is used in many government reports. *See* TASK FORCE, *supra* note 3; OFFICE OF TECHNOLOGY ASSESSMENT, TECHNOLOGY-DEPENDENT CHILDREN: HOSPITAL V. HOME CARE: A TECHNICAL MEMORANDUM (1987) [hereinafter OTA REPORT].

Disability rights advocates reject the term "technology-dependent" because it emphasizes the medical condition and not the individual. Advocates have asked that writers use the phrase "people with disabilities"

the Office of Technology Assessment (OTA) defines as

a small subset of the disabled child population who rely on life-sustaining medical technology and typically require complex, hospital-level nursing care [T]he technology-dependent child is defined as one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability.⁴⁰

A substantial subset of technology-dependent children qualify for Medicaid services either because of their families' low income or because of a waiver program. Because the Medicaid program does not compile statistics on the number of children receiving home health care services,⁴¹ the following section will rely on a recent OTA study that estimated the number of technology-dependent children.⁴² These figures serve as a rough approximation of the number of children potentially affected by the Medicaid regulations at issue. The OTA report is also a useful description of the disabilities that cause children to require technology and nursing care.

OTA identified four subgroups of "technology-dependent" children, all of whom would likely be affected by an 'at-home' limitation on their nursing services.⁴³ The first group consists of children who require ventilators and numbers between 680 and 2,000.⁴⁴ The second group contains children who need intravenous nutrition or drugs. OTA estimates that 350 to 700 children need parenteral nutrition and 68 to 8,275 require intravenous drugs for pro-

to put the focus on the person. The term "handicapped" is no longer used to describe people with disabilities; rather, it is used only to describe conditions in society that limit the mobility and freedom of people with disabilities. See THE RESEARCH & TRAINING CENTER ON INDEPENDENT LIVING, GUIDELINES FOR REPORTING AND WRITING ABOUT PEOPLE WITH DISABILITIES 2-3.

40. OTA REPORT, *supra* note 39, at 3. The Office of Technology Assessment is a Congressional research office that produces technical reports at the request of Congressional committees. It should be noted that OTA did not limit the group of technology-dependent children to those children whose care is provided by a nurse, as skilled nursing care can be provided by family members and friends. To avoid this complication, the Task Force on Technology-Dependent Children preferred a definition specifying the need for "daily, ongoing care or monitoring by trained personnel." In addition, the Task Force specified that the term "children" encompassed those who had not reached their twenty-second birthday. TASK FORCE, *supra* note 3, at 88.

41. See OTA REPORT, *supra* note 39, at 7 n.7. As part of the discovery process in the *Skubel* case, Yale Legal Services asked the Department of Health and Human Services for an estimate of the number of people receiving home health services. Plaintiff's First Set of Interrogatories, *Skubel v. Sullivan*, No. N-90-279 (D.Conn. filed Nov. 26, 1990). The Department filed a motion for a protective order, contending that the production of such information would be burdensome. Defendant's Motion for a Protective Order, *Skubel*, No. N-90-279 (pending). HCFA's policy analysis is flawed without this data because its cost and benefit assessments cannot be accurate.

42. The House Energy and Commerce Committee and the Senate Labor and Human Resource Committee wished to examine the issue of financing the health care needs of technology-dependent children. The committees specifically asked for an estimate of the number of children who are technology-dependent. See OTA REPORT, *supra* note 39, at iii.

43. The OTA Report relied on health surveys as well as on information from state-based programs. The number ranges are so large because no major health surveys contain information about this specific group of children. States do not keep accurate records of these children either. Only six states kept records on the numbers of ventilator-dependent children, the most easily identifiable of technology-dependent children. From these states' records, OTA extrapolated data for the nation—a very crude approximation. For greater detail, see OTA REPORT, *supra* note 39, at 12-32.

44. OTA REPORT, *supra* note 39, at 21.

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longed periods.⁴⁵ Group three includes children who require other respiratory or nutritional devices, such as tracheotomies, suctioning, or tube feeding. The estimated number of these children ranges from 1,000 to 6,000.⁴⁶ Thus, a subtotal for those strictly defined as technology-dependent includes between 2,300 and 17,000 children.⁴⁷

A fourth group of children, who have not traditionally been defined as technology-dependent, require nursing care but use less intensive medical devices for bodily functions. This group includes, for example, infants with cardiorespiratory monitors (6,800-45,000), those requiring renal dialysis (1,000-6,000) and those requiring other devices such as urinary catheters and colostomy bags, as well as nursing care (unknown, perhaps over 30,000).⁴⁸ It is impossible to determine how many of the fourth group of children are restricted by a place limitation on nursing services, because some require only intermittent services that can be provided by a parent, while others may need only those nursing services that their schools can provide. Nevertheless, it is likely that the number of children currently affected by the 'at-home' restrictions is in the tens of thousands.⁴⁹

OTA's estimates are of limited use because they are wide in range, are a crude proxy for recipients of home health services, and focus exclusively on the medical needs of children with severe disabilities. Medicaid uses medical criteria and, like many third party payors, has adopted a cost-based definition of the children.⁵⁰ Both cost-based and medically-based definitions eliminate the children as individuals, with disturbing implications for policy formation. If children with disabilities were viewed as valued members of the community, instead of as medical conditions and public expenses, then their home health services would be structured to maximize their integration and opportunities to interact with others.

The case of a Yale Legal Services client illustrates the implications of the perspective chosen. From a medical perspective, Travis Hardy is a six year old boy who has severe bronchopulmonary dysplasia, a marked immaturity of

45. *Id.* at 22.

46. *Id.* at 23.

47. *Id.* at 4. It should be noted that only those children receiving home health nursing care as opposed to private duty nursing care will be affected by the 'at-home' restriction, pursuant to a recent change in Medicaid policy regarding private duty nursing. See Memorandum from Christine Nye, Director of the Medicaid Bureau, to All Regional Administrators (Oct. 24, 1990) (stating that private duty services can be provided in the community) [hereinafter Memorandum] (copy on file at Yale Legal Services). Before 1990, however, these restrictions affected all children who received Medicaid nursing services.

48. *Id.* at 4.

49. This number can be expected to grow in the future. According to OTA, the number of technology-dependent children has been increasing over the last decade because of the increasing survival of low birthweight babies and children with inherited and congenital disorders. The growing number of children with AIDS will increase the population further. OTA REPORT, *supra* note 39, at 32.

50. For example, a waiver program must be cost effective. 42 U.S.C. § 1396n(c)(2) & 42 C.F.R. § 441.301(a)(3) (1990).

the lung, a seizure disorder, mental retardation, and vision impairment. Because Travis requires frequent suctioning of his tracheotomy, the state of Connecticut provides him with forty hours per week of Medicaid home health nursing services. Yet Travis is also a child from a loving family who enjoys family activities. According to his mother, the child "loves being around people." When she took him to church "it stimulated him so much he almost jumped out of my arms."⁵¹ When asked how she can tell that her son is excited, she noted "he laughs and smiles and sometimes he starts to kick his legs. His brother comes in and says anything and [he] gives a big, big smile"⁵²

II. LITIGATION CHALLENGING THE INTERPRETATION OF THE MEDICAID REGULATIONS AND APPLICABLE CASE LAW

Travis Hardy receives Medicaid home health nursing services, which are subject to a place restriction. He therefore cannot take his nurse into the community to attend movies, religious services, and other events.⁵³

Private duty nursing services were also originally restricted to the confines of the recipient's residence.⁵⁴ Litigation challenging these restrictions began in 1986 when an eight year old child named Melissa Detsel, who required nursing attendance to monitor her respiration, suction her tracheotomy and tubally feed and medicate her, filed suit in a New York federal court asking that her private duty nurse be allowed to accompany her to school.⁵⁵ Melissa's school district had recommended placement for her at a local school pursuant to the directives of the Education for All Handicapped Children Act (EHA).⁵⁶ The Medicaid place restrictions, however, prevented her from taking her Medicaid-funded nurse to school.

Melissa first sought nursing services under the EHA, which provides funds to states for special education and "related services" for children with disabilities.⁵⁷ After the Second Circuit Court of Appeals affirmed the Commissioner

51. State of Connecticut Department of Income Maintenance, Fair Hearing Transcript No. 89-1121AP, at 5 (July 27, 1989) (copy on file at Yale Legal Services).

52. *Id.* at 9.

53. Complaint in Intervention, *Skubel v. Sullivan*, No. N-90-279 (D. Conn. filed Dec. 21, 1990).

54. *See Detsel v. Sullivan*, 895 F.2d 58, 63 (2d Cir. 1990).

55. *Detsel by Detsel v. Board of Educ. of Auburn Enlarged City School Dist.*, 637 F. Supp. 1022, 1022-23 (N.D.N.Y. 1986), *aff'd* 820 F.2d 587 (2d Cir. 1987).

56. 20 U.S.C. §§ 1400-1485 (1988). The EHA provides funding to the states for special education services and is wholly separate from the Medicaid program.

The title of this act has been changed to the Individuals With Disabilities Education Act, Pub. L. No. 101-476, § 901, 1990 U.S. CODE CONG. & CONG. NEWS (104 Stat.) 1141 (codified as amended at 20 U.S.C.A. § 1400(a) (West Supp. 1991)). Throughout this Article, we will continue to refer to the act as the EHA, since most of the litigation discussed was brought under the old title.

