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# RIGHTS FOR DEVELOPMENTALLY DISABLED CITIZENS: A PERSPECTIVE FOR THE 80s

H. Rutherford Turnbull, III\*

#### **AUTHOR'S PREFACE**

The article that follows this preface was completed in December, 1980. Events since its completion render it somewhat dated; although its analyses remain valid, its premise—that the federal government would remain active in the lives of developmentally disabled people—is highly debatable nowadays. In this preface, I address the debate. In the article, I address a future that might still be but is increasingly less likely. I have not addressed the legislation passed or rejected by the 1980-81 Congress (97th Congress, 1st Session).

A crisis of major proportions looms before developmentally disabled people in the wake of the November, 1980 elections. The current debate about the federal budget is not the crisis, only symptomatic of it. The true crisis is not even the future relationship of the federal government to mentally handicapped citizens. It is—one would have thought the issue is beyond cavil—whether mentally and other disabled citizens are expendable, whether the benefits of this rich country should go only to the most meritorious, where merit equates with intelligence or physical capacity or both. The relationship is the pivot for the real debate and, as such, is worthy of our careful scrutiny. Indeed there is no more propitious time than now to examine that relationship and its prospects. To fail to do so would be to concede that the relationship is ill conceived; it would be to acquiesce to the present Administration's vindictive injustice, its attempt to redefine it. I will analyze the relationship and argue that it must be maintained in the face of the immediate frontal attack upon it. To permit an atrocious distortion of that relationship, such as is now proposed, would be to jettison disabled citizens from the community of humane people.

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As pointed out below, the federal-citizen relationship is a direct one, one in which the federal government acts directly for, with, and upon handicapped people. There is a compelling reason for the direct federal-citizen relationship. Quite simply, it is that a handicap is a distinction that makes a difference in a person's life; it is a characteristic that not only justifies but also requires a special relationship of the federal government to handicapped citizens. All too often, the handicapped citizen has been denied an opportunity for education, employment, community residence, and other opportunities that nonhandicapped people take for granted. And the denial has been occasioned solely by reason of the fact that the person is handicapped. State and local governments either have not served these citizens at all or have served them only inadequately and, in important ways, unconstitutionally. Were it not for their handicaps and the ways those handicaps have burdened them in state-local governments' activities, handicapped citizens would not be able to lay such a compelling claim to the direct relationship. Because of their handicaps and a bitter state-local history, the relationship must be continued.

The present relationship of the federal government to handi-capped people takes five different forms. First, in order to help them cope with the extraordinary demands of handicaps, the federal government provides direct assistance to handicapped people and their families as, for example, by the provisions of the Social Security Act granting financial aid to disabled people, social services for needy handicapped citizens, and medical-care assistance to incomeeligible disabled people. Second, to discover ways of ameliorating or preventing handicaps, it performs a leadership role in research, model program demonstration, and training in areas of vital importance to handicapped people; the National Institute of Health and the National Institute of Habilitation Research are but two examples of this role. Third, the federal government induces and assists states in adopting and maintaining such essential cost-effective and humane state-local services as education, vocational training, and institutional and community housing. Next, the federal government assures handicapped people that they will have rights to services; the Education for All Handicapped Children Act and the Developmentally Disabled Assistance and Bill of Rights Act illustrate this role. In a sense, antidiscrimination laws, such as section 504 of the Rehabilitation Act, also assure services. Finally, it assures handicapped people that they will have the means to acquire and enjoy their

rights; to this end, Congress has established and funded the Legal Services Corporation and, under the DD Assistance and Bill of Rights Act, the "protection and advocacy" systems and state planning councils for developmentally disabled citizens.

Should the unique direct relationship between the federal government and its developmentally disabled citizens be allowed to continue? In its omnivorous appetite for simplicity, its constitutional intolerance for complexity, the present Administration proposes to change the relationship dramatically. In essence, it would substitute "block grants" for "categorical grants" to state and local governments in the following areas: education, social services, health, preventive health, and energy and emergency assistance. To put it another way, federal programs that directly and indirectly benefit developmentally disabled citizens would be consolidated with each other and with programs for other citizens, and federal financial assistance, presently required to be spent for disabled people, would be spent on them only in the unlimited discretion of state and local governments.

The Administration favors block grants because they purportedly will 1) reduce the costs of administering federal, state, and local programs; 2) reduce the burdens of regulations; and 3) increase the flexibility available to state and local governments in serving, or not serving, handicapped citizens. There is, however, another way of looking at block grants, particularly if one's major concern is with the life-time status of developmentally disabled citizens. A careful analysis of these platitudes will show them to be as barren for developmentally disabled citizens as a desert.

A hallmark of block grants is the unfettered discretion they give to state and local governments to spend none, some, or all of the federal money on retarded and other handicapped citizens. Given that developmentally disabled citizens are a minority of relatively powerless handicapped people, they have no assurances that they will receive the benefit of any federal funds. This prospect is made more real because, under the education and social services block grants, their present rights to service (e.g., under the Education for All Handicapped Children Act and the Developmental Disabilities Bill of Rights Act) would be repealed. Without rights to service, they will have no leverage to require any federally financed services.

(1) It is not justifiable to approach administrative costs-savings by imposing unacceptable consequences on developmentally disabled citizens. Nor is it clear that administrative costs would be

substantially reduced by block grants. Block grants will not assure increased state and local government efficiency; indeed, many administrative costs are incurred solely because of state and local regulations, not federal ones. Federally financed programs still will have to be administered; the planning and coordinating functions of state DD planning councils still will be required. Unlike present federal categorical-grant laws, block grants will not impose a ceiling on administrative costs; there will be no assurances that more money will be spent for direct-service purposes. And, even if one assumes a 10% administrative cost saving, the reduction of federal aid by 25%, coupled with an inflation rate of nearly 10%, will still result in 25% less money for direct services.

- (2) Under the pretense of "reducing regulatory burdens," block grants actually repeal developmentally disabled citizens' federally assured rights to federally financed services. For example, the education block grant will repeal the Education for All Handicapped Children Act, P.L. 94-142; the social services block grant will repeal the Developmental Disabilities Bill of Rights, the protection and advocacy systems, the Legal Services Corporation, and the ICF-MR program. These rights and their implementing regulations are necessary because they enable developmentally disabled citizens and their representatives to cure the default of state and local governments to serve them at all or serve them adequately; they implement these citizens' federal constitutional rights; and they set professionally sound standards for state and local governments.
- (3) The claim that block grants will grant state and local governments increased flexibility undoubtedly is true. But with such expansive flexibility, state and local governments can choose not to serve developmentally disabled people at all or at diminished levels; they can substitute federal money for state and local money, thereby reducing the overall level of services for such citizens; and they can shift the taxing responsibility to local governments. To do this is to incur the likelihood of a Proposition 13 response; this in turn would be to the detriment of disabled and all other dependent citizens, including many nonhandicapped ones, and to the likely detriment of members of Congress who endorse—and will come to rule—the shift of responsibility. The voters cannot be so easily fooled.

More dramatic, however, would be the irresponsible overall effect of block grants, as presently proposed, on mentally disabled citizens. Unless the block grant concept is abandoned or substantially modified, it will cause intolerable adversities for these citizens and

their families. In fact, block grant proposals are nothing less than a frontal assault on the network of services that constitutes the only guarantee that developmentally disabled citizens will not be consigned to lives of unwarranted and unnecessary indignity, frustration, nonproductivity and dependency.

Preventive services—prenatal care, maternal and child health, elimination of lead-based paint causes of retardation, and genetic disease counselling—will be consolidated into block grants (H.R. 2562, 3223 and 3224 and S. 1027, 1028, and 1102.) By subjecting preventive services to competition with direct services for reduced federal money, they insure lower funding of prevention and, in the long run, higher costs of care.

The education block grants (S. 1103 and H.R. 3645) will, among other things, consolidate early childhood programs; repeal the Education for All Handicapped Children Act (P.L. 94-142); repeal the federal education assistance to institutionalized children (P.L. 89-313); target education money only for severely handicapped children; and fold in teacher training programs of national significance. These grants will jeopardize and, in some instances, completely abolish the basic right of handicapped children to an appropriate public education.

The social services block grant will repeal the Developmentally Disabled Assistance and Bill of Rights Act, the Rehabilitation Act, and Title II of the Social Security Act; it also will consolidate and make discretionary such important programs as DD, child abuse, foster care and adoption, and social and child welfare services and training. Its impact will be catastrophic. Developmentally disabled people will lose assurances to such essential programs as vocational rehabilitation, supplemental security income, social security disability payments, and representation by the Legal Services Corporation because all of these programs are marked for elimination; they may be deprived of the benefit of planned services because the State Developmental Disabilities Councils may be discontinued; they can expect that they will lose the protection of the antidiscrimination regulations implementing section 504 of the Rehabilitation Act because the act is targeted for repeal; and they can expect such newly authorized services as the subsidy for hard-to-place children will never be launched.

By repealing rights-granting laws (e.g., the Education for All Handicapped Children Act and the Developmental Disabilities Assistance and Bill of Rights Act); by making ICF-MR programs

optional; and by withdrawing mandates for protection and advocacy systems and authority for the Legal Services Corporation, block grants make it unlikely that developmentally disabled citizens will have any way to enforce their constitutional rights. For them, that sturdy oak, the Constitution, would be whittled into a toothpick.

By making education and vocational training optional, block grants remove any assurances of cost-effective training. They make it possible—perhaps likely—that developmentally disabled citizens will be made more dependent and more costly to care for.

By making the ICF-MR program optional, they make it possible for states to avoid the life-safety and staff-resident ratio standards that make for humane and constitutionally acceptable institutions and community-based facilities. They also make it probable that states, facing the demands to keep their large institutions, will deliver federal money into them, to the exclusion of community-based programs; in short, they may put the brakes on institutional reform and deinstitutionalization.

By putting personnel preparation and training money in the jurisdiction of state educational and social service agencies, themselves consumers of higher education, they make it difficult to expect that nationally significant innovations in training and demonstration models will occur.

By allowing states to abandon foster care, adoption, and child abuse programs, they directly and immediately jeopardize the well being of developmentally disabled children and their families.

Like most excesses of vogues, the Administration's proposals overreach themselves; they are anodynes whose potential to harm surpasses the likelihood they will temporize our pain. These "consolidation programs" wholly vitiate the direct relationship of the federal government to developmentally disabled people. They entirely disregard the fact that a handicap is a distinction that makes a difference, that justifies a special relationship between the federal government and retarded people. They blindly ignore two important facts of history: many states never performed these services or performed them inadequately. At the insistence of fanatical ideologues, they overgenerously and incorrectly interpret the 1980 election results—there was no mandate to repeal the special relationship to special citizens. With unblemished chicanery, they attempt to sell a cruel hoax to states, local governments, and the electorate—that fewer services will indeed satisfy the interests of the citizenry.

In short, the health, education, and social services block grants are apocalyptic for developmentally disabled citizens. If enacted, they would reverse years of progress.

#### INTRODUCTION

The law affecting mentally retarded and other developmentally disabled people (hereafter referred to as "disabled") has become increasingly labyrinthian in the last several years. Professional and consumer consensus over goals and strategies has been rent nearly asunder. An incremental judicial retrenchment, coupled with the failure of the 96th Congress to enact important mental retardation-developmental disabilities legislation and incipient Reaganism, make it timely to reexamine the nature of the recent rights movement, including the nature of recent legislation, some of the future legislative issues, and some of the policy dilemma raised. These factors strongly suggest that a major issue of the next several years will be the enforcement of existing rights. In that connection, the private bar has an indispensable role.

This article will analyze the nature of the rights movement, the enforcement issues, and the potential role of the private bar. It is hoped that it will serve at least two purposes: to provide an analytical framework for thoughtful approaches to law benefitting disabled citizens, and to serve as a background for the other articles in this symposium issue of the *Law Journal*.

#### I. THE NATURE OF THE RIGHTS MOVEMENT

A. The Nature of Recent Legislation. Although any effort to establish a taxonomy of law concerning disabled citizens is risky,<sup>5</sup>

<sup>1.</sup> See generally Mentally Retarded People and the Law, 31 STAN. L. REV. 541 (1979).

<sup>2.</sup> See H. Turnbull, Law and the Mentally Retarded Citizen: American Responses to the Declarations of Rights of the United Nations and International League of Societies for the Mentally Handicapped—Where We Have Been, Are, and Are Headed, 30 Syracuse L. Rev. 1093, 1139-43 (1979).

<sup>3.</sup> See E. Breslin, Backlash Against the Disabled, 4 MENTAL DISABILITY L. REP. 345 (1980).

<sup>4.</sup> Child Health Assessment Act, S. 1204, 96th Cong., 1st Sess., 125 Cong. Rec. S6407 (daily ed. May 22, 1979); Child Health Assurance Act, H.R. 4962, 96th Cong., 1st Sess., 125 Cong. Rec. H11767 (daily ed. Dec. 11, 1979); Fair Housing Amendments Act of 1979, S. 506, 96th Cong., 1st Sess., 125 Cong. Rec. S1938 (daily ed. March 1, 1979); Fair Housing Amendments Act of 1979, H.R. 5200, 96th Cong., 1st Sess., 125 Cong. Rec. H7428 (daily ed. Sept. 6, 1979).

<sup>5.</sup> E. Boggs, A Taxonomy of Federal Programs Affecting Developmental Disabilities, X Mental Retardation and Developmental Disabilities 214 (1978).

classification nevertheless is essential. For the purposes of this article, there are four major types of legislation.

1. Rights to Services or Substantive Benefits. Much of the legislation establishes a qualified right to service or substantive benefits. Examples of such legislation include federal and state right-to-education laws,<sup>6</sup> employment-related rights,<sup>7</sup> rights to treatment<sup>8</sup> or against treatment,<sup>9</sup> rights against involuntary commitment<sup>10</sup> or institutionalization,<sup>11</sup> rights to residential placement in the least restrictive alternative setting,<sup>12</sup> rights to life<sup>13</sup> and even to a healthy life,<sup>14</sup> and rights to reproductive freedom.<sup>15</sup> These rights are not absolute, especially when they are created by courts relying on various statutory or constitutional grounds. The Supreme Court's decision in the

<sup>6.</sup> Education for All Handicapped Children Act, 20 U.S.C. §§ 1412(5)(B), 1414(a)(1)(C)(iv) (1976), and Turnbull, supra note 2, at 1109.

<sup>7.</sup> Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. §§ 6001-6081 (1976 & Supp. III 1979); Rehabilitation Act of 1972, 29 U.S.C. §§ 701-796i (1976 & Supp. III 1979); Fair Labor Standards Act, 29 U.S.C. § 214(c) (1976).

