

Article

The Future of Disability Law

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Since its enactment in 1990, the Americans with Disabilities Act (ADA)¹ has dominated discussions of disability law in the legal academy. Literally volumes of work have been devoted to defending, criticizing, and analyzing the statute, the cases interpreting it, and the effects it has had in the real world.² That scholarly focus is in many respects entirely appropriate. The ADA was a historic achievement. It represented our society's first comprehensive acknowledgment that people with disabilities are truly equal citizens, fully entitled to participate in all areas of political, economic, and civic life. And in large and small ways the statute has improved the lives of countless individuals who have disabilities. The ADA has made buildings more accessible and people with disabilities more visible in the community, and it has accelerated the process of removing the stigma from disability.

But while the ADA's achievements must be celebrated, the statute's limitations have become increasingly apparent. In particular, the statute appears to have had little, if any, positive effect on the overall employment of people with disabilities, and a number of commentators assert that it has had a negative effect.³ That result has occurred, I contend, not because of the narrowing interpretations the Supreme Court has placed on the ADA,⁴

1. 42 U.S.C. §§ 12101-12213 (2000).

2. A list of all of the ADA-focused articles that have appeared in the law reviews would go on for pages. In addition to countless individual articles, the ADA has also been the principal subject of at least eight law review symposia. See Symposium, *The Americans with Disabilities Act: Directions for Reform*, 35 U. MICH. J.L. REFORM 1 (2001-2002); *The Americans with Disabilities Act Symposium: A View from the Inside*, 64 TEMP. L. REV. 371 (1991); Symposium, *Backlash Against the ADA*, 21 BERKELEY J. EMP. & LAB. L. 1 (2000); Symposium, *Defining the Parameters of Coverage Under the Americans with Disabilities Act: Who Is "an Individual with a Disability?"*, 42 VILL. L. REV. 327 (1997); Symposium, *Disability and Identity*, 44 WM. & MARY L. REV. 907 (2003); Symposium, *Facing the Challenges of the ADA: The First Ten Years and Beyond*, 62 OHIO ST. L.J. 1 (2001); Garrett, *Disability Policy, and Federalism: A Symposium on Board of Trustees of the University of Alabama v. Garrett*, 53 ALA. L. REV. 1075 (2002); Symposium, *Individual Rights and Reasonable Accommodations Under the Americans with Disabilities Act*, 46 DEPAUL L. REV. 871 (1997). Among legal scholars alone, the ADA has been the subject of at least three full-fledged books and two edited volumes. See BACKLASH AGAINST THE ADA: REINTERPRETING DISABILITY RIGHTS (Linda Hamilton Krieger ed., 2003); EMPLOYMENT, DISABILITY, AND THE AMERICANS WITH DISABILITIES ACT: ISSUES IN LAW, PUBLIC POLICY, AND RESEARCH (Peter David Blanck ed., 2000) [hereinafter EMPLOYMENT, DISABILITY]; DAVID M. ENGEL & FRANK W. MUNGER, RIGHTS OF INCLUSION: LAW AND IDENTITY IN THE LIFE STORIES OF AMERICANS WITH DISABILITIES (2003); SUSAN STEFAN, HOLLOW PROMISES: EMPLOYMENT DISCRIMINATION AGAINST PEOPLE WITH MENTAL DISABILITIES (2002); SUSAN STEFAN, UNEQUAL RIGHTS: DISCRIMINATION AGAINST PEOPLE WITH MENTAL DISABILITIES AND THE AMERICANS WITH DISABILITIES ACT (2001). A number of legal scholars also contributed to the edited volume AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS (Leslie Pickering Francis & Anita Silvers eds., 2000), which likewise focused on the ADA.

3. See *infra* Section I.B.

4. Much of the legal academic commentary on the ADA criticizes various decisions of the Supreme Court and other courts that have narrowed the scope of the ADA. See Samuel R. Bagenstos, *The Americans with Disabilities Act as Welfare Reform*, 44 WM. & MARY L. REV.

but because of the inability of antidiscrimination laws to eliminate the deep structural barriers to employment that people with disabilities face. The ADA's antidiscrimination requirement can prevent an employer from refusing to hire a qualified person simply because the person has a disability, and the ADA's accommodation requirement can force the employer to make some changes in facilities or job tasks to enable individuals with disabilities to perform particular jobs. But those mandates do not require the employer to provide in-home personal-assistance services or transportation to enable an individual with a disability to get to work, nor do they require the employer to provide the individual with health insurance coverage that is as adequate as he or she can receive through Medicaid.⁵ The solutions to these problems require more than simply mandating that individual employers cease discriminating and provide accommodations; they require more direct and sustained government interventions such as the public funding and provision of benefits.