57. The EHA defines the term "related services" as "transportation, and such developmental, corrective, and other supportive services (including speech pathology and audiology, psychological services, physical and occupational therapy, recreation, and medical and counseling services, except that such medical

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of Education's judgment that suctioning, tubal medication and feeding were outside the scope of the EHA,⁵⁸ Melissa brought suit under the Administrative Procedure Act (APA). She challenged the Secretary of Health and Human Services' interpretation of the private duty nursing regulation as contrary to congressional intent and as an unreasonable, arbitrary, and capricious action in excess of the Secretary's statutory authority.⁵⁹

While the Second Circuit found no clear legislative intent to provide nursing services outside the home, it held that the agency's explanations for the 'at home' restriction did not meet the standard of reasonableness.⁶⁰ First, the court rejected the agency's argument that the 'at-home' limitation was rational because it reflected the common understanding of the services at the time the regulation was promulgated in the mid-1960s. While the court questioned the evidentiary basis for the claim,⁶¹ it stated that even if it should accept the premise that the regulation originally intended to limit, rather than merely to describe, the nursing services, the restriction would not necessarily remain reasonable in 1990. The court recognized that the contemporary understanding of the nursing service is setting-independent and refers to the level of care, rather than to the location where it is provided.⁶²

The court rejected as well the agency's claim of economic efficiency. While noting the deference usually given to cost considerations, the court found that the Secretary had failed to show *any* legitimate costs of extending nursing services out of homes, since Medicaid would pay for the necessary equipment and nursing care regardless of the location where it was provided. Moreover, the court noted that the place restriction could actually increase total public expenditure because the EHA would require a home tutor for Melissa if she could not attend school.⁶³

While the *Detsel* case thus provided important precedent for invalidating place restrictions on nursing care, its effect was nonetheless limited in a

services shall be for diagnostic and evaluation purposes only) as may be required to assist a handicapped child to benefit from special education. . . ." 20 U.S.C. § 1401(a)(17) (1988).

58. *Detsel by Detsel v. Board of Educ. of Auburn Enlarged City School Dist.*, 820 F.2d 587, 588 (2d Cir. 1987), *aff'd* 637 F. Supp. 1022 (N.D.N.Y. 1986).

59. *Detsel by Detsel v. Bowen*, 1988 WL 101020 (N.D.N.Y.). The Administrative Procedure Act, 5 U.S.C. § 702, provides a cause of action for people who suffer legal wrongs because of agency action. The United States Supreme Court has interpreted the APA to mean that "agencies must articulate a logical basis for their decisions, including 'a rational connection between the facts found and the choices made.'" *Detsel v. Sullivan*, 895 F.2d 58, 63 (2d Cir. 1990) (quoting *Burlington Truck Lines Inc. v. United States*, 371 U.S. 156, 168 (1962)).

60. *Detsel*, 895 F.2d at 63-66. See *infra* notes 151-54 and accompanying text for a discussion of the "reasonableness" standard in administrative law.

61. All documents relating to the decisionmaking process at the time the regulation was promulgated were lost in 1977. Thus, the agency task force posited that the process was "probably a common understanding" of private duty nursing. *Detsel*, 895 F.2d at 64.

62. The court relied heavily on statements by various nursing associations represented as amici curiae by the Yale Legal Services. *Detsel*, 895 F.2d. at 59, 61-66.

63. *Detsel*, 895 F.2d at 60-66.

number of ways. First, the court's decision is binding only on states in the Second Circuit, which encompasses New York, Connecticut, and Vermont.⁶⁴ Second, although *Detsel* is binding precedent, the Secretary could have imposed the restriction on another child within the Second Circuit and tried to make a better case in support of its position.⁶⁵ Third, since Melissa Detsel sought only to attend *school* with her nurse, the court did not reach the more general question of travel within the community. Finally, the court's holding applied only to private duty nursing, not home health services.⁶⁶

The limitations of the *Detsel* holding inspired both further litigation and government response. In June 1990, Melissa's attorney reactivated a nationwide class action, *Pullen v. Cuomo*,⁶⁷ which sought to enjoin the Secretary of HHS "to include in administrative manuals, and otherwise notify Medicaid administrators and adjudicators in every state and territory . . . that the 'at home' restrictions are null and void" ⁶⁸ The class action sought to extend the *Detsel* holding both beyond the Second Circuit and to all community activities. The action did not, however, address the exclusion of home health services.⁶⁹

In October 1990, the Director of the Medicaid Bureau, Christine Nye, sent a memorandum to all regional administrators that instructed them that HHS adopted the *Detsel* court's decision nationally. The letter stated that "private duty nursing rendered during those hours when the recipient's normal life activities take him or her outside of his or her home are coverable."⁷⁰ Thus, services are to be provided in the community as well as in school.

Like the class action litigation, however, the Nye memorandum did not reach the place restrictions on home health services. Yale Legal Services became involved in challenging the continued application of these place restrictions in 1988 when it requested information about extended home health services for its clients with severe disabilities. In response to the clinic's request, the state of Connecticut asked the federal Health Care Financing Administration (HCFA) for clarification regarding the provision of Medicaid

64. As of October 1, 1988, eighteen other states and the District of Columbia included private duty nursing in their state plans. First Amended Complaint at 5, *Pullen v. Cuomo*, No. 88-CV-774 (N.D.N.Y. filed June 22, 1990). In addition, under new amendments to the Medicaid Act's Early Periodic Screening Diagnosis and Treatment Services, private duty nursing would be provided to all Medicaid-eligible children if that treatment is determined to be necessary. 42 U.S.C. § 1396d(r)(5) (1988). Thus, severely disabled children in every state may be subject to the 'at-home' limitation.

65. The policy of relitigating the same issue within a circuit is called non-acquiescence. Agencies resort to this tactic when they fundamentally disagree with a circuit court. J. MASHAW & R. MERRILL, *ADMINISTRATIVE LAW: THE AMERICAN PUBLIC LAW SYSTEM* 268-69 (1985).

66. See *supra* notes 37-38 and accompanying text for a discussion of the differences between the two services.

67. Attorney Golinker amended the complaint in light of the *Detsel* decision. See First Amended Complaint, *Pullen v. Cuomo*, No. 88-CV-774.

68. *Id.* at 14.

69. As this Article goes to press, settlement negotiations in that class action are continuing.

70. Memorandum, *supra* note 47.

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home health services in the community.⁷¹

HCFA initially relied on the lower court's opinion in *Detsel*,⁷² which upheld the place restrictions on private duty nursing, to deny community-based home health services. Alfred Fuoroli, the Assistant Regional Director of HCFA wrote:

Therefore, since HCFA does have a defined position that covered private duty nursing services will not be extended, without an exception such as a waiver, beyond the settings specified in the regulations, and this has recently been tested and upheld in District Court, my response to you must be that home health and private duty nursing services will only be covered in settings in the regulations.⁷³

After the Court of Appeals reversed the district court and struck the 'at-home' limitation for private duty nursing,⁷⁴ Yale Legal Services requested an updated clarification of the agency's policy. Instead of following the logic of his first letter and adhering to the court's decision regarding private duty nursing, Mr. Fuoroli contradicted his former position and contended that "since the *Detsel* case dealt only with the place of service restrictions on private duty nursing, it does not apply to the long-standing regulation at 42 CFR 440.70."⁷⁵ In refusing to lift the place restrictions, however, Mr. Fuoroli provided no reasons for differentiating between the services.⁷⁶ This contradiction and the lack of substantiating evidence prompted Yale Legal Services to sue the agency in federal district court in Connecticut. The suit sought a preliminary injunction to allow Jacinta Skubel, a child with severe disabilities, to use her home health services whenever her normal life activities took her into the community. Since her insurance would no longer pay for a nurse to go to school and Medicaid's place restrictions prohibited her from using those services to attend school, the action sought an injunction to allow her to remain in school and to travel in the community with her nurse.

The court granted a preliminary injunction lifting the place restrictions on Jacinta's home health services.⁷⁷ The court found that the plaintiff was likely

71. The State of Connecticut asked for an official statement of policy from HCFA following a request for clarification from Miriam Berkman, an attorney at Yale Legal Services. See Letter from Miriam Berkman to Sally Bowles (July 18, 1988), and Letter from Debbi Jo Garcia, Policy Consultant, to Miriam Berkman (Feb. 2, 1989) (relaying the federal government's response) (copies on file at Yale Legal Services).

72. *Detsel v. Bowen*, 1988 WL 101020 (N.D.N.Y.), *rev'd* by *Detsel v. Sullivan*, 895 F.2d 58 (2d Cir. 1990).

73. Letter from Alfred G. Fuoroli to Stephen Heintz, *supra* note 36.

74. *Detsel v. Sullivan*, 895 F.2d 58 (2d Cir. 1990).

75. Letter from Alfred G. Fuoroli, Associate Regional Administrator, HCFA, to Andrew S. Golub, Law Student Intern (Apr. 4, 1990) (on file at Yale Legal Services).

76. *Id.* Contrary to Mr. Fuoroli's contentions, however, the distinctions between the services strengthen the case for lifting the restrictions on home health services. Home health services are more intermittent than private duty nursing services. See 42 C.F.R. §§ 440.70 & 440.80. Therefore, the recipients of home health services are less disabled and more likely to be able to use their nursing services within the community to achieve integration.