<sup>8.</sup> Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. §8 6001-6081 (1976 & Supp. III 1979); Jackson v. Indiana, 406 U.S. 715 (1972); Covington v. Harris, 419 F.2d 617 (D.C. Cir. 1969); Rouse v. Cameron, 373 F.2d 451 (D.C. Cir. 1966); Eubanks v. Clarke, 434 F. Supp. 1022 (E.D. Pa. 1977); Dixon v. Weinberger, 405 F. Supp. 974 (D.D.C. 1975); Welsch v. Likins, 373 F. Supp. 487 (D. Minn. 1974), aff'd in part and vacated in part, 550 F.2d 1122 (8th Cir. 1977); New York Ass'n for Retarded Children, Inc. v. Rockefeller, 357 F. Supp. 752 (E.D.N.Y. 1973); Horacek v. Exon, 357 F. Supp. 71 (D. Neb. 1973); Lessard v. Schmidt, 349 F. Supp. 1078 (E.D. Wis. 1972), rev'd on other grounds, 414 U.S. 473 (1974); Wyatt v. Stickney, 344 F. Supp. 387 (M.D. Ala. 1972), aff'd in part and rev'd in part sub nom. Wyatt v. Aderholt, 503 F.2d 1305 (5th Cir. 1974); Dixon v. Attorney General, 325 F. Supp. 966 (M.D. Pa. 1971); Lake v. Cameron, 267 F. Supp. 155 (D.D.C. 1967).

<sup>9.</sup> Rogers v. Okin, 478 F. Supp. 1342 (D. Mass. 1979), rev'd in part, 634 F.2d 650 (1st Cir. 1980); Rennie v. Klein, 462 F. Supp. 1131 (D.N.J. 1978).

<sup>10.</sup> Vitek v. Jones, 445 U.S. 480 (1980); O'Connor v. Donaldson, 422 U.S. 563 (1975); Jackson v. Indiana, 406 U.S. 715 (1972); Lessard v. Schmidt, 349 F. Supp. 1078 (E.D. Wis. 1972), rev'd on other grounds, 414 U.S. 473 (1974).

<sup>11.</sup> Secretary of Public Welfare v. Institutionalized Juveniles, 442 U.S. 640 (1979); Parham v. J.R., 442 U.S. 584 (1979).

<sup>12.</sup> Medley v. Ginsberg, 492 F. Supp. 1294 (S.D. W. Va. 1980); Wuori v. Zitnay, No. 75-80-SD (D. Maine June 2, 1980); Kentucky ARC v. Connecticut, No. C78-0157 L(A) (W.D. Ky. March 21, 1980).

<sup>13.</sup> Bothman v. Warren B. (*In re* Phillip B.), 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980); Superintendent of Belchertown State School v. Saikewicz, 373 Mass. 728, 370 N.E.2d 417 (1977).

<sup>14.</sup> See, e.g., Curlender v. Bio-Science Laboratories, 106 Cal. App. 3d 811, 165 Cal. Rptr. 477 (1980); Stills v. Gratton, 55 Cal. App. 3d 698, 127 Cal. Rptr. 652 (1976).

<sup>15.</sup> Doe v. Bolton, 410 U.S. 179 (1973); Roe v. Wade, 410 U.S. 113 (1973); Eisenstadt v. Baird, 405 U.S. 438 (1972); Stanley v. Georgia, 394 U.S. 557 (1969); Griswold v. Connecticut, 381 U.S. 479 (1965); Skinner v. Oklahoma, 316 U.S. 535 (1942); Pierce v. Society of Sisters, 268 U.S. 510 (1925); and Meyer v. Nebraska, 262 U.S. 390 (1923).

Pennhurst case, 16 discussed in Boyd's article in this issue of the Journal, failed to define the rights against institutionalization and to placement in the least restrictive alternative setting. Based on the Court's earlier decisions in O'Connor v. Donaldson, 17 in which it predicated its holding on a right-to-liberty ground and cast doubt on its willingness to follow the right-to-treatment principle; Parham v. J.R., 18 in which it established the primacy of parental and professional rights over minors' liberty, due process, and "least restriction" rights, and Vitek v. Jones, 19 in which it arguably watered down procedural due process safeguards in involuntary commitment cases, it was unlikely that the Court would have sustained the district court's wholesale attack on mental retardation institutions. Indeed, the Parham-Pennhurst strategy—to prevent minors' institutionalization and cause the dismantling of large state institutions for retarded people—had been less than unequivocably successful in Parham and there was little reason to suspect it would prevail in the final decision in Pennhurst.

2. Rights Not to be Subject to Discrimination. It is one thing to be the beneficiary of substantive rights because of a handicap; it is quite another to be protected from discrimination on the basis of a handicap. The former recognizes a disabled person's claim to an affirmative benefit; the latter, while sometimes taking various postures,<sup>20</sup> represents an affirmative attempt to put the disabled person on a roughly equal footing with nonhandicapped people.

Section 504 of the Rehabilitation Act Amendments of 1973,<sup>21</sup> the most comprehensive of the nondiscrimination acts, is successful in terms of creating substantive rights. It is fraught, however, with procedural and enforcement difficulties.<sup>22</sup> Section 504 and its implementing regulations grant rights of access to facilities (the so-called "barrier-free" provisions)<sup>23</sup> and services.<sup>24</sup> The regulations

<sup>16.</sup> Pennhurst State School & Hosp. v. Halderman, 101 S. Ct. 1531 (1981).

<sup>17. 422</sup> U.S. 563 (1975).

<sup>18. 442</sup> U.S. 584 (1979).

<sup>19. 445</sup> U.S. 480 (1980). But cf., Addington v. Texas, 441 U.S. 418 (1979) (standard of proof and procedures).

<sup>20.</sup> See, e.g., the "reasonable accommodation" requirements in the employment regulations to Section 504 of the Rehabilitation Act of 1973, 34 C.F.R. §§ 104.11-.14 (1980). Cf. Southeastern Community College v. Davis, 442 U.S. 397 (1979), on the duty of a person (university) to the handicapped wherein the Court held there is no affirmative action.

<sup>21. 29</sup> U.S.C. §§ 701-796i (1976 & Supp. III 1979), 34 C.F.R. § 104 (1980).

<sup>22.</sup> See infra Part II-D.

<sup>23. 34</sup> C.F.R. § 104.12 (1980).

<sup>24. 34</sup> C.F.R. §§ 104.11-.14, 104.31-.39, 104.41-.47, 104.51-.54 (1980).

also grant rights to equal, nondiscriminatory treatment in other areas. In employment,<sup>25</sup> the enforcement picture is muddied in part because of how the courts view who is qualified for employment notwithstanding the presence of a handicap<sup>26</sup> and in part because the courts have limited the application of section 504 to a limited class of people<sup>27</sup> and have created procedural obstacles to ready enforcement.<sup>28</sup> In preschool, elementary, and secondary education,<sup>29</sup> judicial enforcement is promising.<sup>30</sup> In postsecondary education,<sup>31</sup> judicial enforcement seems to be on the right track.<sup>32</sup> In health and social services,<sup>33</sup> the pattern of judicial enforcement is not clear.<sup>34</sup>

Other legislative efforts in the area of nondiscrimination fared poorly. In the opinion of some, the 96th Congress weakened the right of access to mass transit by enactment of the Dole Amendment,<sup>35</sup> and the courts seem divided over the vigor with which they will enforce transportation nondiscrimination legislation.<sup>36</sup> After a

<sup>25. 34</sup> C.F.R. §§ 104.11-.14 (1980).

<sup>26.</sup> See, e.g., Carmi v. Metropolitan St. Louis Sewer Dist., 620 F.2d 672 (8th Cir. 1980), cert. denied, 101 S. Ct. 249 (1980); H. TURNBULL, THE LAW AND THE MENTALLY HANDICAPPED IN NORTH CAROLINA, ch. 11 (2d ed. 1979).

<sup>27.</sup> Compare Trageser v. Libbie Rehabilitation Center, Inc., 590 F.2d 87 (4th Cir. 1978), cert. denied, 442 U.S. 947 (1979) and Carmi v. Metropolitan St. Louis Sewer Dist., 620 F.2d 672 (8th Cir. 1980), cert. denied, 101 S. Ct. 249 (1980) with Hart v. Alameda County Probation Dep't, 485 F. Supp. 66 (N.D. Cal. 1979).

<sup>28.</sup> See infra Part II-D.

<sup>29. 34</sup> C.F.R. §§ 104.31-.39 (1980).

<sup>30.</sup> See New Mexico Ass'n for Retarded Citizens v. New Mexico, 495 F. Supp. 391 (D.N. M. 1980); Gurmankin v. Costanzo, 411 F. Supp. 982 (E.D. Pa. 1976), aff'd, 566 F.2d 184 (3d Cir. 1977), 626 F.2d 1115 (3d Cir. 1980) (on the issue of remedies); Mattie T. v. Holladay, No. D.C. 75-31-5 (N.D. Miss. July 28, 1975); cf. Camenisch v. Univ. of Texas, 616 F.2d 127 (5th Cir. 1980), vacated and remanded, 101 S. Ct. 1830 (1981).

<sup>31. 34</sup> C.F.R. §§ 104.41-.47 (1980).

<sup>32.</sup> Compare Southeastern Community College v. Davis, 442 U.S. 397 (1979) (limited holding) with Camenisch v. Univ. of Texas, 616 F.2d 127 (5th Cir. 1980), vacated and remanded, 101 S. Ct. 1830 (1981) (on the question of how much burden a university bears). See also Crawford v. Univ. of North Carolina, 440 F. Supp. 1047 (M.D.N.C. 1977); Barnes v. Converse College, 436 F. Supp. 635 (D.S.C. 1977).

<sup>33. 34</sup> C.F.R. §§ 104.51-.54 (1980).

<sup>34.</sup> See NAACP v. Medical Center, Inc., 599 F.2d 1247 (3d Cir. 1979); Sites v. McKenzie, 423 F. Supp. 1190 (N.D.W. Va. 1976).

<sup>35.</sup> The Dole Amendment to the Transportation Appropriations Act for FY '81, Pub. L. No. 96-400, 94 Stat. 1681, states that the Zorinsky Amendment to S2720, 96th Cong., 2d Sess., 126 Cong. Rec. S8174 (daily ed. June 25, 1980, legislative day June 12, 1980), shall take effect even though S2720 was not enacted. The Zorinsky Amendment gives a locality certain flexibility, based on population size, about the extent to which its mass transportation system must be accessible to the handicapped.

<sup>36.</sup> See Leary v. Crapsey, 566 F.2d 863 (2d Cir. 1977); United Handicapped Fed'n v. Andre, 558 F.2d 413 (8th Cir. 1977); Lloyd v. Regional Transportation Auth., 548 F.2d 1277 (7th Cir. 1977); Atlantis Community, Inc. v. Adams, 453 F. Supp. 825 (D. Colo. 1978); Vet-

bitter last-minute fight, the same Congress also failed to enact fair housing laws that would have protected handicapped citizens from discrimination in residential choices.<sup>37</sup>

3. Entitlement and Eligibility Legislation. By far the most common legislation assisting disabled citizens is the type which grants benefits to persons who meet certain entitlement or eligibility criteria. Like legislation or court decisions that create rights to service or other substantive benefits, entitlement/eligibility laws acknowledge and advance disabled citizens' claims to affirmative rights; unlike such legislation or court decisions, however, entitlement/eligibility legislation creates means tests or other pass-fail standards.

Typical of this type of legislation is the protean Social Security Act. Among other things, the Act provides federal financial assistance to income-eligible disabled people through dependents' benefits<sup>38</sup> as well as to such people in their own rights through Supplemental Security Income—"SSI"—payments.<sup>39</sup> It also provides federal financial assistance to qualifying individuals to help offset their medical expenses<sup>40</sup> and to supply them with certain social services.<sup>41</sup> The 96th Congress' enactment of the Disability Insurance and SSI Amendments<sup>42</sup> improves the program by allowing more disabled people to receive SSI benefits and to earn more money and still retain SSI benefits; it also extends Title XX Social Services to disabled SSI recipients even after they are no longer eligible for SSI benefits. The Congress also reauthorized Title XX for

erans of America v. Coleman, 451 F. Supp. 7 (E.D. Mich. 1977); Vanko v. Finley, 440 F. Supp. 656 (N.D. Ohio 1977); Philadelphia Council of Neighborhood Organizations v. Coleman, 437 F. Supp. 1341 (E.D. Pa. 1977), aff'd without opinion, 578 F.2d 1375 (3d Cir. 1979); Snowden v. Birmingham-Jefferson County Transit Auth., 407 F. Supp. 394 (N.D. Ala. 1975), aff'd without opinion, 551 F.2d 862 (5th Cir. 1977).

<sup>37.</sup> Fair Housing Amendments Act of 1979, S. 506, 96th Cong., 1st Sess., 125 CONG. REC. S1938 (daily ed. March 1, 1979, legislative day Feb. 22, 1979); Fair Housing Amendments Act of 1979, H.R. 5200, 96th Cong., 1st Sess., 125 CONG. REC. H7428 (daily ed. Sept. 6, 1979).

<sup>38.</sup> Federal Old Age, Survivors, and Disability Insurance Benefits, 42 U.S.C. §§ 402(d), 403 (1976 & Supp. III 1979); 20 C.F.R. §§ 404.415, .416, .320, .429 (1980).

<sup>39.</sup> Supplemental Security Income for the Aged, Blind and Disabled, 42 U.S.C. §§ 1381-1383 (1976 & Supp. III 1979); 20 C.F.R. §§ 416.231, .901, .1101, .1125, .1136, .1201, .1205 (1980).

<sup>40.</sup> Grants to States for Medical Assistance, 42 U.S.C. § 1396 (1976 & Supp. III 1979).

<sup>41.</sup> Grants to States for Services, 42 U.S.C. § 1397 (1976 & Supp. III 1979), 45 C.F.R. § 228 (1978).

<sup>42.</sup> Social Security Disability Amendments of 1980, Pub. L. No. 96-265, 94 Stat. 441.

five more years.<sup>43</sup> Unlike the medical-expenses reimbursement portion of the act (Medicaid-Title XIX), the social services portion (Title XX) is not open-ended; that is, Congress has set a financial ceiling on Title XX.