In short, the future of disability law lies as much in social welfare law as in antidiscrimination law. Although this point may not be obvious from a scan of legal scholarship,⁶ activists "on the ground" have increasingly

921, 930-52 (2003) (collecting examples of that commentary). Examples of the Supreme Court's narrowing decisions include the restrictive readings of the statute's definition of "disability" in cases like *Sutton v. United Air Lines*, 527 U.S. 471 (1999), and *Toyota Motor Manufacturing, Kentucky v. Williams*, 534 U.S. 184 (2002); the expansive reading of employers' defenses in *Albertson's, Inc. v. Kirkingburg*, 527 U.S. 555 (1999), and *Chevron U.S.A. v. Echazabal*, 536 U.S. 73 (2002); and the invalidation of the abrogation of state sovereign immunity under the ADA's employment title in *Board of Trustees v. Garrett*, 531 U.S. 356 (2001).

5. See *infra* Part II.

6. There are remarkably few exceptions to the ADA-centrism of post-1990 academic discussions of disability law. Some scholars have argued that the ADA cannot achieve its goals unless societal attitudes toward disability also change, but those scholars have not pointed to any policy intervention—aside from the ADA itself—that would cause such a change in attitudes. See, e.g., Linda Hamilton Krieger, *Socio-Legal Backlash*, 21 BERKELEY J. EMP. & LAB. L. 476 (2000); Michael Ashley Stein, *Employing People with Disabilities: Some Cautionary Thoughts for a Second-Generation Civil Rights Statute*, in EMPLOYMENT, DISABILITY, *supra* note 2, at 51, 52-53. Professors Matthew Diller and Mark Weber have provided the most notable exceptions to ADA-centrism in the law reviews. Professor Diller has written two significant articles that have focused on the role of disability in social welfare law—one of which explored the "dissonance" between the ADA's response to disability and the social welfare system's response to disability. See Matthew Diller, *Dissonant Disability Policies: The Tensions Between the Americans with Disabilities Act and Federal Disability Benefit Programs*, 76 TEX. L. REV. 1003 (1998) [hereinafter Diller, *Dissonant Disability Policies*]; Matthew Diller, *Entitlement and Exclusion: The Role of Disability in the Social Welfare System*, 44 UCLA L. REV. 361 (1996) [hereinafter Diller, *Entitlement and Exclusion*]. Professor Weber has written about the limitations of the ADA as a tool for improving the employment rate for people with disabilities and has urged expanded welfare protections and a system of job set-asides for disabled individuals. See Mark C. Weber, *Beyond the Americans with Disabilities Act: A National Employment Policy for People with Disabilities*, 46 BUFF. L. REV. 123 (1998) [hereinafter Weber, *Beyond the ADA*]; Mark C. Weber, *Disability and the Law of Welfare: A Post-Integrationist Examination*, 2000 U. ILL. L. REV. 889 [hereinafter Weber, *Disability and the Law of Welfare*]. Professor Jerry Mashaw has also been centrally involved in work (outside of the law reviews) that focuses on the treatment of disability in the social welfare system. See DISABILITY: CHALLENGES FOR SOCIAL INSURANCE, HEALTH

understood the importance of the social welfare system to achieving the goals of the disability rights movement.⁷ Litigation to enforce the Medicaid statute is a growth industry for disability rights lawyers. And the legislative priorities of disability rights advocates have turned in recent times to social welfare legislation: the Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999,⁸ which removes some of the work disincentives in the social-security-disability programs; the proposed Medicaid Community-Based Attendant Services and Supports Act (MiCASSA),⁹ which would eliminate the “institutional bias” in the Medicaid program and require states to provide in-home personal-assistance services for people with disabilities; and other initiatives I discuss below. A major purpose of this Article is to bring these developments to the attention of the legal academic community and to make a case for treating them as central to future discussions of disability law.