77. *Skubel v. Sullivan*, No. N-90-279, 1990 WL 125170 (D. Conn. July 6, 1990) (order granting preliminary injunction).

to prevail on the merits because the Secretary's emphasis on the words "home health" was an insufficient explanation for the place restriction, and because it doubted that Congress intended to replace the "sterility and inflexibility characteristic of institutional settings with an equally sterile and inflexible setting."⁷⁸ Moreover, the court reiterated the *Detsel* court's holding that an agency may be required to respond to advances in technology and to the changing needs of the population served. The court stated that "in light of advances in medical technology which have made the provision of nursing care 'setting independent,' such a rigid formulation is unreasonable."⁷⁹

Despite this strong adverse ruling, the Department of Health and Human Services has continued to litigate the home health services restrictions. Yale Legal Services has amended the complaint in the case to include a class of all recipients of home health services, thus avoiding the duplicative lawsuits that occurred following *Detsel*.⁸⁰ That motion is pending as this Article goes to press.⁸¹

Throughout the litigation of these place restrictions, plaintiffs have benefited from a fortuitous combination of two factors: courts that are not willing to defer to mere assertions of costs by agencies and an agency that has no rational reason for its policy. Advocates, however, cannot rely on the continuation of these factors; closer cases may be thwarted by the deferential standard of review articulated by the Supreme Court in *Chevron USA v. Natural Resources Defense Council*.⁸² Under the *Chevron* standard, if the agency's choice is reasonable, the courts should not disturb the policy unless "the accommodation is not one that Congress would have sanctioned."⁸³

The implications of *Chevron* for future cases are unclear. If *Chevron* is read broadly, an agency that could show a slight increase in costs would be entitled to deference even if there were substantial benefits to a policy.⁸⁴ We

78. *Id.* at *5-6.

79. *Id.* at *6.

80. The class is defined broadly to include adults and children who receive home health services. The class is set forth as: "all persons in the United States who have been or in the future will be determined to be eligible for home health services by any state or territory receiving funds pursuant to the federal Medicaid Act, 42 U.S.C. § 1396 *et seq.*, and who, pursuant to the interpretations of the text of the federal Medicaid Act or its implementing regulations, have been or will be limited in the receipt of those home health services to the physical confines of their homes, and may thereby be prevented from engaging in normal life activities outside of their homes." First Amended and Substituted Complaint, *Skubel v. Sullivan*, No. N-90-279 (D. Conn. filed Nov. 5, 1990).

81. The federal government has shown no inclination to settle the case.

82. 467 U.S. 837 (1984). Judicial review of administrative policies has evolved to a standard of great deference. *Id.* (according "considerable weight" to agency interpretations). The *Chevron* case has been characterized as a "soft glance" at agency decisions as opposed to the "hard look" courts have applied in the past. See MASHAW & MERRILL, *supra* note 65, 1989 Supplement, at 109.

83. 467 U.S. at 845 (quoting *United States v. Shimer*, 367 U.S. 374, 382-83 (1961)).

84. Under *Chevron*, if a cost argument is articulated, it would be difficult for a court to find the policy to be one that Congress would not sanction. In *Detsel*, the Second Circuit noted that "economic considerations can provide an important basis for upholding congressional and regulatory action in this area." 895 F.2d at 65 (citations omitted). The *Detsel* court quoted the Supreme Court in *Califano v. Jobst*, "'General

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believe, however, that courts and Congress should require agencies to undertake a more thorough review of the costs and benefits when fundamental interests are at stake.⁸⁵ The agency's behavior throughout the litigation history indicates a need to require in-depth analysis. The next section of this Article is an example of such an analysis of the place restrictions on home health services.

III. THE CASE FOR COMMUNITY INTEGRATION

Community integration will not increase Medicaid costs. In fact, a detailed analysis reveals that lifting the 'at-home' restrictions may decrease public expenditures. These cost savings alone, however, are not large enough to motivate policymakers to lift the restrictions. An understanding of the multiple benefits of community integration—which include physical strengthening, opportunities for relationships and an increase in social acceptance—would provide the impetus needed to break the status quo. Most important, community-based services allow children with disabilities to exercise the freedoms that their able-bodied peers take for granted, such as attending school, movies, family outings, and other events. The combination of increased freedoms, multiple benefits and decreased costs calls for lifting this barrier to community integration.

A. The Costs of Community-Based Home Health Care

While many policymakers are concerned that increasing the quality of health care services will also increase costs, lifting the place restrictions on nursing care will have the opposite effect because Medicaid will no longer have to duplicate services already provided by other public agencies. Lifting the restrictions will also increase economic efficiency by allowing children to receive the full benefit of preexisting resources.

As the Second Circuit noted in *Detsel*, total public expenditures are increased when services already provided by the public schools have to be duplicated at home because a child's nurse is not permitted to accompany her

rules are essential if a fund of this magnitude is to be administered with a modicum of efficiency, even though such rules inevitably produce seemingly arbitrary consequences in some individual cases.” *Id.*

85. See *infra* notes 151-56 and accompanying text for an expanded discussion of this standard. The courts or Congress should require such a review to correct for possible biases in ascertaining costs and benefits. Martha McCluskey has argued that bias against people with disabilities informed the cost analysis of the Department of Transportation regarding accessibility for people with disabilities. Note, *supra* note 23, at 877. McCluskey also draws a parallel between feminist jurisprudence and jurisprudence for people with disabilities. In both cases, courts have found the needs of these groups “unmanageable.” McCluskey cites Professor Martha Minow for the insight that the “fears about the unmanageability of considering ‘different’ needs stem from a biased perspective.” *Id.* at 875 n.87 (citing Minow, *The Supreme Court, 1986 Term—Foreword: Justice Engendered*, 101 HARV. L. REV. 10, 68 (1987)).

to school.⁸⁶ Under the EHA, a home tutor, as well as computer equipment and toys used communally at school, may be required if a child is not able to attend school.⁸⁷ Moreover, the 'at home' limitation requires that Medicaid pay for services that would otherwise be funded by the EHA as related educational expenses.⁸⁸ For example, the EHA provides physical and occupational therapy to children attending public school as part of a normal school activity. School and therapy may thus be coordinated to provide the most efficient use of time and resources. When a child is unable to attend school, she must travel to a hospital to receive these services in isolation.⁸⁹ In addition, to the extent that school and community activities strengthen and stimulate the child, they reduce the necessary hours of Medicaid-funded special therapy.⁹⁰

As the district court noted in its preliminary injunction order for Jacinta Skubel, the government's policy significantly increases transportation costs as well.⁹¹ When Jacinta goes to the doctor or therapist, her father must take time off from work to drive Jacinta while her mother attends to her. While the state contends that state-subsidized transportation may be available to ease the financial burden on the family, such a policy is not cost-effective. Absent the place restrictions, Jacinta's nurse, who is already provided, could attend to the child while her mother drives to the appointments in the family car. Therefore, the government's policy unnecessarily burdens the family and prevents resources from being used most effectively.

The government's reluctance to lift place restrictions on home health services seems linked to a fear of the "woodwork effect," the theory that improved services will cause people to "come out of the woodwork," demand more services, and thus increase overall costs.⁹² An OTA report comparing home and hospital care, for example, states that "at least to some extent, enhanced home care benefits will replace family care rather than hospital or other institutional care."⁹³ The "woodwork" concern, however, appears to

86. *Detsel v. Sullivan*, 895 F.2d 58, 65 (2d Cir. 1990).

87. The EHA entitles every child to an appropriate education, including related services necessary for the child to benefit from his or her education. 20 U.S.C. § 1401(a)(17). Jacinta Skubel has learned to communicate with a computer. She can do this more effectively at school. In addition, her 'at-home' tutor brings as many toys as she can carry, but they are not comparable to the wide array of stimulation available at school. Affidavit of Patty Acampora, Jacinta Skubel's teacher, *Skubel v. Sullivan*, No. N-90-279 (D. Conn. 1990). If more toys and equipment are required at home as related educational services, the 'at home' tutoring will become an expensive policy.

88. See *supra* note 57 for a definition of "related services" under the EHA.

89. Dennis Pullen, a ten year old boy who is a quadriplegic and requires a ventilator, was restricted by the 'at home' limitation on his nursing services; as a result, Medicaid paid for occupational and physical therapy at a hospital that would have been provided by the school. First Amended Complaint at paragraph 38, *Pullen v. Cuomo*, No. 88-CV-774 (N.D.N.Y. filed June 22, 1990).

90. See *infra* notes 111-14 and accompanying text for a summary of the physical benefits of community integration and school attendance.

91. *Skubel v. Sullivan*, No. N-90-279, 1990 WL 125170 (D. Conn.) (order granting preliminary injunction).

92. TASK FORCE, *supra* note 3, at 12.

93. OTA REPORT, *supra* note 39, at 9.

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be unwarranted in the case of home health services.

Concern about a woodwork effect has two components: that children not currently receiving services will begin to request them and that children already receiving some care will request more. The first aspect, that children not currently receiving benefits will request them, is misplaced because the vast majority of children with severe disabilities are already receiving publicly-funded services. The Task Force on Technology-Dependent Children concluded that “[n]o significant ‘woodwork effect’ is likely for technology-dependent children meeting the Task Force’s definition because the severity of their conditions makes it unlikely that they would be unknown to tertiary medical care facilities in their areas.”⁹⁴ The Department of Health and Human Services will not, therefore, face an influx of new applications for nursing care from children who were not receiving any care.