Other entitlement/eligibility legislation affects housing for disabled citizens by establishing various loan and subsidy programs;<sup>44</sup> job training under the CETA program;<sup>45</sup> minimum nutrition guarantees through the food stamp program;<sup>46</sup> and vocational rehabilitation<sup>47</sup> and education.<sup>48</sup>

- 4. Rights to Enforcement. Finally, Congress and the courts have created various avenues whereby disabled citizens may enforce their rights to services or other substantive benefits, their rights not to be subject to discrimination, and their rights to entitlement/eligibility benefits. Since these will be discussed in detail in Part II of this article, it will suffice here to mention that the federal right-to-education law (P.L. 94-142, the Education for All Handicapped Children Act<sup>49</sup>), section 504, and provisions of the Civil Rights Act<sup>50</sup> are the major enforcement statutes. The extent of their availability is, however, uncertain (see Part II).
- B. Nature of Law Reform. To establish these rights, it has been necessary to use three separate techniques of law reform. Good illustrations of these techniques are available in special education law.

The first technique is to extend to handicapped people the same rights as are available to nonhandicapped people. This technique reflects a pure "equal treatment" ideology: handicapped and nonhandicapped people should be treated exactly alike in the eyes of

<sup>43.</sup> Adoption Assistance and Child Welfare Act of 1980, Pub. L. No. 96-272, 94 Stat. 500.

<sup>44.</sup> Housing and Community Development Act, 42 U.S.C. § 1437 (1976), 24 C.F.R. §§ 885.1-.425 (1980); Housing Act, 12 U.S.C. § 1701q (1976 & Supp. III 1979), 24 C.F.R. §§ 277.1-.11 (1980).

<sup>45.</sup> Comprehensive Employment and Training Act, 29 U.S.C. §§ 871(b), 876 (Supp. III 1979).

<sup>46.</sup> The Food Stamp Act, 7 U.S.C. § 2011 (1976 & Supp. III 1979), 7 C.F.R. §§ 271-279 (1981).

<sup>47.</sup> Rehabilitation Act of 1973, 29 U.S.C. §§ 701-796i (1976 & Supp. III 1979).

<sup>48.</sup> Vocational Education Amendments to the Elementary and Secondary Education Act, 20 U.S.C. §§ 2301-2461 (1976 & Supp. III 1979).

<sup>49.</sup> Education for All Handicapped Children Act, 20 U.S.C. §§ 1401-1461 (1976 & Supp. III 1979).

<sup>50.</sup> Civil Rights Act, 42 U.S.C. §§ 1983, 1988 (1976).

the law. The rule of equal treatment is reflected in some of the major principles of the Education for All Handicapped Children Act, P.L. 94-142. The principle of zero reject, whereby no handicapped child should be excluded from a free appropriate public education on account of his handicap, however severe it may be and whatever its nature, is an equal treatment technique because it requires the schools to educate both handicapped and nonhandicapped students.

The second technique is to make available to handicapped people the same rights as are available to nonhandicapped people, but to do so only after making modest adaptations. The adaptations take into account that the handicapped person may not fully benefit from exactly equal treatment because of his handicap. This technique requires incremental deviation from pure equal treatment. It reflects equal treatment "plus" adaptations. A good example of this technique in P.L. 94-142 is the requirement for IEPs—individualized educational programs—and related services. (The IEP may also illustrate the third technique of law reform, but it will be used here as an illustration of the second.) The IEP is the linchpin of an appropriate education; it defines who will be providing what kind of services to a handicapped child and the manner in which he will be educated appropriately. Unlike nonhandicapped children who do not have a right to an IEP and for whom public schools are assumed to be appropriate, handicapped children must have an IEP (an incremental deviation from the same treatment given to nonhandicapped children) because public schools cannot be assumed to be appropriate for them; instead, they must be made appropriate. Likewise, handicapped children have the right to "related services" (such as physical and occupational therapy, social work services, psychological services, medical evaluation, speech therapy, and audiological services) if these services are necessary for them to benefit from specially designed instruction. The right to related services rests on the assumption that public school education, even special education, may not be effective unless accompanied by other services. The contrary assumption with nonhandicapped children is that public school education will be appropriate and they therefore do not need any additional or "related" services.

The final technique is to enact legislation that takes into account the fact that a handicapped person may not be able to benefit fully from adaptations in programs because of the nature or extent of his handicap. Legislation of this type makes available to handicapped people special and substantially different opportunities or

rights than those available to nonhandicapped people. In special education law, the requirement of "nondiscriminatory evaluation," to determine the nature and extent of a child's handicap, and "procedural due process," the right to a hearing if schools do not satisfy a handicapped child's other rights, illustrate this technique. Nonhandicapped children are not given nondiscriminatory evaluations because it is assumed that they do not need to be assessed carefully; they have no handicaps and thus no special characteristics that require special education. Also, nonhandicapped children do not have the same due process rights as handicapped children because it is assumed that their rights—to be included in school, to a fair evaluation, to an appropriate education, and to placement in beneficial programs—will not be as often jeopardized as handicapped children's.

The basic concept underlying the second and third techniques is really quite simple: exactly equal treatment may not be sufficient to make rights truly available to handicapped people or to prevent schools from discriminating against them on account of their handicaps. That being the case, different or special treatment may be necessary to assure handicapped people an equal educational opportunity.

- C. Future Issues in Federal Legislation. It should be apparent from the foregoing that the rights movement by no means achieved all its goals. Discussed below are three areas for future federal legislation that now seem most critical to the ultimate success of the movement. These relate directly to community-based efforts to educate handicapped children in the community, to deinstitutionalize traditional institutions, to prevent unnecessary or inappropriate institutionalization, and to foster least restrictive but enhancing rights to community or home-based residential choices.
- 1. Residential Services. Until quite recently, the most typical residential setting for a significant number of disabled people was "the institution"—a state-operated facility with a large number of residents.<sup>51</sup> In part because of the right-to-treatment, right-against-treatment, and least-restriction cases,<sup>52</sup> and in part because of an

<sup>51.</sup> Address by Paul Marchand, Executive Director, National Governmental Affairs Office, Association of Retarded Citizens, 1522 K. Street, N.W., Suite 516, Washington, D.C. 20005, Considerations for Mental Retardation Residential Programming (November 24, 1980).

<sup>52.</sup> See cases cited note 8 supra.

ideological revolution that rejects such institutional placement,<sup>53</sup> there has been a gradual shift from traditional institutional or athome care to creating a variety of residential options within "the community."

The process of deinstitutionalization has been hampered by professional, parental, and community disagreement concerning (a) the role of the traditional institution in the continuum of residential services and (b) the extent to which community-living arrangements ("CLAs") should be available for all disabled people. It also has been impeded by the difficulty in financing CLAs, particularly in assembling a wide variety of federal funding sources to serve a particular CLA program, and by insufficient planning for their development and for deinstitutionalization of residents. The practical difficulties also are great.

SSI and the traditional social security insurance benefits are available to some disabled people; some even benefit from both programs.<sup>54</sup> But neither payment is sufficient for a person to live alone.<sup>55</sup> The section 202 loan program for housing construction, renovation, and acquisition and the section 8 rental assistance program, both administered by the Department of Housing and Urban Development, have helped. In the last two years alone, \$140 million were awarded in loans for non-elderly handicapped people, allowing about 5,000 individuals, of whom about 25% are retarded, to live in group homes or small apartment complexes.

Title XX (social services), the Developmental Disabilities program's CLA priority,<sup>56</sup> the Independent Living Programs in the Rehabilitation Act,<sup>57</sup> and the HUD Congregate Housing Services program<sup>58</sup> all provide important services for CLA living. But by

<sup>53.</sup> See W. Wolfensberger, Principles of Normalization (1972); H. Turnbull et al., The Least Restrictive Alternative—Principles and Practices (1981).

<sup>54.</sup> SSI and regular social security benefits can be used to pay rent, buy food, and purchase other goods and services to enable people to live in CLAs; these benefits ordinarily are not sufficient to enable a person to live alone. There are about 400,000 retarded people receiving SSI and 250,000 receiving regular social security. (There is some double counting.) Federal Old Age, Survivors, and Disability Insurance Benefits, 42 U.S.C. §§ 402(d), 403 (1976 & Supp. III 1979); Supplemental Security Income for the Aged, Blind and Disabled, 42 U.S.C. §§ 1381-1383 (1976 & Supp. III 1979); Grants to States for Medical Assistance, 42 U.S.C. § 1396 (1976 & Supp. III 1979); Grants to States for Services, 42 U.S.C. § 1397 (1976 & Supp. III 1979); Address by Paul Marchand, supra note 51.

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<sup>56.</sup> Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. §§ 6000-6081 (1976 & Supp. III 1979).

<sup>57.</sup> Comprehensive Services for Independent Living, 29 U.S.C. § 796 (Supp. III 1979).

<sup>58.</sup> Housing and Community Development Act of 1980, Pub. L. No. 96-399, 94 Stat.

themselves they generally are not adequate to provide full residential services; SSI and HUD funding must be tied to them to accomplish that goal. The Intermediate Care Facilities for the Mentally Retarded, a Title XIX program of the Social Security Act, can finance the full cost of residential settings and support services, provides open-ended funding, and has the advantage of single-agency accountability and governance, but it is medically, not developmentally, oriented. It emphasizes medically-related facility and program standards, and in most states it is administered by a public health, not a mental retardation-developmental disabilities, agency. Also, only a small segment of the \$1.5 billion available in the ICF/ MR program supports CLAs; most of the money supports traditional "institutions." The 96th Congress' enactment of the Disability Insurance and SSI Amendments<sup>59</sup> and its reauthorization of Title XX, with new provisions for adoption for hard-to-place children and modification and extension of traditional foster care and child welfare provisions,60 will help in deinstitutionalization and community placements if Congress sufficiently funds these new laws and the executive agencies implement them.

Still, there are major shortcomings in the deinstitutionalization-CLA efforts. No single federal program fully meets disabled persons' residential needs. ICF/MR standards are not always appropriate for CLAs and no other federal program is as accessible and capable as ICF/MR to support CLAs adequately. The overwhelming flow of ICF/MR funds to states for support of institutional placements is a powerful disincentive to state use of such funds for CLAs. Brick-and-mortar investments must be maintained and the states are not deaf to the voices of organized labor and parents objecting to deinstitutionalization. Skilled CLA advocates must confront local opposition. Ongress failed to enact two promising CLA-oriented bills in 1980, the Medicaid Community Care Act of 1980 and the Noninstitutional Long-Term Care Services for the

<sup>1614;</sup> Housing and Community Development Act, 42 U.S.C. § 1437 (1976), 24 C.F.R. §§ 885.1-.425 (1980); Housing Act, 12 U.S.C. § 1701q (1976 & Supp. III 1979), 24 C.F.R. §§ 277.1-.11 (1980).

<sup>59.</sup> Social Security Disability Amendments of 1980, Pub. L. No. 96-265, 94 Stat. 441.

<sup>60.</sup> Adoption Assistance and Child Welfare Act of 1980, Pub. L. No. 96-272, 94 Stat. 500.

<sup>61.</sup> H. TURNBULL, supra note 26.

<sup>62.</sup> Medicaid Community Care Act of 1980, Amendments to Title XIX of the Social Security Act to Provide Comprehensible Assessments and Community Based Services, H.R. 6194, 96th Cong., 1st Sess., 125 Cong. Rec. H12352 (daily ed. Dec. 19, 1979).

Elderly and Handicapped Act,<sup>63</sup> as well as the antidiscrimination in housing acts.<sup>64</sup> Even with the passage of those bills, there would remain substantial difficulties in monitoring the quality of care in CLAs. Surely the inappropriate use of nursing homes for mentally retarded people<sup>65</sup> indicates that all types of CLAs require continuous external scrutiny.

2. In-Home Services. Despite the large number of retarded people who are in traditional "institutions" (approximately 150,000), in large private facilities (approximately 25,000), in nursing homes or general intermediate care facilities (approximately 80,000), and in the nearly 4,000 CLAs with less than twenty residents each (approximately 27,000), the greatest number of retarded people (approximately 282,000) reside in their parents' or other individual care-takers' homes.<sup>66</sup> To assist them in continuing to live there when they and their parents or other direct care-takers make that choice and when that type of residential living arrangement is appropriate, it is not enough for the federal government to make available simply the existing social security and housing benefits described above.<sup>67</sup>

The failed efforts of the 96th Congress must be resuscitated. The Medicaid Community Care Act, for example, would have provided, among other things, increased Medicaid matching funds to states that expand the range of home-based services for people at risk of institutionalization who chose to live at home.<sup>68</sup> If a state were to participate in the program, it would have to make medical assistance available for, among other things, part-time or intermittent nursing services, home health-aide services, medical supplies and equipment suitable for home use, various therapeutic services (physical and occupational therapy), adult day health services, respite care, short-term full-time nursing care, homemaker services,

<sup>63.</sup> Non-Institutional Long-Term Care Services for the Elderly and Handicapped Act, S. 2809, 96th Cong., 2d Sess., 126 Cong. Rec. S6645 (daily ed. June 11, 1980).

<sup>64.</sup> Fair Housing Amendments Act of 1979, S. 506, 96th Cong., 1st Sess., 125 CONG. REC. S1938 (daily ed. March 1, 1979, legislative day Feb. 22, 1979); Fair Housing Amendments Act of 1979, H.R. 5200, 96th Cong., 1st Sess., 125 CONG. REC. H7428 (daily ed. Sept. 6, 1979).

<sup>65.</sup> Association for Retarded Citizens, Board of Directors, *Position Statement*, 9 ARC's Government Report No. 10, 2 (October, 1980).

<sup>66.</sup> Address by Paul Marchand, supra note 51.

<sup>67.</sup> Supra notes 54-60 and 62-66.

<sup>68.</sup> Medicaid Community Care Act of 1980, Amendments to Title XIX of the Social Security Act to Provide Comprehensible Assessments and Community Based Services, H.R. 6194, 96th Cong., 1st Sess., 125 Cong. Rec. H12352 (daily ed. Dec. 19, 1979).

and nutrition counselling. The Noninstitutional Long-Term Care Services for the Elderly and Disabled Act<sup>69</sup> also sought to change federal financial incentives that promote institutionalization. It would have made home health services, homemaker-home health aide services, adult care services, and respite-care services available to disabled citizens who qualify for certain Social Security Act benefits. Finally, a tax-credit bill<sup>70</sup> would have allowed taxpayers with a disabled dependent living in their homes to set off a portion of the excess costs of the dependent's care against their federal tax liability; the bill was a more indirect form of federal aid for residential living than the other two, but equally meritorious. It is to the Congress' credit, however, that it enacted foster-care and special-child adoption legislation this past session; the amendments to Title XX should, if adequately funded, go a long way toward preventing unnecessary or inappropriate institutionalization.<sup>71</sup>

3. Employment. The foregoing discussions about federal aid programs should have made one indelible point: federal financial support for retarded or other developmentally disabled individuals is inadequate. It is primarily for this reason that federal legislation must be amended or enacted to better enable qualified disabled adults to earn high wages without thereby jeopardizing their entitlements to means-tested federal aid. Only by combining federal aid with earnings will many disabled adults acquire the wherewithal to live outside of institutions without being unduly burdensome on the federal or state fiscs.