But I hope to contribute to the discussion as well as start one. The turn to social welfare law is one about which disability rights advocates might understandably feel uneasy. Much of the thinking of the disability rights movement in this country developed as a reaction to the perceived paternalism and oppression that attended a welfare-based response to disability.¹⁰ Although the disability rights critique of disability welfare programs had its roots in the broader welfare rights movement of the late 1960s and early 1970s, disability rights advocates ultimately grew a great deal more ambivalent about the very idea of welfare than did welfare rights advocates more generally. By the 1970s, many disability rights advocates were presenting antidiscrimination laws as an alternative to social welfare provision for people with disabilities—a tool that would obviate welfare programs by giving people with disabilities opportunities to make a living on their own. If it is to be true to the disability rights movement, any turn

CARE FINANCING AND LABOR MARKET POLICY (Virginia P. Reno, Jerry L. Mashaw & Bill Gradison eds., 1997) [hereinafter *DISABILITY: CHALLENGES*]; *DISABILITY POLICY PANEL, NAT'L ACAD. OF SOC. INS., THE ENVIRONMENT OF DISABILITY INCOME POLICY: PROGRAMS, PEOPLE, HISTORY, AND CONTEXT* (Jerry L. Mashaw & Virginia P. Reno eds., 1996); *DISABILITY, WORK AND CASH BENEFITS* (Jerry L. Mashaw et al. eds., 1996); see also MICHAEL J. GRAETZ & JERRY L. MASHAW, *TRUE SECURITY: RETHINKING AMERICAN SOCIAL INSURANCE* 210-26 (1999) (discussing disability benefits policy in the context of a broader discussion of social welfare policy). In a very significant sense, this paper stands on the shoulders of the important work of Professors Diller, Mashaw, and Weber. I go beyond their work in a number of respects, however, by highlighting the tension between disability rights goals and a social welfare approach to disability, by analyzing the doctrinal means by which the ADA's accommodation requirement has been stripped of power to eliminate deep-rooted structural barriers to the employment of people with disabilities, and by focusing far more heavily on access to adequate health insurance as the major barrier to employment for many people with disabilities.

7. See *infra* Part III.

8. Pub. L. No. 106-170, 113 Stat. 1860 (codified in scattered sections of 26 and 42 U.S.C.).

9. H.R. 2032, 108th Cong. (2003); S. 971, 108th Cong. (2003).

10. See *infra* Section I.A.

(back) to social welfare law must seek to solve the problems of paternalism and oppression that advocates identified in an earlier generation of disability welfare programs. I hope to show some of the ways that current social welfare initiatives pursued by disability rights advocates do and do not take account of these problems, and to highlight the dilemmas advocates face in relying on the social welfare system.

My argument proceeds as follows. In Part I, I provide an overview of the causes and consequences of the shift from a social welfare to an antidiscrimination approach to disability law. I begin in Section A with the arguments of disability rights activists in the 1970s and 1980s. I discuss the ways in which activists criticized welfare programs for people with disabilities and describe how their critiques evolved into an embrace of antidiscrimination as an alternative to the social welfare paradigm of disability law. The disability rights movement's argument that antidiscrimination law would move significant numbers of people with disabilities off the benefits rolls and into the workforce strongly influenced both the drafting and the passage of the ADA. As I show in Section B, however, events have not worked out as disability rights advocates hoped. The antidiscrimination paradigm, as embodied in the ADA, has failed to achieve significant improvements in employment for people with disabilities. Although commentators are hotly debating the question whether the ADA has caused a decline in disability employment, it should be clear that any positive effect of the statute has occurred at the margins. For literally millions of working-age people with disabilities—the overwhelming majority—the ADA has been entirely irrelevant to their ability to get jobs.

In Part II, I offer a reason why this is so: Antidiscrimination laws are not suited to eliminating deep-rooted structural barriers to employment. One might think that the ADA's requirement of accommodation provides a tool to attack those structural barriers. But a number of features of ADA doctrine—features that are not nearly as controversial as one might expect—operate to assimilate the accommodation requirement very closely to a nondiscrimination rule. Those features of the doctrine have made the ADA a poor mechanism for eliminating structural employment barriers. I give particular attention to the statute's (lack of) effect on access to adequate health insurance because that is, by many accounts, the most significant obstacle to entering the workforce that people with disabilities collectively face.¹¹

11. The unavailability of adequate health insurance is obviously not the most significant employment barrier for each and every individual with a disability who is not working. For some, such as those with mental retardation, employer prejudice and the need for workplace accommodations may be the most significant barriers. But access to health insurance is plainly a

In Part III, I point to some of the ways in which disability rights advocates have begun to (re)embrace a social welfare approach to disability law. I also try to identify some respects in which these recent developments threaten to ignore the important critiques of welfare programs offered by the disability rights movement in the 1970s, and I suggest some ways in which a renewed embrace of social welfare law might be crafted to take account of those critiques.