The second concern, of requests for increased levels of services, is equally unlikely since current waiver provisions require that home care be cost-effective.⁹⁵ State agencies limit the number of nursing hours received at home to an amount equal to the cost of institutional care.⁹⁶ Those children who receive enough care to be close to their limit cannot increase their nursing hours without risking institutionalization. Thus, lifting the place restrictions cannot increase Medicaid costs for those children. Children who are not at their maximum level of allowable services are also unlikely to request increased nursing service,⁹⁷ since the regulations specifically require that the amount of nursing and other home health services be prescribed by a physician as part of a written care plan.⁹⁸ This stipulation assures that the nursing services will be provided according to medical need, not recipients’ demands.

Any possible “woodwork” effects can be constrained by states’ preexisting procedures for handling requests for increased nursing time.⁹⁹ Indeed, HCFA has instructed the states to use such measures to control costs for community-based private duty nursing services.¹⁰⁰ In her October 1990 memorandum, the Director of the Federal Medicaid Bureau lifted the place restrictions on

94. TASK FORCE, *supra* note 3, at 9.

95. 42 U.S.C. § 1396n(C) and 42 C.F.R. § 441 (1990).

96. Deposition of Linda Schofield, Director of Medical Care Administration, Department of Income Maintenance, at 19 (Feb. 26, 1991), *Skubel v. Sullivan*, No. N-90-279 (D. Conn. 1990).

97. The Connecticut State Department of Income Maintenance contends that while behavior cannot be predicted with certainty, the Department faces the risk of an increase of \$66,031,298 per year if all children expanded their services up to the cost-effective cap. State Defendants’ Response to Plaintiff’s First Set of Interrogatories at 7-8, *Skubel v. Sullivan*, No. N-90-279 (D. Conn. 1990). However, Ms. Linda Schofield, Director of Medical Care Administration, stated that she had no data to substantiate the claim that recipients would receive or require greater number of service hours if the place restrictions were lifted. Deposition of Linda Schofield, *supra* note 96, at 45-46.

98. 42 C.F.R. § 440.70 (1990).

99. The state of Connecticut reviews requests for increased hours to ensure that the hours are “medically necessary.” Deposition of Linda Schofield, *supra* note 96, at 47.

100. Memorandum, *supra* note 47, at 2.

private duty nursing and instructed that:

This clarification does not require States to authorize any additional hours of private duty nursing services for any individual than would ordinarily be permitted under the terms of its existing State plan. Any limitations imposed under the State plan, for example, maximum hour limits, remain in effect. In general, total time and payment allowed for such services is not expected to exceed that which would have been allowed strictly in a home setting.¹⁰¹

Thus, HCFA has determined that lifting the place restrictions on private duty nursing services will not increase costs. Applying HCFA's own logic to the case of home health services contradicts an assertion of increased costs. If lifting the place restrictions on private duty nursing is cost-neutral, then lifting them on home health would also be cost-neutral.¹⁰²

Cost-neutrality is consistent with Yale Legal Services' own experiences with home health services. In each of the cases brought by the clinic, the recipients did not request additional services, but asked only that the nursing services currently provided be available when their normal life activities take them into their community.¹⁰³ In the case of Jacinta Skubel, for example, the Connecticut Department of Income Maintenance has admitted that it has incurred no additional costs as a result of the preliminary injunction that allowed Jacinta to use her home health services in the community.¹⁰⁴

Allowing children who already receive home services to use them outside of their homes may be more than cost-neutral; it may generate enormous savings if improved services allow families to deinstitutionalize their children. The Task Force on Technology-Dependent Children concluded that "[r]ecent studies indicate that, for pediatric technology-dependent populations, community care is generally cost-effective, as compared with hospital care In some instances, savings in these programs have run as high as 50 percent."¹⁰⁵

The experience of the state of Maryland supports this proposition. The Maryland program permits children with medical technology needs to be cared for in the community instead of in the hospital. Administered by the Coordinating Center for Home and Community Care (CCHCC), the program provides extensive case management services and allows nurses to accompany the children to school. The CCHCC estimates that the sixty children receiving

101. *Id.*

102. *See supra* notes 37-38 and accompanying text for an explanation of the differences between the services and the implications of these differences on costs.

103. Complaint for Declaratory and Injunctive Relief, *Skubel v. Sullivan*, No. N-90-279 (D. Conn. filed June 4, 1990); Complaint in Intervention, *Skubel v. Sullivan*, No. N-90-279 (D. Conn. filed Dec. 21, 1990).

104. State Defendant's Answers to Plaintiff's First Set of Interrogatories at 8, *Skubel v. Sullivan*, No. N-90-279 (D. Conn. 1990). The state notes that costs have not increased because Jacinta is currently receiving the maximum hours she can receive under the cap that limits the total expenses of home care to the cost of institutional care.

105. TASK FORCE, *supra* note 3, at 66.

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services under the waiver have saved the state nearly two million dollars in the first two and one-half years of operation.¹⁰⁶ CCHCC policy analysts note that “since the cost remains the same to medicaid regardless of the location of the service delivery, providing nurses [at school] for these children had no additional financial impact.”¹⁰⁷

An experimental program in Florida also offers persuasive evidence that providing additional services can save money. In the “Rural Efforts to Assist Children at Home” (REACH) program, Medicaid provided pediatric nurses as case managers to help families make the best use of available services for their children with severe disabilities. The program reduced re-hospitalization and emergency room visits for these children, as compared with an equivalent group of children not receiving the case management service.¹⁰⁸

The above programs suggest that intelligent use of preexisting resources increases overall economic efficiency. Currently, children cannot receive the maximum benefit of the resources that the government makes available; the ‘at-home’ restriction prevents them from taking advantage of community programs that could improve the quality of their lives and ameliorate their medical conditions. By removing this regulatory barrier, the government could maximize the value of available resources, providing more utility for the same amount of dollars spent.¹⁰⁹

A thorough cost analysis must include efficiency gains, all possible cost savings, and a careful assessment of the likelihood that demand for the service will increase. Such an analysis of home health services indicates that lifting the place restrictions will be cost-neutral or cost-effective. Government agencies serving people with disabilities should be wary of unsubstantiated assumptions that policies that improve services will increase costs.

Cost analysis, however, must be accompanied by an equally rigorous evaluation of benefits. One of the tragedies of many Medicaid challenges is that they focus on issues of cost, while ignoring the enormous benefits to the people served. Many factors contribute to this emphasis on expense, including the standard for reasonableness in administrative law,¹¹⁰ tight budget constraints, and a failure to value people with disabilities. In the case of home

106. N. Bond & K. Lichtenstein, Coordinating Center for Home and Community Care, Position Paper: Nurses Funded Through Maryland Medicaid Accompanying Children to School 2 (1988).

107. *Id.* at 5.

108. Pierce & Freedman, *The REACH Project: An Innovative Health Delivery Model for Medically Dependent Children*, 12 CHILDREN'S HEALTH CARE 86 (1983).

109. Such inefficiencies are the result of a situation in which the entity defining the service (in this case the government) differs from the recipient who will realize the utility gain from a change in the service provided to her. Thus, the value of the change in policy is not correctly valued. This “externality” could arise from either a lack of communication between the government agency and the individuals which it is supposed to serve or a lack of concern by the government even when it is aware of the needs of its constituency. S. FISCHER & R. DORNBUSCH, *ECONOMICS* (1983).

110. As previously noted, the courts give great deference to agency arguments regarding costs and efficiency. *See supra* notes 82-84 and accompanying text.

health services, the costs of lifting the place restrictions are minimal or nonexistent, while the benefits are significant. The debate needs to be refocused to highlight the benefits side of the cost/benefit equation.

B. The Medical, Physiological and Developmental Benefits of Community-Based Care

Physicians note that children with severe disabilities are physically strengthened by the high level of stimulation that community-based services provide.¹¹¹ Since many of these children have short life expectancies, this strengthening is imperative for their survival. Consequently, a government that has an interest in preserving life must necessarily have an interest in promoting community-based care. As the Second Circuit noted in *Detsel*,

Dr. Gregory Liptak, Melissa's treating physician, insists that such limited home tutoring would be 'medically devastating' for Melissa. Dr. Liptak notes that the physical involvement and general activity level of Melissa's school program would be impossible to duplicate at home. Maximizing Melissa's physical development and stamina is essential, according to Dr. Liptak, 'to better prepare her for the rigors of transplant surgery if her respiratory function deteriorates.'¹¹²

Community-based care is particularly critical for young children. Because the brain matures rapidly in the first years of life, the education and treatment received during this period set the parameters of functioning throughout life.¹¹³

Another reason that community-based services may improve a child's medical treatment is that they allow a physician to gain a deeper understanding of the child's needs. For example, if a child attends school, the pediatrician can obtain crucial data about daily responses and abilities from teachers, therapists, social workers and others. Such treatment teams permit a more sophisticated course of treatment.¹¹⁴

Extending service provision outside of the home may also improve intellec-

111. See Affidavit of Dr. Philip Brunquell, Plaintiff's Motion for Preliminary Injunction, *Skubel v. Sullivan*, No. N-90-279, (D. Conn. 1990). Dr. Brunquell, the treating physician of Jacinta Skubel, is a pediatric neurologist at Newington Children's Hospital and the Director of the Clinical Neurophysiology Laboratories. He is Assistant Professor of Pediatrics and Neurology at the University of Connecticut School of Medicine. See also Affidavit of Doctor Gregory Liptak, Physician for Melissa Detsel, *Detsel v. Bowen*, 1988 WL 101020 (N.D.N.Y.). Dr. Liptak is certified in pediatrics by the American College of Pediatrics and has a subspecialty in Developmental Pediatrics. He is currently Associate Professor of Pediatrics at the University of Rochester Medical School and the Director of its Birth Defects Center.