An initial positive step would be the amendment of the federal Fair Labor Standards Act to increase the wage levels for disabled people employed in sheltered workshops or work activity centers. The workshops employ less severely disabled people than the centers, but both types of employment facilities exist in community as well as institutional settings. Both pay disabled employees on the basis of a prorated wage, the "regular" wage for the job less a set-off that takes into account the inability of the employee to perform the job as well as a "regular" nonhandicapped worker. The formula for

<sup>69.</sup> Non-Institutionalized Long-Term Care Services for the Elderly and Handicapped Act, S. 2809, 96th Cong., 2d Sess., 126 Cong. Rec. S6645 (daily ed. June 11, 1980).

<sup>70.</sup> Tax Credit and Family Care Trust Act, S. 602, 96th Cong., 1st Sess., 125 Cong. Rec. S2366 (daily ed. March 8, 1979, legislative day February 22, 1979).

<sup>71.</sup> Adoption Assistance and Child Welfare Act of 1980, Pub. L. No. 96-272, 94 Stat. 500; 9 ARC's Government Report No. 7, 26 (July 1980); 9 ARC's Government Report No. 10, 12-13 (October 1980).

the prorated wage is set statutorily, but is set too low, particularly in light of inflationary pressures and the inadequacy of federal aid to meet community-living costs.

Another forward step would be the enactment of legislation that would "disregard" for the purposes of Medicaid eligibility all or a portion of the earned income of persons residing in Medicaid eligible facilities, particularly community-based ones. Such legislation would allow individuals to retain some discretion over their earnings so that the facilities could not automatically charge room and board, medical, and other costs of maintaining the individual who, after all, qualifies for federal medical-expense aid. It also would enable the individual to accumulate a reasonable portion of his earnings and to use them, in his discretion, to obtain community-based residential services if he is institutionalized and would be appropriately and adequately taken care of in a community-based facility.

These community-oriented earnings initiatives would be helped if Congress also would retain CETA programs that provide jobtraining for disabled people and that use nonprofit organizations for the training and placement of various disabled CETA-covered workers. It avails disabled people little if their earnings are affected positively by federal laws but their opportunities to be trained to earn and to find employment—often available only with nonprofit organizations formed solely to provide them with work—remain stagnant or are diminished by federal action. Earnings and training-employment action must complement each other if the community-living ideology is to be realized.

Congress itself realized this much when it recently provided additional work incentives for disabled workers under the SSI programs, 72 extended for one year the Targeted Jobs Tax Credit program through 1981, 73 and extended for fiscal years 1981 through 1983 the authority of nonprofit organizations of handicapped workers to participate in small business procurement set-asides. 74 Moreover, the Department of Labor recently was persuaded to modify its interpretations of wage-and-hour regulations covering group home employees by providing that the employees are not, in most cases, entitled to wages for "sleep time"—the hours when they reside and sleep at the group home. 75 If payment for sleep time had been re-

<sup>72.</sup> Social Security Disability Amendments of 1980, Pub. L. No. 96-265, § 201, 94 Stat. 441 (work incentives for disabled workers receiving social security income).

<sup>73.</sup> I.R.C. § 51.

<sup>74.</sup> Small Business Development Act of 1980, Pub. L. No. 96-302, 94 Stat. 833.

<sup>75.</sup> Letter from Henry T. White, Jr., Deputy Administrator, Employment Standards

quired, the wage component for operating a group home could have nearly doubled; the result would have been highly unfavorable for the community-living movement. Federal policy in the multifaceted employment and wage matters must be consistent, however, with federal policy for community living.

- D. Policy Dilemmas in Federal Legislation. The preceding discussions about the nature of recent federal legislation and some related future issues in federal legislation should have made the reader somewhat sensitive to at least several major dilemmas confronting representatives or advocates of retarded or other developmentally disabled people. This section of Part I will discuss these dilemmas in the context of legislative advocacy for such people and will suggest how they relate to the rights-enforcement challenges and opportunities facing existing "MR/DD" lawyers and prospective counsel from the private bar (Parts II and III).
- 1. Competing Equities. The first dilemma can be simply characterized as the problem of "competing equities." A simple problem to characterize, "competing equities" is not so simple to explain and it is harder still to resolve. A rudimentary example from special education will illustrate one of the "competing equities" issues. There are several techniques for the education of deaf children, including total communication, signing, and amplification. A competing equities problem arises if a deaf child has been educated through signing in a school for the deaf and then is placed in a local public school that trains by the technique of total communication. Does the child have the right to be educated only by the signing technique? Alternatively stated, does the child have to be put to a disadvantage in his education in order to accommodate the other deaf children in the local school? What rights does he have with respect to them; what are his "equities" and how much do they compete with theirs?

In this example, the competing equities issue is raised in the context of handicapped children having conflicting rights or claims among themselves. But the issue also arises in the context of the competing rights among the handicapped and nonhandicapped. For example, to what extent should state and local school transpor-

Administration, U.S. Department of Labor, to Joni Fritz, Executive Director, National Association of Private Residential Facilities for the Mentally Retarded (March 13, 1980), and letter from White to Hon. Larry J. Hopkins, House of Representatives (October 3, 1980) (copies available from author). The Department's regulations are codified at 29 C.F.R. §§ 785.1-.50 (1980).

tation systems be modified to accommodate handicapped children on regular school buses? While it is clear under P.L. 94-142 that handicapped children have the right to be transported from home to school and back, it is not at all clear whether they have the right to ride the same buses as nonhandicapped students.

The competing equities problem is this: to what extent should some handicapped or nonhandicapped people be disadvantaged or imposed upon to accommodate the rights of other handicapped people? This is a very real problem not only because it has instructional and fiscal implications, as illustrated above, but also because it has implications for nondiscriminatory evaluation and placement. Thus some of the questions are: Is it permissible to put handicapped carriers of infectious diseases in school with other children?<sup>76</sup> How thorough should each handicapped child's evaluation be when there are limited financial and personnel resources to evaluate all handicapped children? Should a handicapped child who disrupts the education of nonhandicapped children be mainstreamed?<sup>77</sup> Should a twelve-month school year be ordered for some but not all handicapped children?<sup>78</sup> The competing equities quandary affects all of the issues surrounding public policy and handicapped citizens because the establishment of rights, especially costly rights, such as those that rely on the second and third techniques of law reform previously described, always has fiscal and personnel costs.

2. Discrete or Generic Legislation. A second issue revolves around the strategies for establishing rights for handicapped people. While the recent successes in establishing rights for handicapped people are attributable in part to the fact that the handicapped-rights movement is an extension of the civil rights movement from which blacks, women, and other minority groups have benefited, there is something distinctive about the handicapped rights movement. This difference, and the resulting quandary about how to es-

<sup>76.</sup> New York State Ass'n For Retarded Children, Inc. v. Carey, 446 F. Supp. 487 (E.D.N.Y. 1979), aff'd, 612 F.2d 644 (2d Cir. 1979) holds that developmentally disabled Hepatitis B carriers may not be excluded from local schools.

<sup>77. 45</sup> C.F.R. § 84.34 has been interpreted by the Office for Civil Rights to mean that if the handicapped child significantly impairs other children's education, he is misplaced, 42 Fed. Reg. 22691 (1977).

<sup>78.</sup> Armstrong v. Kline, 476 F. Supp. 583 (E.D. Pa. 1979) aff'd sub nom. Battle v. Pennsylvania, 629 F.2d 269 (3d Cir. 1980), holds that an inflexible state regulation of 180 days of school annually violates the federal constitutional and statutory rights of some severely and profoundly handicapped children, those whose development will regress significantly if they are educated only during the 180-day period.

tablish rights for handicapped people, is best illustrated by Brown v. Board of Education,<sup>79</sup> the 1954 school desegregation case. In Brown, the issue was whether it is unconstitutional for states to exclude blacks from schools attended by whites. In the right-to-education movement, the issues were whether it is unconstitutional for states to exclude some handicapped children from any public education and whether, if schools chose to admit handicapped children, they could lawfully exclude them from an education in settings with their nonhandicapped age peers. In both cases, the courts held the exclusion to be unconstitutional.

Such an answer does not, however, put the matter to rest. Progress in school desegregation can be accomplished in large part simply by putting blacks and whites into the same schools and same classes; there are no distinguishing characteristics about race that prevent people of different races from being effectively educated together. That is not the case, however, with respect to handicapped and nonhandicapped people. There are indeed occasions when it is possible to educate handicapped and nonhandicapped students together without making special accommodations on account of the nature or severity of handicaps. More often than not, however, it is not possible to effectively educate a handicapped person simply by putting him into the same school and same programs as nonhandicapped people. Typically, handicapped students need specially designed instruction or other accommodations such as physical access through the removal of physical barriers. Unlike race, a handicap is a distinguishing characteristic that may prevent people of different abilities from being effectively educated together unless special educational techniques and special accommodations are made available for handicapped students.

The quandary for public policy arises out of the distinctive characteristic of a handicap. Unlike race, sex, or some other minority characteristic, a handicap usually requires special attention; at the same time, handicapped people should not be treated all that differently than nonhandicapped people if the policymaker wishes to be successful in creating rights for handicapped people. The policy maker must choose whether his strategy will be to include handicapped people in legislation that benefits all people, handicapped or not, or to include handicapped people in special legislation that benefits them alone.

As the earlier discussion of CLA and at-home residential living

<sup>79. 347</sup> U.S. 483 (1954).

legislation implies, there is the "magic bullet" dilemma: should there be a single, comprehensive, narrowly targeted deinstitutionalization-CLA-residential living bill, a discrete act intended to benefit retarded or other developmentally disabled people only? Or should those people's housing interests be satisfied by being tacked onto generic legislation that benefits not only them but also other claimants?

Choosing the broader strategy—to tie handicapped citizens' rights to "generic" legislation and programs—has the effect of treating handicapped and nonhandicapped people exactly alike; it reflects the "pure equal treatment" ideology. Simultaneously, tacking assures that the handicapped beneficiaries will be integrated into the "mainstream" of the legislation and the administering agency. In terms of real-politics, it is undeniable that tacking can be helpful.

The "generic" approach of including handicapped citizens as beneficiaries in legislation intended to help a heterogeneous population was in evidence in two of the 96th Congress' most deplorable failures. The two CLA/at-home residential living bills<sup>80</sup> were designed to benefit not only medically needy but also elderly people; retarded and other handicapped people were included as well. Likewise, the two fair-housing bills, <sup>81</sup> designed to benefit racial and ethnic minorities, also would have benefited disabled citizens.

One legitimately can question the tacking strategy in light of the failure of these bills. More to the point, however, tacking can mean that the disabled beneficiaries will have low visibility because they normally will be a minority of the general group of beneficiaries and because the generic program is likely to be administered by an agency not familiar with or sympathetic to their interests. Moreover, where the disabled beneficiaries have tied onto generic programs, serious problems of agency coordination and case management can arise. Tacking onto generic legislation is itself an effort to avoid the effects of Social Darwinism, a recognition that might makes right and it is better to be allied with the mighty, whatever

<sup>80.</sup> Medicare Community Care Act of 1980, Amendments to Title XIX of the Social Security Act to Provide Comprehensible Assessments and Community Based Services, H.R. 6194, 96th Cong., 1st Sess., 125 Cong. Rec. H12352 (daily ed. Dec. 19, 1979); Non-Institutional Long-Term Care Services for the Elderly and Handicapped Act, S. 2809, 96th Cong., 2d Sess., 126 Cong. Rec. S6645 (daily ed. June 11, 1980).

<sup>81.</sup> Fair Housing Amendments Act of 1979, S. 506, 96th Cong., 1st Sess., 125 Cong. Rec. S1938 (daily ed. March 1, 1979, legislative day Feb. 22, 1979); Fair Housing Amendments Act of 1979, H.R. 5200, 96th Cong., 1st Sess., 125 Cong. Rec. H7428 (daily ed. Sept. 6, 1979).

the cost, than not. Yet exactly equal treatment, putting handicapped and nonhandicapped in the same programs, may not be effective for some handicapped people; a handicap is a distinction that usually does make a difference.

Sometimes the policy maker must elect the second strategy and create legislation that benefits handicapped people alone. The problem with the second strategy lies not only with the competing equities issues that it raises, but also with the undeniable fact that, in a majoritarian process, handicapped people are a very small minority, often powerless to defend against the effects of majority rule and often the recipients of the fewest benefits of generic public policy.

Consider the dilemma in the terms of Brown and handicapped children's education. If the Brown principle had been applied across the board to handicapped children, their rights would have been to attend school with nonhandicapped children, nothing more. Generic policy—that blacks should be treated in the same way as whites—would have been educationally unacceptable with respect to handicapped children because generic policies would simply have called for handicapped children to be in schools with nonhandicapped children, not for them to have any special rights not made available to nonhandicapped children. It therefore becomes necessary for public policy to adopt a different stance. Generic policy, providing that handicapped and nonhandicapped children must all be admitted to public education programs, must be accompanied by specific policies recognizing that handicapped children have rights in public education that nonhandicapped children do not have and do not need. The quandary for policy makers was acute: the strategy of generic policy would have been only partially effective and would have to be supplemented by specially justified specific legislation.