112. *Detsel v. Sullivan*, 895 F.2d 58, 60 (2d Cir. 1990).

113. See Letter from Dr. Robert LaCamera, the treating physician of Travis Hardy, to Ms. Ann Mattioli, Fair Hearing Officer for the State of Connecticut Department of Income Maintenance (July 12, 1989) (noting that "[s]ince the maturation of his brain is concentrated in the earliest years of his life, the treatment and education that he receives now could well set the parameters of his life functioning") (copy on file at Yale Legal Services). Dr. LaCamera is a distinguished expert in the field of rehabilitation of disabled children. He is a faculty member at Yale Medical School and serves as medical consultant to the Area Cooperative Educational Services (ACES) program in New Haven. He is also the medical director of the Benhaven School for autistic and neurologically impaired children and the chairman of the Handicapped Child Committee of the Connecticut State Academy of Pediatrics.

114. *Id.* at 4-5.

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tual, psychological and social development. In one of the few studies of the social and intellectual development of severely disabled children, Richard P. Brinker and Margaret E. Thorpe found that the degree of integration with nondisabled students can often accurately predict educational achievement.¹¹⁵ The researchers studied 240 severely disabled students over the course of one school year by analyzing their written education evaluations and by directly observing the rate of interaction between nondisabled and disabled students. Brinker and Thorpe concluded that

it is time to move beyond discussion of whether integration is a positive or negative feature of educational plans for severely handicapped students. Integration appears to be a positive feature of such educational plans as found from this analysis of a large number of severely handicapped students in a relatively large number of schools.¹¹⁶

The results of this study are consistent with those of studies showing positive effects of integration for mentally retarded children.¹¹⁷ Such studies have demonstrated that when mildly mentally retarded children are integrated into a regular class, they model their behavior on their nondisabled peers and reduce violent behavior.¹¹⁸

Community-based services allow children with disabilities to form a healthy range of relationships, from casual to intimate, with people of all ages. An integrated classroom and playground provide these children with numerous opportunities to interact with and be accepted by students without disabilities. A recent Australian study, for example, reported that the children with disabilities interacted with nondisabled peers for fifty percent of the time sampled.¹¹⁹ Services that allow children to attend school also allow them to forge relationships with adult role models, such as teachers and aides.¹²⁰

Integration may also benefit children with disabilities by reforming the attitudes of nondisabled children. A study conducted in Hawaii administered attitudinal surveys to 2,636 second to seventh grade students attending schools with varying numbers of students with disabilities.¹²¹ The researcher conclud-

115. Brinker & Thorpe, *Integration of Severely Handicapped Students and the Proportion of IEP Objectives Achieved*, 51 EXCEPTIONAL CHILDREN 168 (1984). Under the EHA, the school board is responsible for convening a planning and placement team, usually composed of the child's teacher, parents, and school administrator. This team formulates an individual education plan (IEP) with a number of educational and developmental objectives. The authors used the proportion of the educational objectives achieved as the measure of educational achievement.

116. *Id.* at 173.

117. Roberts, Pratt & Leach, *Interaction of Students with Disabilities*, 57 EXCEPTIONAL CHILDREN 212 (1991); Gampel, Gottlieb & Harrison, *Comparison of Classroom Behavior of Special-Class EMR, Integrated EMR, LOW IQ, and Nonretarded Children*, 79 AM. J. MENTAL DEFICIENCY 16 (1974).

118. Gampel, Gottlieb & Harrison, *supra* note 117, at 16.

119. Roberts, Pratt & Leach, *supra* note 117, at 223.

120. *Dep't of Income Maintenance Fair Hearing Transcript* 30 (May 4, 1988) (statement of Dr. Robert LaCamera) (on file at Yale Legal Services).

121. Voeltz, *Children's Attitudes Toward Handicapped Peers*, 84 AM. J. MENTAL DEFICIENCIES 455 (1980).

ed that students without disabilities were most likely to indicate a desire to interact with children with disabilities if they were enrolled in a school where such interactions were possible.¹²²

Other studies have confirmed that children integrated with children with mental or physical disabilities have fewer prejudices and misconceptions. A study of 148 elementary children who were integrated with children with orthopedic disabilities showed a positive change in attitude.¹²³ The researcher noted that after integration, "handicapped children were seen as less weak and less in need of attention and help, i.e., orthopedically handicapped children were perceived as more able to care for themselves than originally thought."¹²⁴ A study that analyzed second and third graders' attitudes and understanding of autism before and after a week of daily half-hour play sessions with autistic children noted an increased understanding of autism as a result of the contact with these children. The degree of understanding was correlated to the frequency of communication between autistic and nonautistic children on the first day of interaction.¹²⁵

These studies suggest that the process of educational integration may result in a significant change in attitude and understanding. Perhaps one of the self-perpetuating problems with the government's 'at-home' restriction is that future legislators and administrators, the majority of whom do not have disabilities, are not integrated with children with disabilities from early childhood. They thus lack the opportunity to learn about the needs and capabilities of those with disabilities.

Moreover, integration may benefit the community as well as the children with disabilities.¹²⁶ Robert Brannigan, a school administrator, noted that having Melissa Detsel in the classroom benefitted her classmates and school:

 Melissa's presence in school also has carryover benefits to her classmates. Her determination and participation in classroom activities provides a very positive example for any under-achievers in her classes; her teachers report that Melissa is 'magic' to have in the classroom.¹²⁷

The foregoing demonstrates that children exhibit significant improvements in their medical, social, intellectual, and psychological development as a result of contacts with the community. Policies that allow children with severe disabilities to interact with members of the community also enhance the public's understanding of and sensitivities to their medical conditions. In a

122. *Id.* at 461.

123. Rapier, Adleson, Carey, & Croke, *Changes in Children's Attitudes Toward the Physically Handicapped*, 39 EXCEPTIONAL CHILDREN 219 (1972).

124. *Id.* at 222.

125. McHale & Simeonsson, *Effects of Interaction on Nonhandicapped Children's Attitudes Towards Autistic Children*, 85 AM. J. MENTAL DEFICIENCY 18 (1980).

126. Researchers have identified the community benefits from integration as a frontier for future investigation. Nisbet, Clark, & Covert, *supra* note 7, at 137.

127. *Detsel v. Sullivan*, 895 F.2d 58, 60 (2d Cir. 1990).

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cost/benefit analysis of services for children with disabilities, these significant gains weigh heavily in favor of integrated, community-based services.

C. The Civil Rights Aspect of Community Integrated Nursing Services

While the physical and psychological gains from integrated services are substantial, the policy analysis cannot end with these benefits. Important civil rights are also at stake: the right to travel, to free association, to family integrity, and to practice religion.¹²⁸ The disability rights movement is unlike other civil rights movements in part because people with disabilities may require specific services. Nevertheless, a discussion about the needs of children with disabilities cannot focus merely on the costs of those services, but must include a discussion of rights and liberties.

A civil rights perspective recognizes that services afforded to a group without social and political power will often be inferior if they are provided in a segregated setting.¹²⁹ It suggests, for example, that the education provided at home to children with severe disabilities often will be inferior to the education provided at school.¹³⁰ Yet, children subject to the 'at-home' limitation are more than segregated: they are entirely denied the opportunity to engage in activities most people regard as routine. They cannot go to a movie or a family picnic; they cannot form friendships with non-family members; they cannot attend religious services. Interpreting the children's desire to participate in these activities as a request for "extra" services reveals a prejudice in favor of the able-bodied, since these are activities that able-bodied people do not consider "extra" in their own lives.¹³¹

A civil rights perspective recognizes that people often discriminate against

128. A broad view of "liberty" was articulated by Justice McReynolds in *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923): "Without doubt, [liberty] denotes not merely freedom from bodily restraint but also the right of the individual to contract, to engage in any of the common occupations of life, to acquire useful knowledge, to marry, establish a home and bring up children, to worship God according to the dictates of his own conscience, and generally to enjoy those privileges long recognized at common law as essential to the orderly pursuit of happiness by free men." The right to travel has been recognized by the Court, *Aptheker v. Secretary of State*, 378 U.S. 500 (1964) (striking down legislation prohibiting Communists from travel as violating Fifth Amendment liberty); the right to freedom of association has been expanded beyond the first amendment to a broader right in the realm of "freedom of intimate association," *Roberts v. United States Jaycees*, 468 U.S. 609 (1984).

129. See *Brown v. Board of Education*, 347 U.S. 483, 494 (1954) (recognizing the inferiority of racially segregated schools); Note, *supra* note 23, at 876 n.94 (special segregated transportation system for people with disabilities inferior and stigmatizing).

130. Jacinta Skubel's teacher testified to the inferior education provided in a segregated setting. Affidavit of Patty Acampora, *Skubel v. Sullivan*, No. N-90-279 (D. Conn. 1990). Jacinta's physician, Travis Hardy's physician, and Melissa Detsel's physician all testified that home-bound education was inferior. See *supra* notes 111-12 and accompanying text.

131. For an in-depth analysis of the able-bodied prejudice in perceiving services for the disabled as "extra" or "exceptional," see Note, *supra* note 23, at 875.

and do not wish to associate with those who are different.¹³² It is the responsibility of the government to protect disfavored groups by recognizing their right to be included.¹³³ The 'at-home' restriction, however, undercuts this ideal by actively excluding children with disabilities. These children thus learn from an early age that they are different and will be limited, not only by their medical conditions, but also by governmental barriers.¹³⁴

Courts have recognized a very limited right to services to protect the fundamental liberties of those dependent on the state.¹³⁵ While arguing a constitutional claim to community-based services under the fifth and fourteenth amendments would be extremely complex and beyond the scope of this Article, a brief sketch is useful to outline both the role of the state in these children's lives and the liberty interests at stake.¹³⁶

Children with severe disabilities are in a unique position relative to the government. First, they are not entirely in the custody of their parents because their placement at home is contingent on the state's provision of life-sustaining medical services, yet they are not entirely in state custody because they reside at home. The state thus has more responsibility toward these children than to

132. There is ample evidence of prejudice against people with disabilities. *See generally* TASK FORCE ON THE RIGHTS AND EMPOWERMENT OF AMERICANS WITH DISABILITIES, *EQUALITY FOR 43 MILLION AMERICANS WITH DISABILITIES: A MORAL AND ECONOMIC IMPERATIVE* (1990) (excerpts from hearings in which people with disabilities testified to discrimination and prejudice).

133. Justice Stone suggested in a famous footnote that the Court may have to afford heightened scrutiny because "prejudice against discrete and insular minorities may be a special condition, which tends seriously to curtail the operation of those political processes ordinarily to be relied upon to protect minorities." *United States v. Carolene Products*, 304 U.S. 144, 153 n.4 (1938). The Supreme Court declined to apply heightened scrutiny in a case involving mentally retarded plaintiffs. *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432 (1985). The Court found that mentally retarded people were different from others because of their cognitive disability and thus they are presumptively treated differently by legislation. Justice Marshall dissented and noted that while the Court objected to the label of "heightened scrutiny," it took a more careful look than it had in other cases. Justice Marshall labelled this a "second order" rational test. *Id.* at 458 (Marshall, J., dissenting). The Supreme Court has not ruled directly on the appropriate level of scrutiny for people with physical disabilities.

134. The Supreme Court noted that in the race context, "to separate them from [children] of similar age and qualifications solely because of their race generates a feeling of inferiority as to their status in the community." *Brown v. Board of Educ.*, 347 U.S. 483, 494 (1954).

135. *See Youngberg v. Romeo*, 457 U.S. 307, 324 (1982) (granting residents of an institution the rights to safety, to freedom from undue restraint, and to the training needed to protect these rights); *Society for Good Will to Retarded Children v. Cuomo*, 737 F.2d 1239 (2d Cir. 1984) (extending rights of residents of a school for mentally retarded children to include the right to training to prevent self-deterioration); *Thomas S. by Brooks v. Flaherty*, 902 F.2d 250 (4th Cir.) (extending right to training to those released from hospital whose rights had been violated while in state custody), *cert. denied*, 111 S.Ct. 393 (1990).

136. The cases that recognize a right to limited services have been brought under the equal protection clause of the fourteenth amendment. Since the Medicaid interpretation is federally imposed, the challenge in this case might have to be brought under the fifth amendment. In *DeShaney v. Winnebago County Dep't of Social Services*, 109 S.Ct. 998 (1989), the Supreme Court noted that "[l]ike its counterpart in the Fifth Amendment, the Due Process Clause of the Fourteenth Amendment was intended to prevent government 'from abusing [its] power, or employing it as an instrument of oppression.'" *Id.* at 1003 (quoting *Davidson v. Cannon*, 474 U.S. 344, 348 (1986)). *See also* *Bolling v. Sharpe*, 347 U.S. 497 (1954) (holding that racial discrimination in public schools in the District of Columbia violates due process of law guaranteed by the fifth amendment because the concepts of due process and equal protection are not mutually exclusive and both stem from notions of fairness).

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others who are in the custody of their parents.¹³⁷ Whether a court would hold that this degree of state control mandates a level of care is an open question.¹³⁸ Nonetheless, the state's control over the children's lives is an important reason for Congress and courts to scrutinize carefully governmental policies that affect them.

Second, it is unclear whether the freedoms at issue here reach the level of constitutionally protected freedoms that mandate services.¹³⁹ Courts have held that institutionalized people have a right to bodily safety, freedom from undue restraint and the training needed to prevent deterioration.¹⁴⁰ Strapping mobile people into wheelchairs has been considered a form of undue restraint.¹⁴¹ Perhaps restricting children in their homes is a similar undue restraint. In addition, while courts have held that institutionalized people have a right not to deteriorate, children who are institutionalized from an early age and denied services do not develop these minimal self-care skills to then protect from deterioration. One judge has argued that the right to be free from deterioration should be expanded into a right to attain minimal skills if plaintiffs are children.¹⁴² Like children confined to institutions, children subject to the place restrictions are unable to develop minimal skills.

A rights-based analysis would take into account the gravity of the consequences of an 'at home' restriction to these children and the state's responsibility to them. Agencies, courts and Congress should use the impact on basic liberties to require greater scrutiny of agency policies or to establish a presumption in favor of ensuring the greatest degree of freedom.

A comprehensive analysis of disability policy cannot ignore the dynamic that renders people with disabilities a disadvantaged group in society. As two commentators noted, "It is as if the study of disability were reduced to vocational counseling or rehabilitation medicine. Imagine confusing gynecology with the study of women in society or dermatology with the study of racism."¹⁴³ The indifference and neglect directed toward those with disabilities is a convincing explanation for the agency's policy restricting the provision

137. Compare the children with severe disabilities to the plaintiff in *DeShaney*, 109 S.Ct. 998, who was released by the state to the custody of his father after his parents divorced. The Court held that the state did not have in that case a responsibility to protect the child's welfare because he remained in his father's custody.

138. The *DeShaney* Court noted that "[t]he affirmative duty to protect arises not from the State's knowledge of the individual's predicament or from its expression of intent to help him, but from the limitation which it has imposed on his freedom to act on his own behalf." 109 S.Ct. at 1006.

139. The Supreme Court has held that even persons constitutionally due some rights to safe conditions and freedom from undue restraint are due only limited services to protect those freedoms. *Youngberg*, 457 U.S. at 324.

140. *Id.* at 324.

141. *Society for Good Will to Retarded Children v. Cuomo*, 737 F.2d 1239, 1247 (2d Cir. 1984).

142. See Judge Becker's concurring opinion in *Clark v. Cohen*, 794 F.2d 79, 96 (3d Cir. 1986), for a detailed analysis of the right of children to attain those minimal skills.

143. Lifchez & Davis, *What Every Architect Should Know*, in M. EISENBERG, C. GRIGGINS, & R. DUVAL, *supra* note 23, at 93.

of services.

People with disabilities historically have suffered discrimination.¹⁴⁴ Policymakers should use this history of political disempowerment and prejudice to establish a strong presumption against policies that segregate and devalue people with disabilities. As Yale Legal Service's current litigation indicates, such a presumption is needed to focus the debate away from the narrow issue of cost.

IV. RECOMMENDATIONS

We will make mistakes if we go forward, but doing nothing can be the worst mistake. What is required of us is moral ambition. Until our composite sketch becomes a true portrait of humanity we must live with our uncertainty; we will grope, we will struggle, and our compassion may be our only guide and comfort.¹⁴⁵

There are numerous ways to remove the 'at-home' restriction from home health nursing services. Some solutions narrowly focus on the Medicaid interpretation, while others provide a broader framework for improving services for people with disabilities. Federal agencies, Congress, and the courts all offer opportunities for solutions.

A. Judicial Review of Agency Practice

An analysis of *Detsel v. Sullivan*¹⁴⁶ reveals three ways courts can respond to the claims of children with severe disabilities. First, the *Detsel* court emphasized that the plaintiff was a child with developmental as well as medical needs. The opinion quoted extensively from an affidavit of Robert Brannigan, Melissa Detsel's school administrator, which described the child in the classroom and the benefits that she receives from school instruction.¹⁴⁷ The court also noted the medical advice of Melissa's physician regarding the physical, psychological and developmental benefits of attending school in her community.¹⁴⁸ This recognition of the human characteristics of the child, as well as the multiple benefits of community-based services, is exemplary and should be followed by other courts.

Second, the court's opinion expanded upon prior case law, which mandated

144. See *supra* note 132. See also Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 1990 U.S. CODE CONG. & ADMIN. NEWS (104 Stat.) 327 (to be codified at 42 U.S.C. §§ 12101-12211). In this Act, Congress found that "historically, society has tended to isolate and segregate individuals with disabilities, and despite some improvements, such forms of discrimination. . . continue to be a serious and pervasive social problem." *Id.*

145. *DeShaney v. Winnebago County Dep't of Social Services*, 109 S.Ct. 998, 1012 (1989) (Blackmun, J., dissenting) (quoting A. Stone, LAW, PSYCHIATRY, AND MORALITY 262 (1984)).

146. 895 F.2d 58 (2d Cir. 1990).

147. *Detsel*, 895 F.2d at 60.