P.L. 94-142 is both generic and specific. The principle of zero reject is generic in that it requires all handicapped children to be educated, but the principles of nondiscriminatory evaluation, appropriate education through IEPs and related services, and elaborate procedural due process are specific. The "discrete" approach—the "magic bullet"—may indeed be useful; certainly it is not without precedent; and it has the benefit of giving its intended beneficiaries high visibility and easy single-shot, single-issue strategies in the political arena. P.L. 94-142, the Education for All Handicapped Children Act, and the oft-amended Developmental Disabilities

Assistance and Bill of Rights Act82 are two examples of magic-bullet, discrete legislation that have been unusually successful in achieving their respective goals—education and planned and tightly focused state-level services. They are not, of course, without their problems. Among other things, P.L. 94-142 does not satisfactorily define some of the children who might be eligible for its benefits; there is a continuing debate concerning the definitions of "learning disabilities".83 The DD Act, originally narrowly focused on mentally retarded, autistic, epileptic, and cerebral palsied children and adults, was amended in 1978 to include a larger target population,84 whose members cannot be defined consistently by the many human service providers implementing the Act. Even now representatives of mentally retarded persons, the original beneficiaries of the ICF/

- (7) The term "developmental disability" means a disability of a person which— (A)(i) is attributable to mental retardation, cerebral palsy, epilepsy, or autism;
  - (ii) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons; or
  - (iii) is attributable to dyslexia resulting from a disability described in clause
  - (i) or (ii) of this subparagraph;
  - (B) originates before such person attains age eighteen;
  - (C) has continued or can be expected to continue indefinitely; and
  - (D) constitutes a substantial handicap to such person's ability to function normally in society.
- 42 U.S.C. § 6001(7) (1976). The 1978 Amendments changed the definition as follows:
  - (7) The term "developmental disability" means a severe, chronic disability of a person which-
    - (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
    - (B) is manifested before the person attains age twenty-two;
    - (C) is likely to continue indefinitely;
    - (D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and
    - (E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

<sup>82.</sup> Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. §§ 6001-6081 (1976 & Supp. III 1979); Rehabilitation Act of 1972, 29 U.S.C. §§ 701-796i (1976 & Supp. III 1979); Fair Labor Standards Act, 29 U.S.C. § 214(c) (1976).

<sup>83.</sup> Proposed Definition of "Learning Disabilities," Recommendation of the National Joint Committee on Learning Disabilities, from meeting in St. Petersburg, Florida (September 12-13, 1980).

<sup>84.</sup> Under the old law, the definition of "developmental disability" was as follows:

<sup>42</sup> U.S.C. § 6001(7) (Supp. III 1979).

MR program, are forced to resist efforts of advocates for mentally ill citizens to secure the benefits of the program for mentally ill people. 85 Moreover, discrete legislation that creates benefits obtainable from many human service providers can create particularly intractable intra- and inter-governmental problems; this is well illustrated by the "related services" provision of P.L. 94-142.86

Knowing whether and when to choose between generic and specific legislation, or how to combine the two, is the quandary posed in establishing rights for handicapped citizens.

3. Medical Models v. Developmental Models. Another dilemma is well exemplified by the Supreme Court's 1979 Parham<sup>87</sup> decision and the Title XIX Medicaid legislation. The dilemma is whether to abandon in whole or in part the "medical model" for the "developmental model."<sup>88</sup> The "medical model" of case law and legislation approaches the rights and claims of mentally retarded or other developmentally disabled citizens from the point of view that they are "sick" and need to be "made well" by physicians and people in allied health professions. The "developmental model" asserts that the true nature of mental retardation or other developmental disabilities is not rooted in medical etiologies, although these can exist in anyone and medical intervention can be appropriate, but rather in the delayed or slow development of the individual; this view calls for educational, psychological, and other non-medical intervention.<sup>89</sup>

As Professor Burt points out, 90 Parham can be read as a decision that reasserts the primacy of parental and professional (in that case, the medical profession) decision-making with respect to mentally ill children. The decision whether a child should be institu-

<sup>85.</sup> Letter from H. Gilbert Johnson, President, Association for Retarded Citizens, to Howard Newman, Administrator, Health Care Financing Administration, Department of Health and Human Services (Oct. 8, 1980) (re: tracking mentally ill persons into Intermediate Care Facilities for the Mentally Retarded program).

<sup>86.</sup> See H. Turnbull, N. Barnes, & B. Strickland, Special Education and "Related Services" for Handicapped Children (1980).

<sup>87.</sup> Secretary of Public Welfare v. Institutionalized Juveniles, 442 U.S. 640 (1979); Parham v. J.R., 442 U.S. 584 (1979).

<sup>88.</sup> Compare the Medicaid provisions in Title XIX of the Social Security Act, 42 U.S.C. §§ 1396-1396j (1976 & Supp. III 1979), which use the "medical model," with Education for All Handicapped Children Act, 20 U.S.C. §§ 1401-1461 (1976 & Supp. III 1979), which uses the "developmental model."

<sup>89.</sup> Roos, The Law and Mentally Retarded People: An Uncertain Future, 31 STAN. L. REV. 613 (1979).

<sup>90.</sup> Burt, The Constitution of the Family, 1979 Sup. Ct. Rev. 329.

tionalized may be made by independent experts without the requirement of a traditional judicial or quasi-judicial due process hearing. The experts' decision is whether to accept the child for institutionalized treatment. It is not whether the child can be equally or better served in settings that would undergird his "normal development," such as in community mental health or other settings; the Supreme Court explicitly rejected the "liberty" and "least restriction" arguments made on the plaintiff/children's behalf and arguably thereby also rejected the developmental model.

By the same token, ICF/MR regulations carry forward an obsolete notion that institutions for retarded or other developmentally disabled people should be operated like hospitals, 91 caring for "sick" people but not sufficiently training them for discharge into more normal living circumstances. Even the proposed Medicaid amendments in H.R. 6194, Medical Community Care Act of 1980, were predicated on adapting the existing medical-model basis of Medicaid for community-based services. That bill's great merit was that it would have provided federal funding for deinstitutionalization, whereas both *Parham* and ICF/MR impede that movement and its implicit developmental-model predicate. S. 2809, the Noninstitutional Long-term Care Services Act, however, was based on an entirely different foundation, a developmental model, and would have addressed the residential-placement and other needs of disabled people by amending the Social Security Act.

The dilemma posed by these two failed bills, as well as by *Parham* and the ICF/MR provisions of the Medicaid Act, is whether as a matter of policy it is any longer appropriate to regard retarded and other developmentally disabled people as "sick" when they have no medically related etiologies or conditions. To regard them as proper objects for medical intervention when they do not have medical needs of nonhandicapped people fundamentally seems to deny that they should be treated by educational, vocational, or habilitation techniques. Such a policy, whether administered as a matter of constitutional law as in *Parham* or as legislation as in ICF/MR regulations or H.R. 6194, jeopardizes the deinstitutionalization movement, continues unnecessarily to subject many handicapped people to inappropriate and sometimes harmful institutionalization, and prevents the conceptualization of their status and rights as citizens, not patients. As a matter of legislative strat-

<sup>91. 42</sup> C.F.R. §§ 442.400-.516 (1979). See E. Goffman, Asylums—Essays on the Social Situation of Mental Patients and Other Inmates (1961).

egy, however, there is some merit in continuing to adopt and, if possible, adapt federal medical legislation, whose adoption is sought not only by powerful medical lobby interests but also by institutionally based mental retardation professionals and some parents of institutionalized retarded citizens. On balance, the preference should be for the policy that adheres to the developmental model but accommodates the medical model for programs that would serve the purely medical needs of disabled citizens.

4. The Locus of Control. The underlying issue in the dilemma of generic-discrete legislation, as well as in the medical-developmental model dilemma, is who shall control the lives of those who cannot act for themselves because of the severity of their disabilities or even because they have disabilities, however mild. Indeed, that is the issue posed by the entire rights-movement: shall retarded and other developmentally disabled citizens enjoy the rights that the rest of us take for granted and, if so, to what extent? Generic legislation can assist those citizens by bringing them into the mainstream of law making and service delivery systems; it seems to proclaim that they should be treated like nonhandicapped citizens to the extent appropriate to their abilities and disabilities. In that respect, it arguably asserts that they, like nonhandicapped citizens, should be entitled to set their own paths in life. Discrete legislation, however, is more likely to grant them specific rights,<sup>92</sup> including rights to participate in decisions about their own welfare.<sup>93</sup> In this respect, some discrete legislation clearly asserts that they shall have a say about their own lives.

The Parham issue, reduced to its kernel, was a control issue. That issue arises in every aspect of developmental disabilities law, and it is a fundamental error for the attorney representing any disabled litigant or the advocate pressing for any type of MR/DD legislation to view the particular issue of the moment without reference to the control dilemma. When counsel undertake to represent disabled citizens, their parents, or their service providers, they must bear in mind that disabled individuals differ from each other; thus,

<sup>92.</sup> See, e.g., the Education for All Handicapped Children Act, 20 U.S.C. §§ 1401-1461 (1976); the Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. §§ 6001-6081 (1976 & Supp. III 1979).

<sup>93.</sup> Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. §§ 6001-6081 (1976 & Supp. III 1979); 45 C.F.R. § 1386.47(b) (1979); Education for All Handicapped Children Act, 20 U.S.C. §§ 1401-1461 (1976 & Supp. III 1979); 45 C.F.R. § 121a.344(a)(4) (1979).

the extent of control appropriate for any of the three parties is not necessarily the same in every case. That is the challenge and opportunity that faces lawyers when they seek to enforce rights or advance the rights movement.<sup>94</sup>

### II. AN ISSUE FOR THE 1980s: ENFORCEMENT

It may be unduly pessimistic to foretell a bleak future for mentally retarded and other developmentally disabled people when gazing into the federal legislative crystal ball. But recent congressional initiatives have not been overwhelmingly favorable; certainly the highwater marks made by section 504 and P.L. 94-142 have yet to be approached by even the most enlightened successful legislation, such as the community-living acts described above in Part I-B-1. The beach is awash with hopeful but failed bills.

On the other hand there are reasons to believe that the future can bring an improved status for disabled people if their existing rights are vigorously enforced and the energies of the private bar are brought to bear on their behalf. This result is not by any means unattainable. Much, but not everything, depended on the *Pennhurst* result. The great irony is that the Court already has created a promising beachhead for disabled citizens by putting new teeth into section 1983 of the Civil Rights Act of 1871,95 which provides that everyone who, under color of law, deprives another of "any rights, privileges, or immunities secured by the Constitution and laws," shall be liable for the deprivation.

A. Civil Rights Remedies. In two important precedent-setters, Maine v. Thiboutot<sup>96</sup> and Maher v. Gagne,<sup>97</sup> the Court held that the 1871 Civil Rights Act, together with its 1978 amendments,<sup>98</sup> entitles the prevailing party to recover his attorney fees in section 1983 cases successfully brought on federal statutory grounds. In Thiboutot, the

<sup>94.</sup> E. Boggs, Who is Putting Whose Head in the Sand or in the Clouds as the Case May Be?, and H. Turnbull, Jay's Story, in Parents Speak Out: Views from the Other Side of the Two-Way Mirror (1979).

<sup>95. 42</sup> U.S.C. § 1983 (1976 & Supp. III 1979). An unsuccessful state-court action challenging an unconstitutional deprivation of rights may collaterally estop a § 1983 suit. See Case Comment, Collateral Estoppel in Section 1983 Actions After Stone v. Powell: McCurry v. Allen, 64 MINN. L. REV. 1060 (1980).

<sup>96. 448</sup> U.S. 1 (1980).

<sup>97. 448</sup> U.S. 122 (1980).

<sup>98. 42</sup> U.S.C. § 1988 (1976). For a discussion of attorney fees under the Civil Rights Act, see Comment, Attorney's Fees in Damage Actions Under the Civil Rights Attorney's Fees Awards Act of 1976, 47 U. CHI. L. REV. 332 (1980).

plaintiffs brought a state-court action against state welfare officials. charging them with wrongfully depriving them of Social Security Act benefits—AFDC payments<sup>99</sup>—to which they were entitled. The defendants argued that section 1983 should not be read to include deprivations under just any "laws" but only under civil rights and equal protection laws. They also argued that attorney fees are available under the 1978 amendments only for violations of constitutional, not statutory, rights. The Court's flat rejection of these defenses could not give a clearer message to rights-hungry retarded or other disabled citizens: there are now available civil rights remedies that may be pursued in either federal or state courts for deprivations of a host of federal statutory rights; more important, there is a powerful way to enforce the rights through attorney-fees recovery. Not only does the "plain language" of section 1983 make it clear that federal statutory deprivations may be remedied, but the Court's recognition of its consistent practice of allowing statutorily grounded claims in section 1983 actions to go forward and be decided on their merits underscores the new enforcement powers now available to disabled claimants of federal statutory benefits. Finally, the attorney-fees recovery provision of the 1978 amendments is "plain language" that means that such fees can be recovered in any section 1983 action. As Justices Powell, Burger, and Rehnquist stated in their dissent, the "practical effect" of the decision is that "state and local governments, officers, and employees now may face liability whenever a person believes he has been injured by the administration of any federal-state cooperative program, whether or not that program is related to equal protection or civil rights."100 This result will obtain—and states and local governments will bear the entire burden of liability even when federal officials are involved equally in administering the program—in state courts, not solely federal courts.<sup>101</sup> The effects of Thiboutot are to transfer the plaintiffs' remedies from federal officials, whose liability must be expressly or (as is "relatively rare" 102) implicitly set forth in federal assistance laws and who are not answerable for their opponents' attorney fees, 103 to state and local officials; alternatively stated, the enforcement difficulties that have arisen in connection with section 504 of the Rehabilitation Act have been substantially—even radically—

<sup>99. 42</sup> U.S.C. § 602(a)(7) (1976).

<sup>100.</sup> Maine v. Thiboutot, 448 U.S. 1, 22 (1980) (Powell, J., dissenting).

<sup>101.</sup> Id. at 23-24.

<sup>102.</sup> Id. at 24.

<sup>103.</sup> Id.

ameliorated by *Thiboutot*. *Maher* underscores this result<sup>104</sup> and enlarges the means of enforcement. There also, the suit was based on alleged wrongful deprivations of Social Security Act benefits (AFDC), as well as on fourteenth amendment equal protection and due process grounds. Unlike *Thiboutot*, however, the plaintiff and defendants settled the case and the district court entered a consent decree that, among other things, granted the plaintiff most of the relief she had sought with respect to state interpretation of AFDC regulations. But the parties submitted to an adversarial hearing the issue whether the plaintiff was entitled to attorney fees under section 1988 of the Civil Rights Act. The district court held, and the court of appeals and Supreme Court affirmed, that, notwithstanding the settlement by consent decree, the plaintiff was entitled to recover her attorney fees. She was the "prevailing party" under section 1988 because she had obtained "substantially all of the relief originally sought in her complaint" in the consent decree. <sup>105</sup> It is not required under section 1988 that the prevailing party win "in every particular" so long as she ultimately vindicates her rights. <sup>106</sup>

The Court did not find it necessary to resolve the state's defense that the eleventh amendment prohibits a federal court from awarding attorney fees against a state in a case involving a "purely statutory, non-civil-rights claim." Instead, because the plaintiff had sued on constitutional grounds that had been resolved in her favor in the consent decree, it was permissible for a federal court to award counsel fees against a state. In the absence of joined constitutional and statutory grounds, however, a court's power to do so remains unresolved.<sup>107</sup>

Maher's message to rights-seeking disabled plaintiffs expands Thiboutot's: federal courts are appropriate forums for section 1983 and section 1988 remedies; attorney fees are recoverable if joined statutory and constitutional allegations prevail, either in a consent decree or in a fully litigated case. As in Thiboutot, the impasses created by the federal courts in section 504 litigation seem to be avoidable, and state and local recipients of federal aid can be held accountable for statutory rights deprivations. Previously powerless plaintiffs—handicapped citizens whose effective recourse to the

<sup>104.</sup> Maher explicitly reaffirms the *Thiboutot* result that suits lie against state and local officials for violating federal statutory rights of AFDC-eligible plaintiffs. Maher v. Gagne, 448 U.S. 122, 123 (1980).