148. *Id.*

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that agencies' policies reflect the current state of technology in areas such as trucking, appliances, television, and medical practices.¹⁴⁹ The court stated, "agencies must interpret their regulations in light of changing circumstances, particularly in areas characterized by rapid technological development."¹⁵⁰ It thus required the agency to provide both the current medical equipment and the nursing services that were needed to make full use of the advanced equipment and to allow travel in the community. This critical link is an important precedent for disability rights advocates.

Third, the *Detsel* court carefully scrutinized the agency's rationale for its policy by strictly interpreting the "reasonableness" test. Courts have traditionally used this "reasonableness" standard when they review informal rulemaking or agency actions.¹⁵¹ The standard of reasonableness covers a wide spectrum—from accepting any possible justification for a policy to requiring evidence to support such explanations.¹⁵² Recently, the Supreme Court took a deferential stance when reviewing environmental regulations.¹⁵³ The implications of that decision for future administrative law cases are unclear, however, because the decision did not eliminate courts' discretion in choosing the degree of scrutiny and because the holding could be limited to the facts of that case. The *Detsel* court, for example, chose to be exacting and examined each of the agency's contentions thoroughly.¹⁵⁴

The *Detsel* court did not articulate a basis for its careful review. Future

149. The *Detsel* court, 895 F.2d at 64, relied upon *American Trucking Ass'n v. Atchison, T. & S.F. Ry.*, 387 U.S. 397, 416 (1967) ("flexibility and adaptability to changing needs and patterns of transportation is [sic] an essential part of the office of a regulatory agency"); *City of Akron v. Akron Center for Reproductive Health, Inc.*, 462 U.S. 416 (1983) (advances in medicine undermine reasonableness of regulations); *American Civil Liberties Union v. FCC*, 823 F.2d 1554, 1565 (D.C. Cir. 1987) ("we would not expect the Commission to adhere blindly to regulations that are cast in doubt by new developments or better understanding of the relevant facts"), *cert. denied*, 485 U.S. 959 (1988).

150. *Detsel*, 895 F.2d at 64.

151. In contrast, formal rules are reviewed under a "substantial evidence" test, § 706(2)(E) of the APA. Congress and the courts have treated the "substantial evidence" test as more stringent than the test for arbitrariness. However, both standards regarding rules are more exacting than the rationality test applied to legislation. *Motor Vehicle Mfrs. Ass'n v. State Farm Mut. Auto. Ins. Co.*, 463 U.S. 29, 43 & n.9 (1983). For a general discussion of the traditional presumptions regarding these tests, see J. MASHAW & R. MERRILL, *supra* note 65, at 333.

152. *Compare* *Automotive Parts & Accessories Ass'n v. Boyd*, 407 F.2d 330 (D.C. Cir. 1968) (careful inquiry into agency's decision to require installation of safety device) and *Nat'l Tire Dealers & Retreaders Ass'n v. Brinegar*, 491 F.2d 31 (D.C. Cir. 1974) (intensive review of NHTSA's tire rules) with *Chevron, USA v. NRDC*, 467 U.S. 837 (1984) (deferential analysis of EPA regulations on air pollution). Also, note that the district court and court of appeals in the *Detsel* case purported to use the same tests but reached different conclusions. *Detsel v. Bowen*, 1988 W.L. 101020 (N.D.N.Y.); *Detsel v. Sullivan*, 895 F.2d 58 (2d Cir. 1990).

153. *Chevron*, 467 U.S. 837, called into question the standard of review for agency rules. In *Chevron*, the Court adopted the deferential position that the Court should not disturb the agency's decision "unless it appears from the statute or its legislative history that the accommodation is not one that Congress would have sanctioned." 467 U.S. at 845 (quoting *United States v. Shimer*, 367 U.S. 374, 383 (1961)). Many commentators have noted the inconsistency between the "soft glance" accorded to the regulation in *Chevron* as opposed to the "hard look" the Court took in other cases. J. MASHAW & R. MERRILL, *supra* note 83, supplement at 109.

154. See *supra* notes 60-63 and accompanying text.

courts, however, could determine the appropriate level of scrutiny by assessing the degree of political disempowerment of the plaintiffs, the nature of the harm and the extent of the infringement on liberty interests. One commentator has addressed the issue of judicial scrutiny of agency rulemaking and suggested, "[c]ourts should, first of all, reserve their closest scrutiny for rules least likely to be subject to effective political discipline. . . courts should be most sensitive to the plaint of the unorganized beneficiary of regulatory protection and the adversarially disadvantaged public assistance recipient."¹⁵⁵ These criteria would be particularly helpful for disabled individuals who often lack political power and depend on the state for the means to enjoy their liberty interests.¹⁵⁶ Moreover, the agency's weak explanations for the place restrictions on nursing services indicate a need for heightened scrutiny in similar cases.

B. Congressional Oversight of Agency Practice

The most obvious solution to the problems facing technology-dependent children subject to place restrictions is for HHS to rewrite or reinterpret the regulation governing home health care services¹⁵⁷ in light of current nursing practices, the *Detsel* opinion, and the recent Congressional amendment to home health care services. As the extensive litigation history indicates, however, HCFA has not been willing to reevaluate its policy. Thus, if the courts do not invalidate the 'at home' restriction on nursing services, congressional oversight will be the only other recourse. Congressional oversight could take place informally, by a review of important subcommittees in the House and Senate,¹⁵⁸ or formally, in legislation that unequivocally requires that Medicaid home health nursing services be provided in the community.¹⁵⁹

In November of 1990, Congress amended the Medicaid statute to include personal care services as one of the services under the category of home health services and to lift HCFA's place restrictions on such services.¹⁶⁰ Whether the statutory language lifts the restriction on only this subset of home health

155. Diver, *The Optimal Precision of Administrative Rules*, 93 YALE L.J. 65, 108 (1983).

156. See *supra* notes 128-144 and accompanying text for discussion of state control in the lives of children with disabilities and the policy's infringement on civil liberties.

157. 42 C.F.R. § 440.70.

158. The Senate Finance Committee, the Senate Committee on Labor and Human Resources and the House Committee on Energy and Commerce are a few committees that have been involved in Medicaid or developing policies to aid children with severe disabilities. The latter two committees commissioned the Task Force Report on Technology-Dependent Children. TASK FORCE, *supra* note 3. The report specifically recommended setting independent, community-based services. *Id.* at 42. These committees could work with HCFA to implement the report's findings.

159. In her ruling on a preliminary injunction against the 'at-home' limitation, Judge Burns indicated that Congress in effect spoke to the issue when it authorized home health services in order to encourage alternatives to institutionalization. She noted that it would be anomalous for Congress to intend to replace institutionalization with an "equally sterile and inflexible setting." *Skubel v. Sullivan*, No. N-90-279, 1990 WL 125170 (D. Conn. July 6, 1990) at 16 (preliminary injunction ruling).

160. Omnibus Reconciliation Act of 1990, Pub. L. No. 101-508, § 4721, 104 Stat. 1388 (1990).

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services or on all home health services remains an issue of statutory construction for the agency and the courts. The agency should construe the amendment as governing all home health services; when it rewrites the regulation governing home health services to add personal care services, it should also explicitly state that home health nursing services can be provided outside of the home.

There are, moreover, more broad-based legislative possibilities that would address the fundamental problems that gave rise to the 'at-home' restrictions. For example, Congress could mandate that HCFA produce a "disability impact" report to justify its policies. In *Alexander v. Choate*,¹⁶¹ the Supreme Court defined such a statement as a requirement "to evaluate the effect on the handicapped of every proposed action . . . and then to consider alternatives for achieving the same objectives with less severe disadvantage to the handicapped."¹⁶² The evaluation could include a cost/benefit analysis similar to that set forth in Section III of this Article.

The Supreme Court speculated that allowing claims under section 504 of the Rehabilitation Act, a statute that prohibits discrimination against the disabled, to challenge Medicaid policies would in effect require such a "handicap impact" statement for each policy, which would impose an undue administrative burden on the states that the Act had not specifically required.¹⁶³ Congress, however, could specifically legislate that HCFA must prepare such a report. This would not be more burdensome than present practice because it would avoid subsequent litigation to force the agency to conduct such an analysis to justify its policies.¹⁶⁴ Moreover, claims of administrative infeasibility may stem from a bias that presumes that considering the effect of policies on people with disabilities will be more burdensome than considering the effects on people without disabilities.¹⁶⁵

Medicaid is a particularly important target for such a report because of its tendency to focus on medical treatment to the exclusion of developmental needs. This tendency often biases Medicaid recommendations toward institutionalization in hospitals and long-term care facilities. In 1986, the National Council on the Handicapped recommended that Congress require HCFA to

161. 469 U.S. 287 (1985).

162. *Alexander v. Choate*, 469 U.S. at 298.

163. *Id.* at 298-99. The Court noted that Congress did not require such a statement in the statute, as they had in other legislative initiatives such as the National Environmental Policy Act, 42 U.S.C. § 4321 *et. seq. Id.*

164. As the *Detsel* court noted, "Congress delegates substantial authority to administrative agencies principally because agencies, given time and experience, acquire a special sensitivity to the evolving needs in the regulated field" *Detsel v. Sullivan*, 895 F.2d 58, 64 (2d Cir. 1990). Since the agency is not acquiring this sensitivity, Congress must mandate a procedure to assure that the agency acquire this knowledge.