<sup>105.</sup> Id. at 127 (quoting the district court opinion).

<sup>106.</sup> Id. (citing the Congressional history).

<sup>107.</sup> Id. at 130.

courts has been so uncertain—have received a real boon from the Supreme Court, notwithstanding that the Court, in earlier disabilities cases, had been less than wholly sympathetic to their claims.

B. Other Enforcement Legislation. The preceding discussion of the availability of section 1983 as an enforcement device is narrowly focused on only one of several federal enforcement remedies. There are other enforcement techniques as well; together with section 1983, they constitute the "fourth category" of federal legislation (see Part I-A-4)—laws that create specific enforcement rights.

Two excellent examples of such legislation are the Developmental Disability Assistance and Bill of Rights Act<sup>108</sup> and the Civil Rights of Institutionalized Persons Act. 109 Section 6010 of the DD Act creates a right to treatment in the "least restrictive" environment, to individualized habilitation plans, and to minimum environmental standards for institutional living. Although affirmed on other grounds and therefore less authoritative than otherwise, a federal district court has held that the right to appropriate treatment to treatment that will "maximize the developmental potential" of an individual, not to treatment that controls or merely "maintains" him—is enforceable under section 6010 by a section 1983 suit and that a state "protection and advocacy" organization created by state action in order to receive federal DD funds under the Act has standing to sue to enforce individuals' rights and need not prove damage to itself.<sup>110</sup> Indeed, one of the specific purposes of the Act was to create state-level protection and advocacy ("P & A") agencies that would assist DD individuals to enforce a broad range of their legal rights.<sup>111</sup> The *Pennhurst* decision, however, settled whether the DD Act does indeed create a judicially enforceable right to treatment under the Act. While it is too early to tell exactly how vigorously it will be enforced or how effective it could be if vigorously pursued, the Civil Rights of Institutionalized Persons Act<sup>112</sup> enables the United States Department of Justice to institute civil actions in federal court to obtain equitable relief on behalf of institutionalized disabled persons whose federal constitutional or statutory rights are violated by state or local officials. But the Act itself is narrowly

<sup>108. 42</sup> U.S.C. §§ 6001-6081 (1976 & Supp. III 1979).

<sup>109.</sup> Pub. L. No. 96-247, 94 Stat. 349 (1980).

<sup>110.</sup> Naughton v. Bevilacqua, 458 F. Supp. 610 (D.R.I. 1978), aff'd, 605 F.2d 586 (1st Cir. 1979).

<sup>111. 42</sup> U.S.C. § 6012 (1976 & Supp. III 1979).

<sup>112.</sup> Pub. L. No. 96-247, 94 Stat. 349 (1980).

drawn and an optimistic view of its usefulness is not warranted. It covers only publicly operated facilities, not the typical private nursing homes.<sup>113</sup> It requires the Department to have "reasonable cause to believe" that a state or local official is subjecting an institutionalized person to "egregious or flagrant conditions" which deprive him of his federal constitutional or statutory rights and cause him "grievous harm, and that such deprivation is pursuant to a pattern or practice of resistance to the full enjoyment of such rights. . . ."<sup>114</sup>

Obviously this tightly circumscribed jurisdictional prerequisite can vitiate rights-enforcement efforts for at least three reasons: it will be the subject of immensely time-consuming pretrial activity, the result of which may gut the lawsuit before trial even begins; its restrictively drawn language offers comfort to defendants as well as courts that are reluctant to intervene in the operation of state institutions; and the vigor with which the Attorney General will pursue his powers under the act can be determined on political grounds under the "reasonable cause" phrase.

Moreover, the Attorney General must certify that he has notified the potential defendants in advance of filing the suit of the allegedly depriving conditions and minimum measures that could remedy the conditions; he also must certify that he has consulted with the appropriate defendants concerning the availability of federal aid that may help correct the conditions, that he has attempted unsuccessfully to obtain voluntary correction of the conditions, and that the defendants have had a reasonable time to correct the conditions. Finally, he must certify that he believes the suit "is of general public importance" and will "materially further the vindication" of institutionalized persons' rights. The Attorney General may intervene in pending litigation, subject to similar certification requirements.

Clearly the certification requirements are rights-attenuating provisions. They, too, will be the subject of time absorbing pretrial hearings; they provide prelitigation "discovery" for the defendants; they forestall some types of effective investigation of conditions in institutions; and they give the defendants a prelitigation opportunity to cure their defaults.

<sup>113.</sup> Id. at § 2(1)(2).

<sup>114.</sup> Id. at § 3(a).

<sup>115.</sup> Id. at § 4(a)(1), (2).

<sup>116.</sup> Id. at § 4(a)(3).

<sup>117.</sup> Id. at § 5.

Other general enforcement legislation is hard to identify. There may be, however, an imaginative use of the theory of "federal constitutional torts"118 and the Federal Tort Claims Act. 119 The federal government itself directly operates and administers programs and facilities for disabled people, such as Department of Defense or Bureau of Indian Affairs schools and veterans' hospitals. When students or patients in such programs or facilities are subjected to actions or conditions that would violate their constitutional rights under the due process or equal protection clauses of the fourteenth amendment if a state or local government were the infringing party. it may be possible for them to recover damages for fifth amendment due process violations under the Supreme Court's recent decisions in Butz v. Economou<sup>120</sup> and Davis v. Passman. 121 This is particularly true since the Court's reasoning in those cases parallels its accountability doctrine in section 1983 cases. It is less likely that such individuals can use the Federal Tort Claims Act unless they join their constitutional-tort complaint with their Torts Claim Act action. Despite these uncertainties, disabled persons' enforcement of rights against the federal government itself is likely to be explored in the next several years, as it should be.

In summary, the prospects for successfully using specific enforcement legislation—"category four" legislation described in Part I-A-1, above—is mixed. Section 1983 is by far the most promising avenue; the DD Act and the institutionalized persons civil rights act are uncertain roads, at best; and the combined Federal Tort Claims Act-constitutional tort route undoubtedly requires trailblazing into unknown territory. It is appropriate now to discuss the enforcement prospects under "category two" and "category three" legislation—law that creates rights to substantive benefits and law that creates rights against discrimination.

C. P.L. 94-142's Enforceability. P.L. 94-142, the Education for All Handicapped Children Act, 122 provides four substantive rights for schoolaged handicapped children: the right not to be excluded from a free appropriate education ("zero reject"); the right to

<sup>118.</sup> See Davis v. Passman, 442 U.S. 228 (1979); Butz v. Economou, 438 U.S. 478 (1978); Cox v. Brown, 4 MDLR 405 (1980). The theory is explored in Dolan, Constitutional Torts and the Federal Torts Claims Act, 14 U. RICH. L. REV. 281 (1980).

<sup>119. 28</sup> U.S.C. §§ 1346, 1402, 1504, 2110, 2410, 2412, 2671-2680 (1976).

<sup>120. 438</sup> U.S. 478, 501 (1978).

<sup>121. 442</sup> U.S. 228 (1979).

<sup>122. 20</sup> U.S.C. §§ 1232, 1401, 1405-1406, 1411-1420, 1453 (1976).

a nondiscriminatory evaluation; the right to an appropriate education; and the right to educational placement in the least restrictive, most "regular" appropriate program. To safeguard these rights, the Act also provides two accountability techniques: procedural due process, also called "procedural safeguards," and parent participation. State and local educational agencies that accept federal aid for educating handicapped children must comply with these six principles.

The procedural safeguards<sup>123</sup> include the right, exercisable either by the parents, guardians, or state-appointed surrogate parents of a handicapped child or by the local educational agency that is responsible for the child's education, to a quasi-administrative, quasi-judicial "due process hearing" before an "impartial hearing officer." The hearing may be triggered on nearly fifty specific grounds, 124 all of which relate to the child's identification as handicapped, his evaluation, his placement in school programs, or his right to a free appropriate education. Upon request for a hearing, parents are entitled to be notified by the agency about the availability of any low-cost or free legal aid in the nearby geographical area. At the hearing, both parties are entitled to be accompanied and advised by counsel and other persons with special knowledge or training with respect to handicapped children; to present evidence and confront, examine, cross-examine, and compel the attendance of witnesses; to make written and oral argument; to receive a written or electronically recorded verbatim record of the hearing; and to receive a written account of the findings of fact. An appeal lies by an aggrieved party to a state-level hearing officer, who must make an independent decision after reviewing the record or calling for oral or written argument or both. Thereafter, an aggrieved party may file a civil action in a state or federal district court; for federal jurisdictional purposes, the dollar amount rules do not apply. The court is to receive the records of the previous administrative proceedings, hear additional evidence if offered, and, on the basis of the preponderance of the evidence, grant appropriate relief.

Several enforcement issues have arisen concerning the Act's procedural safeguards. There seems to be unanimous agreement that a local educational agency may not expel a handicapped child under its school-discipline procedures for engaging in disruptive be-

<sup>123. 45</sup> C.F.R. §§ 121a.500-.514 (1980).

<sup>124.</sup> Turnbull, Turnbull, & Strickland, Procedural Due Process: The Sword the Untrained Should Not Unsheath, 161 B.U.J. EDUC. 40 (1979).

havior that is caused by his handicap without first granting him a hearing that complies with the Act's procedural safeguards. <sup>125</sup> The determination of causation apparently must be made by special educators and other handicapped-child specialists; evidently, it is not within the province of a school board to make that decision. But suspension for short periods of time seems allowable (although the duration is unclear), and a change of educational placement from a "less" to a "more" restrictive ("less regular") program clearly is allowable even without a prior hearing under the provisions for change of the child's program as circumstances warrant. However, the parents must receive prior notice of the proposed placement decision and may challenge it in a due process hearing. <sup>126</sup>

The enforcement of P.L. 94-142 rights seems equally clear when the issue is not protection against expulsion procedures, but whether the procedural safeguards may be by-passed or whether the Act itself grants a private right of action. These issues are obviously vexatious with respect to section 504 enforcement; they are not nearly as difficult in the context of P.L. 94-142. A facial reading of the Act would seem to lead to the conclusion that a state or federal civil action does not lie until the administrative remedies have been exhausted. The cases seem to support this proposition. At least one federal court, however, has allowed a private right of action to be pursued without requiring exhaustion;<sup>127</sup> three have held that exhaustion is not a prerequisite to suit; 128 and three have applied the "futility" doctrine and allowed the private right of action to go forward without resort to administrative remedies.<sup>129</sup> In one of the cases finding that exhaustion is not required, however, the defendants did not raise an exhaustion-of-remedies defense. 130 In another of those cases, the plaintiff was seeking monetary damages, not chal-

<sup>125.</sup> See S-1 v. Turlington, 635 F.2d 342 (5th Cir. 1981); Doe v. Koger, 480 F. Supp. 225 (N.D. Ind. 1979); Mrs. A.J. v. Special School District No. 1, 478 F. Supp. 418 (D. Minn. 1979); Howard S. v. Friendswood Independent School Dist., 454 F. Supp. 634 (S.D. Tex. 1978); Stuart v. Nappi, 443 F. Supp. 1235 (D. Conn. 1978); and Southeast Warren Community School Dist. v. Dep't of Public Instruction, 285 N.W.2d 173 (Iowa 1979).

<sup>126.</sup> S-1 v. Turlington, 635 F.2d 342 (5th Cir. 1981); Doe v. Koger, 480 F. Supp. 225 (N.D. Ind. 1979); Stuart v. Nappi, 443 F. Supp. 1235 (D. Conn. 1978).

<sup>127.</sup> Larry P. v. Riles, 495 F. Supp. 926 (N.D. Cal. 1979).

<sup>128.</sup> North v. District of Columbia Bd. of Educ., 471 F. Supp. 136 (D.D.C. 1979); Loughran v. Flanders, 470 F. Supp. 110 (D. Conn. 1979); Oster v. Boyer, No. 77-0348 (D.R.I., Feb. 5, 1979).

<sup>129.</sup> Harris v. Campbell, 472 F. Supp. 51 (E.D. Va. 1979); U.C.P. of N.Y.C., Inc. v. Board of Educ., No. 79-C-560 (E.D.N.Y., Aug. 10 and Dec. 14, 1979); Jose P. v. Ambach, No. 79-C-270 (E.D.N.Y., May 16, 1979).

<sup>130.</sup> North v. District of Columbia Bd. of Educ., 471 F. Supp. 136 (D.D.C. 1979).

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lenging his identification, evaluation, or placement; the court's holding that exhaustion was not required was not made in the context of a challenged action by a school that is specifically covered by the Act and thus is hardly strong precedent. And in the third case the issue was decided on a finding that the plaintiffs had obtained a "final ruling" from local and state authorities and could pursue their section 1983 remedy under the "ripeness" rule. In the one case that allowed the private right of action without exhaustion, the case was filed before P.L. 94-142 was enacted, the court granted a preliminary injunction, retained jurisdiction for eight years before entering its final order, and therefore did not have to face squarely the exhaustion issue. It seems correct to conclude that exhaustion is a prerequisite to a civil action unless the "futility" doctrine can be brought into play.

Finally, it appears that P.L. 94-142 is not yet a vehicle by which a handicapped student may recover monetary damages from a school for its failure to evaluate and educate him appropriately as required by the Act. It is not a new "education malpractice" statute, 134 although as interpreted by the courts it does permit a child's parents to recover their expenses in a private right of action, after exhaustion, for educating him appropriately in the absence of a school's doing so. 135 The cases reaching these results, however, were not predicated on section 1983 claims; *Thiboutot* and *Maher* may well change these results in the properly framed case where relief for denial of federal statutory rights under P.L. 94-142 is sought under section 1983.

D. Section 504's Enforceability. There is indeed a judicially created impasse concerning the enforceability of section 504 and thereby its effectiveness as a remedy for disabled citizens who allege they have been discriminated against, solely because of their handicaps, by recipients of federal aid and that they are qualified to receive the benefits of the recipients' programs. The issues are complex, and only a summary of them is presented here so that section 504's general usefulness, or lack of it, can be brought to the

<sup>131.</sup> Loughran v. Flanders, 470 F. Supp. 110 (D. Conn. 1979).