165. Martha McCluskey has suggested that claims of administrative infeasibility in the disability policy area stem from bias. She writes that "[c]onsidering effects of policies on people with disabilities should not be presumed more troublesome than considering effects of policies on nondisabled people." Note, *supra* note 23, at 876.

conduct a study to examine its institutional biases and to develop appropriate corrective measures.¹⁶⁶ Two years later, in a follow-up report, the Council noted again that

[a]n extraordinary amount of the Medicaid funds administered by the Health Care Financing Administration (HCFA) is spent on nursing services and other long-term institutions that primarily provide custodial maintenance for disabled individuals. The Council believes that strictly maintenance-oriented institutional programming is indefensible and unnecessary.¹⁶⁷

The policy to restrict the provision of Medicaid home health nursing services to the physical confines of the home is a form of maintenance-oriented institutional programming. Congress should require that HCFA identify and eliminate such provisions.

Congress could also require that Medicaid implement state-of-the-art services to foster community integration,¹⁶⁸ such as those mandated for educational services under the Education for All Handicapped Children Act of 1975.¹⁶⁹ HCFA should be required to implement procedures to assure that the agency will acquire and integrate information and research findings on innovations in community-based services.

The federal government has suggested that state governments currently hold the solution to providing community-based services, as they can request community-based home health services under the home and community-based waiver, section 1915 of the Social Security Act.¹⁷⁰ While some states have developed innovative programs using the waiver system,¹⁷¹ there are a number of problems that make this approach inappropriate.

First, states find the HCFA waiver procedures confusing and time consuming.¹⁷² Researchers investigating pediatric home care note that the massive

166. NATIONAL COUNCIL ON THE HANDICAPPED, TOWARD INDEPENDENCE 45 (1986).

167. NATIONAL COUNCIL ON THE HANDICAPPED, ON THE THRESHOLD OF INDEPENDENCE 79 (1988). See also Gerry & McWhorter, *A Comprehensive Analysis of Federal Statutes and Programs for People with Severe Disabilities*, in CRITICAL ISSUES IN THE LIVES OF PEOPLE WITH SEVERE DISABILITIES 495, 509-11 (L. Meyer, C. Peck & L. Brown ed. 1991); TASK FORCE, *supra* note 3, at 42; OTA REPORT, *supra* note 39, at 58.

168. Frank Laski, an advocate for children with disabilities, has suggested that "strong state-of-the-art criteria should be imposed in all programs" having an impact on those with disabilities. Laski, *Achieving Integration During the Second Revolution*, in CRITICAL ISSUES IN THE LIVES OF PEOPLE WITH SEVERE DISABILITIES 409, 418 (L. Meyer, C. Peck & L. Brown ed. 1991).

169. Congress required training and procedures for disseminating information from current research and demonstration projects. Education for All Handicapped Children's Act of 1975, 20 U.S.C. § 1413(a)(3)(A).

170. See Federal Defendants' Opposition to Plaintiff's Motion for Preliminary Injunction at 13, Skubel v. Sullivan, No. N-90-279 (D. Conn. 1990) (noting "the relief plaintiff seeks is within the State's discretionary authority to offer under section 1915(c) of the Social Security Act.") See also letter from Alfred Fuoroli to Stephen B. Heintz, *supra* note 36, explaining, "With respect to other Federal provisions under which such services rendered in a school setting could be included as a covered Medicaid services, you may wish to consider requesting a waiver under section 1915 of the Social Security Act and 42 CFR 441.300 ff."

171. See previous discussion of the Maryland waiver program and the Florida REACH project, *supra* notes 106-08 and accompanying text.

172. OTA REPORT, *supra* note 39, at 66.

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documentation and numerous revisions to applications have made states reluctant to pursue the waiver option.¹⁷³ In response to inquiries about Medicaid coverage of home health services in the community, a Medicaid Policy Consultant at the Connecticut Department of Income Maintenance stated that

a new waiver does not appear to be a viable solution for this long-standing issue. The 1915(c) waiver process is extremely cumbersome and subject to Connecticut legislative review and approval as well as HCFA's review and approval every five (5) years. There are also limited conditions of eligibility and this option would serve only a subset of the population who may require these services.¹⁷⁴

In addition, the Commissioner of the Department noted that the regulations for a waiver require that "individuals in need of waiver services require such services to avoid institutionalization."¹⁷⁵ She further stated that the real issue is not the risk of institutionalization, but the ability to receive a "free and appropriate education."¹⁷⁶ A waiver therefore would not address the needs of children who wanted to travel in the community, because these services are not necessary to avoid institutionalization.

The waiver program is also irrelevant for children who receive Medicaid services categorically rather than by waiver. These children could not take advantage of the community-based services that could theoretically be provided to other children under the waiver system, with the anomalous result that children with greater family resources would get better services from Medicaid than their poorer peers. Moreover, the waiver program is termed an "exception" program.¹⁷⁷ According to the Report of the Task Force on Technology-Dependent Children, "[m]ost current community-based care is delivered under 'exceptions' to normal reimbursement policies."¹⁷⁸ In order for people with disabilities to become part of our communities, they must have access to services designed for integration. Community-based services must become the rule, not the exception. Liberty and freedom to travel are not considered the exception for any other group in our society.

The restriction on home health nursing services is just one of many problems facing families and children with severe disabilities. A thorough discussion of the continuing barriers to deinstitutionalizing and integrating technology-dependent children is beyond the scope of this Article.¹⁷⁹ It should be

173. L. ADAY, M. AITKEN & D. WEGENER, PEDIATRIC HOME CARE RESULTS OF A NATIONAL EVALUATION OF PROGRAMS FOR VENTILATOR ASSISTED CHILDREN 15 (University of Chicago Continuing CHAS Research Series No. 36, 1988).

174. Letter from Debra Jo Garcia to Miriam Berkman, *supra* note 71.

175. Letter from Lorraine Aronson, Commissioner of the Department of Income Maintenance, to Miriam Berkman, Yale Legal Services (April 18, 1989) (on file at Yale Legal Services).

176. *Id.*

177. See letter from Alfred Fuoroli to Stephen Heintz, *supra* note 36, stating that nursing services will not be extended to the community "without an exception such as a waiver."

178. TASK FORCE, *supra* note 3, at 69.

179. Two large reports have been compiled on the subject and readers should refer to these reports for a comprehensive discussion of potential solutions. See TASK FORCE, *supra* note 3 and OTA REPORT, *supra* note 39.

noted, however, that two of the most serious remaining impediments to community-based care for children with severe disabilities are a lack of case management services and delayed Medicaid reimbursements to the states.¹⁸⁰

Congress commissioned the Task Force on Technology-Dependent Children to conduct a comprehensive study on the barriers to community-based care,¹⁸¹ and their insightful report was published in April, 1988.¹⁸² Yet neither Congress nor administrative agencies have implemented the Task Force's long-term suggestions, including the provision of "setting independent" educational and developmental services.¹⁸³ Until Congress and administrative agencies address the needs of these children, services will be provided in a sporadic, inefficient, and uncoordinated manner. The children and their families cannot afford to wait as we litigate and argue. They should not have to wait. They deserve a humane policy that focuses on community integration and family-oriented programming.

CONCLUSION

When Yale Legal Services began litigating these cases involving 'at-home' restrictions on nursing services, we kept asking each other why the Department of Health and Human Services was fighting this issue. More than two years later, we are asking the same question and we still have no answer.

Some argue that the government must seek to contain costs and litigate issues if there is even a slight chance that costs may increase. But such a policy is short-sighted. In this case, even a cursory assessment would show that the risk of increased cost is virtually nonexistent; indeed, lifting the restrictions may actually reduce costs. Moreover, the costs of litigation and of lost opportunities for children with short life expectancies are absolutely certain. These children deserve a more thoughtful balancing of harms and benefits by the agency that controls their lives.

We conclude with a quotation from Lewis Golinker, the attorney for Melissa Detsel, who has been litigating these issues for years. His words summarize for us the motivations and frustrations of advocates for children with severe disabilities.

Maybe talking about Melissa, Dennis, Tim and Jacinta as kids rather than cases

180. TASK FORCE, *supra* note 3, at 33 (noting that the single most important aspect of appropriate care is case management and identifying the current barriers in provision of that service); *see also id.* at 69 for an in-depth discussion of financial barriers. Some pediatricians of children with severe disabilities have concluded that the greatest future challenge to providing community-based health care is developing a comprehensive reimbursement policy. Goldberg, Faure, Vaughn, Snarski, & Seleny, *Home Care for Life-Supported Persons: An Approach to Program Development*, 104 J. PEDIATRICS 785, 786-87 (1984).

181. Consolidated Omnibus Reconciliation Act of 1985, Pub. L. No. 99-272, § 9520, 100 Stat. 217 (1986).

182. TASK FORCE, *supra* note 3.

183. TASK FORCE, *supra* note 3, at 42.

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is what leaves me so unsettled . . . Kids are curious. They can't grow by T.V. or books alone. Their life requires that they see and touch the outside; it is an essential part of their ability to become "people." We are not fighting for them to be "students." These cases . . . should not have any real focus on school access. It is all the little things, far more than school, that make all of us, my son and these technology dependent children, people, that make life worthwhile. I continue to be dumbfounded that we have to fight about this . . . It is amazing to me that our government, which we so blindly accept as being "made" with our interests in mind, can be so unthinking, uncaring and certain of its correctness.¹⁸⁴

184. Letter from Lewis Golinker to Andrew Golub (June 29, 1990) (on file at Yale Legal Services).