<sup>132.</sup> Oster v. Boyer, No. 77-0348 (D.R.I., Feb. 5, 1979).

<sup>133.</sup> Larry P. v. Riles, 495 F. Supp. 926 (N.D. Cal. 1979).

<sup>134.</sup> Loughran v. Flanders, 470 F. Supp. 110 (D. Conn. 1979). But see Halligan, The Function of Schools, the Status of Teachers, and the Claims of the Handicapped: An Inquiry into Special Education Malpractice, 45 Mo. L. Rev. 667 (1980).

<sup>135.</sup> Boxall v. Sequoia Union High School Dist., 464 F. Supp. 1104 (N.D. Cal. 1979).

reader's attention in the context of this more broadly focused article. Significantly, the Supreme Court ducked the issue raised in *University of Texas v. Camenisch*, <sup>136</sup> whether a private right of action exists under section 504. The Court's decision leaves unfilled the decisional vacuum of the private right-of-action issue.

Simply because a handicapped person has been discriminated against, in violation of section 504, it does not necessarily mean that he himself has a remedy.<sup>137</sup> Congress must either expressly or by implication grant him a private right of action; absent that right, his only remedy is to seek termination of federal funds to the violating recipient.<sup>138</sup>

Before its amendment in 1978, the Rehabilitation Act clearly did not explicitly provide for a private right of action under section 504, but most courts found an implied right. The 1978 amendment complicated the issue by providing, among other things, that the rights, procedures, and remedies in Title VI of the 1964 Civil Rights Act were applicable to section 504. An earlier Supreme Court decision held that a person complaining of Title VI discrimination has a private right of action. But another provision of Title VI vitiates that provision as it applies to employment

<sup>136. 616</sup> F.2d 127 (5th Cir. 1980), vacated and remanded, 101 S. Ct. 1830 (1981).

<sup>137.</sup> Cannon v. University of Chicago, 441 U.S. 677 (1979).

<sup>138.</sup> Id. A complainant may initiate an administrative action with the Department of Health and Human Services (formerly Health, Education, and Welfare) to cut off federal aid to the employer. See 45 C.F.R. § 80.8 (1980) (regulations implementing Title VI); 45 C.F.R. § 85.5 (1980) (ordering agencies to use Title VI enforcement and hearing procedures to enforce section 504).

<sup>139.</sup> Lloyd v. Regional Transp. Auth., 548 F.2d 1277 (7th Cir. 1977). In Lloyd, the court applied the test of Cort v. Ash, 422 U.S. 66 (1975), to determine whether Congress had intended a private right of action: (1) Is the plaintiff one of the class for whose special benefit the statute was enacted? (2) Is there any indication of a legislative intent, explicit or implicit, to create or deny a private remedy? (3) Is the implication of a private remedy consistent with the underlying purpose of the legislative scheme? (4) Is the cause of action to be implied one that has traditionally been relegated to the state courts, so that a federal cause of action would be inappropriate? The Lloyd court also relied on the similarity between section 504 and section 601 of Title VI of the 1964 Civil Rights Act to support an implied cause of action. In Lau v. Nichols, 414 U.S. 563 (1974), the Supreme Court inferred a private right of action under Title VI. See also Regents of the Univ. of California v. Bakke, 438 U.S. 265 (1978), on the existence of a private right of action under Title VI.

Lloyd was the first appellate decision on the question of a private right of action. It cited the following district court cases as in accord: Sites v. McKenzie, 423 F. Supp. 1190 (N.D.W. Va. 1976); Hairston v. Drosick, 423 F. Supp. 180 (S.D.W. Va. 1976), appeal dismissed, 614 F.2d 770 (3d Cir. 1980), cert. denied, 101 S. Ct. 1375 (1981); Cherry v. Mathews, 419 F. Supp. 922 (D.D.C. 1976); Gurmankin v. Costanzo, 411 F. Supp. 982 (E.D. Pa. 1976), aff'd, 556 F.2d 184 (3d Cir. 1977).

<sup>140.</sup> Lau v. Nichols, 414 U.S. 563 (1974).

discrimination; section 604 of Title VI provides for a private right of action only when the primary objective of the federal aid to the alleged violator is to provide employment.<sup>141</sup>

The threshold enforcement issue currently is whether a private right of action exists under section 504. Preregulation cases, particularly Lloyd v. Regional Transportation Authority, 142 held that section 504 creates a private right of action. 143 Some post-regulation cases<sup>144</sup> follow *Lloyd*. Indeed, the Supreme Court assumed, without deciding, that a private right of action exists when it held in Southeastern Community College v. Davis 145 that a postsecondary education institution is not required to make substantial changes in its nursing curriculum in order to accommodate the admission of a licensed practical nurse whose hearing was seriously impaired and degenerating. But other courts, while agreeing that a private right of action exists, have insisted upon prior exhaustion of administrative remedies.146 Still others, while agreeing with the right-of-action-exists cases, have found that exhaustion is not required where it would prove futile.147 Some courts have been able to escape the section 504 quagmire by invoking the "primary jurisdiction" doctrine when administrative remedies are being pursued or can be pursued effectively during the pendency of a federal court claim. 148 And

<sup>141. 42</sup> U.S.C. § 2000d-3 (1976).

<sup>142. 548</sup> F.2d 1277 (7th Cir. 1977).

<sup>143.</sup> See also United Handicapped Fed'n v. Andre, 558 F.2d 413 (8th Cir. 1977); Sites v. McKenzie, 423 F. Supp. 1190 (N.D.W. Va. 1976); Hairston v. Drosick, 423 F. Supp. 180 (S.D.W. Va. 1976).

<sup>144.</sup> Camenisch v. Univ. of Texas, 616 F.2d 127 (5th Cir. 1980), vacated and remanded, 101 S. Ct. 1830 (1981); NAACP v. Medical Center, Inc., 599 F.2d 1247, 1258 (3d Cir. 1979); Leary v. Crapsey, 566 F.2d 863 (2d Cir. 1977); United Handicapped Fed'n v. Andre, 558 F.2d 413 (9th Cir. 1977); Kampmeier v. Nyquist, 553 F.2d 296 (2d Cir. 1977); Coleman v. Casey County Bd. of Educ., 510 F. Supp. 301 (W.D. Ky. 1980); Miener v. Missouri, 498 F. Supp. 949 (E.D. Mo. 1980); Guertin v. Hackerman, 496 F. Supp. 593 (S.D. Tex. 1980); Medley v. Ginsberg, 492 F. Supp. 1294 (S.D. W. Va. 1980); Whitaker v. Board of Higher Educ., 461 F. Supp. 99 (E.D.N.Y. 1978); Howard S. v. Friendswood Independent School Dist., 454 F. Supp. 634 (S.D. Tex. 1978); Doe v. New York Univ., 442 F. Supp. 522 (S.D.N.Y. 1978); Barnes v. Converse College, 436 F. Supp. 635 (D.S.C. 1977); Rogers v. Frito-lay, Inc., 433 F. Supp. 200 (N.D. Tex. 1977), aff'd, 611 F.2d 1074 (5th Cir.), cert. denied, 101 S. Ct. 246 (1980).

<sup>145. 442</sup> U.S. 397 (1979). See also Duran v. Tampa, 451 F. Supp. 954 (M.D. Fla. 1978).

<sup>146.</sup> Johnson v. Brelje, 482 F. Supp. 125 (N.D. Ill. 1979); Harris v. Campbell, 472 F. Supp. 51 (E.D. Va. 1979); Sherer v. Waier, 457 F. Supp. 1039 (W.D. Mo. 1978); Doe v. New York Univ., 442 F. Supp. 522 (S.D.N.Y. 1978).

<sup>147.</sup> Whitaker v. Board of Higher Educ., 461 F. Supp. 99 (E.D.N.Y. 1978); Howard S. v. Friendswood Independent School Dist., 454 F. Supp. 634 (S.D. Tex. 1978); Doe v. Grile, No. F-77-108 (N.D. Ind., 1978).

<sup>148.</sup> Stubbs v. Kline, 463 F. Supp. 110 (W.D. Pa. 1978); Crawford v. University of North

some courts have held, apparently with Supreme Court approval, that section 504 does not create a private right of action except in very limited circumstances. 149

A related section 504 enforcement issue is whether damages, injunctive relief, or both are available under section 504. There seems to be no doubt about the availability of injunctive relief. <sup>150</sup> On the other hand the cases are split on whether damages are available. <sup>151</sup>

## III. THE ROLE OF THE PRIVATE BAR

The opportunities for enforcing the established rights of disabled people have been enlarged by *Thiboutot* and *Maher*. But the vigor and imagination with which the established private bar responds will affect whether and how those rights become realities.

A. Extending Thiboutot and Maher. It is instructive to conjure up some of the enforcement suits that might be brought on disabled citizens' behalf by counsel already active in the MR/DD movement or in the established, private-practice bar. A variety of suits based on violations of constitutional rights alone could be brought under section 1983. Violations of the first amendment right to liberty could be attacked under the holding in O'Connor v. Donaldson. There, the Supreme Court allowed a wrongfully detained mental patient to recover damages under section 1983 against a state-em-

Carolina, 440 F. Supp. 1047 (N.D.N.C. 1977); Drennon v. Philadelphia Gen. Hosp., 428 F. Supp. 809 (E.D. Pa. 1977).

<sup>149.</sup> Simpson v. Reynolds Metals Co., 629 F.2d 1226 (7th Cir. 1980); Carmi v. Metropolitan St. Louis Sewer Dist., 620 F.2d 672 (8th Cir.), cert. denied, 101 S. Ct. 249 (1980); Trageser v. Libbie Rehabilitation Center, 590 F.2d 87 (4th Cir. 1978), cert. denied, 442 U.S. 947 (1979); United States v. Cabrini Medical Center, 497 F. Supp. 95 (S.D.N.Y. 1980), rev'd, 639 F.2d 908 (2d Cir. 1981); Hart v. County of Alameda, 485 F. Supp. 66 (N.D. Cal. 1979).

<sup>150.</sup> Cases granting injunctive relief include Camenisch v. University of Texas, 616 F.2d 127 (5th Cir. 1980), vacated and remanded, 101 S. Ct. 1830 (1981); Leary v. Crapsey, 566 F.2d 863 (2d Cir. 1977); New Mexico Ass'n for Retarded Citizens v. New Mexico, 495 F. Supp. 391 (D.N. Mex. 1980). Contra, Guempel v. New Jersey, 159 N.J. Super. 166, 387 A.2d 399 (Super. Ct. Law Div. 1978), modified, 84 N.J. 234, 418 A.2d 229 (1980); Poole v. South Plainfield Bd. of Educ., 490 F. Supp. 948 (D.N.J. 1980).

<sup>151.</sup> Cases granting monetary damages include Leary v. Crapsey, 566 F.2d 863 (2d Cir. 1977); Meiner v. State of Missouri, 498 F. Supp. 949 (E.D. Mo. 1980); Patton v. Dumpson, 498 F. Supp. 933 (S.D.N.Y. 1980); Poole v. South Plainfield Bd. of Educ., 490 F. Supp. 948 (D.N.J. 1980); Boxall v. Sequoia Union High School Dist., 464 F. Supp. 1104 (N.D. Cal. 1979); Stemple v. Board of Educ., 464 F. Supp. 258 (D. Md. 1979), aff'd, 623 F.2d 893 (4th Cir. 1980), cert. denied, 101 S. Ct. 1348 (1981); Guempel v. New Jersey, 159 N.J. Super. 166, 387 A.2d 399 (Super. Ct. Law Div. 1978), modified, 84 N.J. 234, 418 A.2d 229 (1980).

<sup>152. 422</sup> U.S. 563 (1975).

ployed physician; the Court recognized a right-to-liberty claim by the patient. Likewise, violations of wrongful school exclusion can give rise to a fifth and fourteenth amendment cause of action, pursued under section 1983, as in Wood v. Strickland. 153 It might also be possible to pursue other unconstitutional school practices by a section 1983 suit, including the misclassification of children as handicapped, 154 the improper placement of handicapped children in "more restrictive" inappropriate programs, 155 or the failure to comply with constitutionally acceptable due process in classification, placement, or exclusion cases. 156 The constitutionally based rightto-treatment, implied under the equal protection, due process, and cruel and unusual treatment clauses, 157 also might become more enforceable if section 1983 liability actions were filed against state and local officials. By the same token, the constitutionally protected right against treatment<sup>158</sup> is enforceable by a section 1983 suit. The wrongful denial of the fifth amendment right to property already has been successfully pursued in a section 1983 suit against state officials who illegally seized institutionalized persons' private funds without prior notice or hearing on their competency to manage those funds. 159 Finally, the exclusion of group homes, in violation of first amendment association rights, might be remedied in a section 1983 action.160

Nor are enforcement remedies limited to constitutional violations. Under the *Thiboutot-Maher* principle that a section 1983 action, with recoverable attorney fees, will lie for violation by state and local officials of federal statutory rights, it is possible to enforce a wide range of federally created rights. Clearly, any benefit created by the Social Security Act, including dependents' benefits, SSI pay-

<sup>153. 420</sup> U.S. 308 (1975).

<sup>154.</sup> Larry P. v. Riles, 495 F. Supp. 926 (N.D. Cal. 1979).

<sup>155.</sup> Lora v. Board of Educ., 456 F. Supp. 1211 (E.D.N.Y. 1978), remanded for further findings, 623 F.2d 248 (2d Cir. 1980). See also Carey v. Piphus, 435 U.S. 247 (1978).

<sup>156.</sup> See S-1 v. Turlington, 635 F.2d 342 (5th Cir. 1981); Doe v. Koger, 480 F. Supp. 225 (N.D. Ind. 1979); Howard S. v. Friendswood Independent School Dist., 454 F. Supp. 634 (S.D. Tex. 1978); Stuart v. Nappi, 443 F. Supp. 1235 (D. Conn. 1978); Lebanks v. Spears, 60 F.R.D. 135 (E.D. La. 1973).

<sup>157.</sup> See cases listed supra note 8.

<sup>158.</sup> Rogers v. Okin, 478 F. Supp. 1342 (D. Mass. 1979), modified, 634 F.2d 650 (1st Cir. 1980); Rennie v. Klein, 462 F. Supp. 1131 (D.N.J. 1978).

<sup>159.</sup> Vecchione v. Wohlgemuth, 481 F. Supp. 776 (E.D. Pa. 1979), awarding \$200,000 in counsel fees in \$9 million settlement on suit against state officials who illegally seized mental patients' funds without prior notice or hearing on their competency.

<sup>160.</sup> Owen v. City of Independence, 445 U.S. 622 (1980); Monell v. Dep't of Social Serv., 436 U.S. 658 (1978); Doe v. Shutt, No. 7-72755 (E.D. Mich. 1979).

ments, and medical assistance, is enforceable under *Thiboutot-Maher*, which themselves were actions to enforce the Social Security Act (AFDC). The right-to-treatment under the DD Act already has been held enforceable by a section 1983 action. A right to "least restrictive" residential placement under the Community Mental Health Centers Act has been enforced in a similar action. Those two decisions strongly suggest that the new Mental Health Systems Act, a particularly its Bill of Rights provisions, will soon become the focus of section 1983 litigation. By the same token, enforcement of P.L. 94-142 already is underway through section 1983, and *Thiboutot-Maher* will simply expand the litigation opportunities on behalf of handicapped children.

The enforcement prospects are not nearly so bright when the disabled person's rights are subject to being removed or diminished by judicial action. Stump v. Sparkman<sup>164</sup> extended immunity from section 1983 to state judges in involuntary sterilization cases; it is reasonable to expect that the same kind of immunity would be available in cases of involuntary commitment, judicially approved voluntary admissions of minors to psychiatric hospitals or mental retardation centers, 165 or adjudication of incompetency and appointment of a guardian, since each of these actions requires judicial action. Yet there is no principle of unlimited judicial immunity under Stump. The majority opinion set forth five criteria for determining whether the judge will be liable under section 1983; there is no judicial immunity if: (1) the court in which the judge sits is not a court of general jurisdiction; (2) there is a clear absence of all jurisdiction; (3) the court is of limited jurisdiction and there have been procedural errors or an absence of a statute specifically authorizing the judge to act; (4) the judge acts outside his "normal" functions; and (5) the parties did not expect him to be acting as a judge. The dissents by Justices Stewart, Marshall, and Powell would have held there was section 1983 liability, if the judge could have been shown to be acting under color of law and without good faith, in an ex parte petition by a minor's mother to sterilize her daughter because (1) there was no "case" before the court, (2) there were no litigants,

<sup>161.</sup> Naughton v. Bevilacqua, 458 F. Supp. 610 (D.R.I. 1978), aff'd, 605 F.2d 586 (1st Cir. 1979).

<sup>162.</sup> Medley v. Ginsberg, 492 F. Supp. 1294 (S.D.W. Va. 1980).

<sup>163.</sup> Pub. L. No. 96-398, 94 Stat. 1564 (1980).

<sup>164. 435</sup> U.S. 349 (1978).

<sup>165.</sup> Secretary of Public Welfare v. Institutionalized Juveniles, 442 U.S. 640 (1979); Parham v. J.R., 442 U.S. 584 (1979).

- (3) there was no opportunity for appeal, and (4) there was no pretext of principled decision-making. Moreover, recovery against "purely private" citizens who conspire with public officials, 166 including judges, 167 to deprive others of their constitutional rights is clearly allowable. Private citizens, however, tend to enjoy whatever qualified immunity is available to public officials under the principle of derivative immunity. Nonetheless, section 1983 still might be used, albeit in highly limited circumstances, in private citizenjudge "conspiracy" cases, such as those involving involuntary commitment, admissions of minors, or adjudications of incompetence.
- B. The Role of Private Counsel. One of the problems in enforcing the established rights of disabled clients is that the incentives for attorneys to represent them are dismally low. Although there are many reasons why this is true, the poor incentives should not prevent attorneys from representing such clients.

Many cases involving disabled clients will be truly low-paying. The real client may not have resources to pay for legal services; a disabled person not only is usually effectively barred from gainful employment but also is usually marginally compensated when employed. Although attorneys' fees are sometimes recoverable, as pointed out above, the "DD bar" is still largely a "poverty-law" bar. Moreover, many disabled clients will not be "repeaters" who will bring new business to an attorney or generate profitable referrals. Unless the client is involved in major class-action litigation, the attorney usually will represent him once in a single-shot matter. Many clients' cases have not involved large-sized damages because their cases entail the enforcement of statutory or constitutional rights, not the recovery of damages for wrongs. Of course, enforcement of rights can include claims for damage, but it is not clear yet that those cases establish the rule, not the exception. 169

Other DD-law cases have inherent disincentives that do not relate to the financial ones. Many cases are very prolonged. Thus a claim that a student's rights have been violated by a local school usually must move through a local due process hearing and a statelevel procedure before it becomes ripe for review in federal court; similar administrative-remedy delays plague cases brought under

<sup>166.</sup> United States v. Price, 383 U.S. 787 (1966).

<sup>167.</sup> Downs v. Sawtelle, 574 F.2d 1 (1st Cir.), cert. denied, 439 U.S. 910 (1978).

<sup>168.</sup> Haldane v. Chagnon, 345 F.2d 601 (9th Cir. 1965) and Comment, Derivative Immunity: An Unjustifiable Bar to Section 1983 Actions, 1980 DUKE L.J. 568 (1980).

<sup>169.</sup> See cases collected at supra note 151.

section 504 (except where a jurisdiction allows private right of action suits without prior exhaustion of those remedies). Obviously, such cases are slow-turnover cases requiring attorneys to wait long periods of time before concluding the case and submitting final bills.

Many of the DD-law cases are brought against state or local governmental agencies whose financial resources for defending seem nearly inexhaustible. Indeed, a state or local government defendant can litigate seemingly forever because of its financial resources and still justify the extraordinary expenditure on sound economic grounds; the cost of complying with an unfavorable decree in the case (especially if it is a class-action suit) can be staggering and should be avoided at almost all costs.

Restrictions on class-action lawsuits preclude, or at least make dim, the prospects that any case will produce massive, system-wide changes; most litigation will be one-to-one litigation which, if successful, will produce system changes only incrementally. Moreover, judicial decrees calling for widespread or dramatic changes in government service systems are not self-enforcing; obtaining a favorable decision is usually the first round in a series of return-tocourt petitions for enforcement.<sup>170</sup> Prolonged litigation is inherent in some attorneys' practices; but prolonged litigation that does not necessarily produce financial rewards for the client and his attorney is a disincentive to many attorneys. Finally, a victory in one-to-one or class-action litigation against a government agency does not mean that the agency will conform its practices to the court's order in future cases. A local school educational agency, for example, can require DD lawyers to file new charges against it for other similarly situated plaintiffs by treating the decision as binding on that one case only; the placement to which one handicapped child is entitled is not necessarily the same for other similarly handicapped children. The essentially repetitious litigation facing some DD lawyers may drive them out of the DD-law area.

Finally, attorneys representing low-functioning disabled clients

<sup>170.</sup> See, e.g., Wyatt v. Ireland, No. 3195-N (M.D. Ala. Oct. 25, 1979) (court placing mental health and mental retardation institutions into receivership for "substantial and serious non-compliance" with 1972 court-ordered standards for those institutions), Wyatt v. Stickney, 344 F. Supp. 387 (M.D. Ala. 1972), aff'd in part and rev'd in part sub nom. Wyatt v. Aderholt, 503 F.2d 1305 (5th Cir. 1974); Brewster v. Dukakis, No. 76-4423-F (E.D. Mass., June, 1980); and Mills v. D.C. Bd. of Educ., No. 1939-71 (D.D.C., June 18, 1980), holding the defendants in contempt for "willful and deliberate" violations of 1972 court order rendered in Mills v. Board of Educ., 348 F. Supp. 866 (D.D.C. 1972).

face major ethical problems<sup>171</sup> and are not likely to reap any psychic compensation directly from their clients for their work. Such attorneys, engaged in an essentially civil-rights war and lacking many of the financial and other incentives that might attract them to a "private" practice, must derive many of their satisfactions in other ways.

Given these rather substantial obstacles to the creation of a DD bar and the enforcement of disabled clients' rights, what might practicing attorneys and an organized bar do to insure that a powerless minority does not want for effective representation and enforcement of their rights?

It would help initially for the attorneys who represent DD clients to infiltrate the organized bar and work from within it. While it is true that developmentally disabled clients are different than nonhandicapped clients and present unusual ethical or representational problems, their legal problems are not substantially different than those of nonhandicapped people. They have legitimate needs for representation in tort, contract, criminal, family, and estate law matters; and the nature of their interests in these areas of law are remarkably similar to those of nonhandicapped clients. Yet their disabilities may have caused them to go without legal services and may have led to the organized bar's neglect of their legal-service needs. Attorneys familiar with developmentally disabled clients have a duty to demystify their clients, showing that their disabilities may cause peculiar problems of representation, but also that these problems do not disqualify them from being represented. The notion that a separate "mental disability" bar should serve well all of the legal needs of all disabled clients is simply unacceptable; the number of attorneys who will elect to practice for those clients is bound to be small because the incentives are small and the clients' needs may outweigh the ability of that cadre of lawyers to respond. If anything, a disability bar should be the vanguard, but not the only practitioners.

Mainstreaming the mental disability bar into the larger and more comprehensive bar can be accomplished in a variety of ways. Law school education need not be limited to rather familiar courses in "law and psychiatry." While those courses are important and have their very real values, they tend to obscure the functional differences between mentally ill clients and developmentally disabled

<sup>171.</sup> See Mickenberg, The Silent Clients: Legal and Ethical Considerations in Representing Severely and Profoundly Retarded Individuals, 31 STAN. L. REV. 625 (1979), and Herr, The New Clients: Legal Services for Mentally Retarded Persons, 31 STAN. L. REV. 553 (1979).

clients. One result of obscuring the differences is to forestall the development of a DD bar or general-practice attorneys who will not automatically shy away from representing a DD client. Another result is to encourage the development of a body of law that fails to distinguish between the distinctive legal interests of developmentally disabled people on the one hand and mentally ill people on the other.<sup>172</sup>

Continuing legal education in developmental disabilities law, such as that sponsored by the University of Arkansas at Little Rock School of Law, can be a useful way of integrating DD-law capabilities into the arsenal of practicing attorneys and of showing them that there are interesting, important, and even profitable issues for them to consider.

Large firms accustomed to doing pro bono work for criminal defendants or in the poverty-law area can expand their horizons to include disabled clients. Indeed, the resources of talent and the financial stability that those firms enjoy should enable them to be part of the DD bar vanguard, just as some of them were partners of the frontier-breaking attorneys concerned with poverty-law issues during the 1960s and 1970s.

It will not be as difficult in the 1980s to bring DD law matters into the mainstream of legal education and practice as it would have been several years ago. The protection and advocacy agencies established by all states under the Developmental Disabilities Act may have their own limitations, but they at least represent an aggregation of talent and capacity that can be tapped by the practicing attorney. So, too, do the national legal backup centers at Notre Dame Law School (National Center on Law and the Handicapped), the District of Columbia-based Mental Law Project, and the Mid-Central Legal Center in Kansas City, Missouri. Their small bands of attorneys can be called upon from time to time to assist other practicing attorneys.

Members of the ABA Family Law Section, Subdivision on Mental Retardation and Ethics, may be helpful to practicing attorneys unfamiliar with DD clients or their legal interests. The ABA Commission on the Mentally Disabled consists of distinguished attorneys from throughout the United States who are able to advise on

<sup>172.</sup> Note the Supreme Court's failure to make such a distinction in the companion institutionalization-of-juveniles cases, Parham v. J.R., 442 U.S. 584 (1979), involving emotionally disturbed children, and Secretary of Public Welfare v. Institutionalized Juveniles, 442 U.S. 640 (1979), involving retarded children.

DD law matters. The Commission also publishes the best topical law reporter in the nation (*Mental Disability Law Reporter*). And an ABA project on model DD legislation has resulted in readily available research on a host of DD legal issues.

Finally, the availability of counsel will increase as states appropriate funds for representation of disabled indigents in such proceedings as involuntary commitment, incompetency adjudications, admission-to-institution hearings involving minors whose admission is sought by their parents or the state, or similar liberty or rights depriving hearings.

C. Voluntary Compliance. The foregoing discussion assumes voluntary compliance—that which obtains when the governmental agency against which the handicapped person has rights complies with its duties toward him—will not always be forthcoming. One illustration from special education law may show why voluntary compliance is not easy to obtain.

Handicapped children have the right to related services to enable them to benefit from special education. Consider the problems a school might have in voluntarily complying with the related services requirement in the case of a multiply handicapped child who needs both special education as well as traditional health services such as medical evaluation, physical therapy for his physical disabilities, and administration of drugs for his seizures. The school must either provide these services itself or arrange for them to be provided by a local public health agency (such as the public health clinic) or by a local physician or other privately employed person. If it arranges for the services to be provided by the public health agency, enforcement becomes rather more difficult than if it provides them itself or buys the services from a private provider. The public health agency will have its own waiting lists, capabilities, priorities, and funding sources; it will also seek to have the school pay for the services. Problems immediately develop concerning inter-agency cooperation and coordination. Not only that, but there also will be intergovernmental cooperation and coordination problems because both agencies receive local, state, and federal funds and may have to respond to different priorities and regulations. More-over, the local, state, and federal funding sources may be unclear about which level of government will pay for the services, not just which agency at a particular level.

Within just the public agencies, voluntary enforcement is not

easy to obtain. State departments of public instruction are required to monitor local schools' compliance with P.L. 94-142. The federal Department of Education, through the Office of Special Education and Rehabilitation Services and the Office of Civil Rights, likewise is required to monitor state and local compliance with P.L. 94-142; it also is required to attend to any complaints filed with it by representatives of handicapped children who allege that schools are not complying with P.L. 94-142. Neither the Office for Special Education nor the Office of Civil Rights is sufficiently well staffed and funded to handle these duties; at best, its monitoring will be sparse (there are, after all, close to 16,000 local school districts in the United States). Its responsiveness to complaints will be questionable as the docket grows disproportionately to OCR's staff and budget.

## CONCLUSION

The 1970s were years of impressive progress for disabled citizens. It is far from certain that the 1980s will be as fruitful for them; certainly the lesson of the 96th Congress is that progress in creating new rights will be slow and difficult. But the Supreme Court has thrown open a wide door for enforcement of disabled citizens' rights, and there is an increasingly large and active group of attorneys willing and able to represent these citizens in enforcing their rights. Although the disincentives for attorneys to join that vanguard are great, they are not insurmountable; and good, but insufficient, progress has been made to expand the capabilities and willingness of the private bar to represent the underrepresented. But unless more is done to bring a greater number of attorneys into the field and to assure their competency in the disabilities law field, the promise of the 1970s could be largely unfulfilled in the 1980s.