Before proceeding, a word about the nature of my project is in order. I make no effort in this Article to offer any deep normative justification for or critique of disability law. My basic goal is more instrumental—to assess which policy tools are most likely to achieve the objectives that the disability rights movement has itself articulated.

To describe my project in this way introduces a complication. Social movements are not unitary actors. They are collections of people who feel various affiliations and who have a variety of motivations. The goals, strategies, and ideas of a social movement are always evolving and are always contested within the movement.¹² The disability rights movement is no exception. It embraces people with a range of different disabilities, different life experiences, different material needs, and different ideological perspectives.¹³ Thus, it is an oversimplification to write of the “goals of the disability rights movement” as if the term referred to some stable and uncontroversially identified category.¹⁴

Nonetheless, there seems to be broad agreement among diverse disability rights activists on a number of goals.¹⁵ One overarching goal is a negative one: freedom from the control of paternalistic parents, professionals, institutions, and welfare bureaucracies.¹⁶ Another

major obstacle to employment for a broad swath of nonworking people with disabilities, for the reasons I discuss in Part II.

12. See, e.g., William A. Gamson & David S. Meyer, *Framing Political Opportunity*, in *COMPARATIVE PERSPECTIVES ON SOCIAL MOVEMENTS: POLITICAL OPPORTUNITIES, MOBILIZING STRUCTURES, AND CULTURAL FRAMINGS* 275, 283-85 (Doug McAdam et al. eds., 1996).

13. See SHARON BARNARTT & RICHARD SCOTCH, *DISABILITY PROTESTS: CONTENTIOUS POLITICS 1970-1999* (2001) (discussing variety of views among disability rights activists regarding proper goals and means); JAMES I. CHARLTON, *NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT* 121-22 (1998) (describing ideological diversity among disability rights activists); Bagenstos, *supra* note 4, at 1008-13 (discussing diversity among people with disabilities); Andrew I. Batavia, *Ideology and Independent Living: Will Conservatism Harm People with Disabilities?*, 549 *ANNALS AM. ACAD. POL. & SOC. SCI.* 10, 11 (1997) (describing ideological diversity among disability rights activists).

14. I have, alas, done so myself. See Samuel R. Bagenstos, *Subordination, Stigma, and “Disability,”* 86 *VA. L. REV.* 397, 426 (2000).

15. This is what I meant when I referred to the “goals of the disability rights movement” in *Subordination, Stigma, and “Disability.”* See *id.* (describing views of “most disability rights advocates”).

16. See, e.g., Bagenstos, *supra* note 4, at 1010-12; Samuel R. Bagenstos, *The Supreme Court, the Americans with Disabilities Act, and Rational Discrimination*, 55 *ALA. L. REV.* 923, 932 n.70 (2004).

overarching goal may be framed more positively: the full integration of people with disabilities into all areas of public, civic, and community life.¹⁷ As a subsidiary matter, disability rights activists generally seem to agree that the movement should seek expanded opportunities for people with disabilities to obtain gainful employment and that it should seek additional public support for community, rather than institutional, placement options for those people with disabilities who need services and care.¹⁸ These goals do not exhaust the objectives of disability rights activists, and they may not be entirely compatible in principle or in practice. Community placement policies, for example, may serve a population for whom employment is hardly the immediate goal (though such policies may also facilitate employment in the long run), and they may compete for resources with policies such as subsidies that more directly reward work. But the goals of antipaternalism, community integration, and employment do provide a good general statement of the major policy objectives articulated by most disability rights activists.

In this Article, I largely take those goals as a given. My argument is that the antidiscrimination strategy has only limited potential to achieve them. In this respect, my argument is quite distinct from the two major challenges to disability discrimination law that currently compete in the legal academic literature. One challenge holds that the nondiscrimination and accommodation requirements for people with disabilities are themselves misguided because they impose unjustified burdens on private market actors and state and local governments.¹⁹ The other challenge holds that the ADA's nondiscrimination and accommodation requirements should be far-reaching, but that courts have participated in a backlash against the statute by reading its terms unduly narrowly.²⁰ In contrast to the first challenge, I contend that the problem is not that the ADA goes too far; to the contrary, it does not go far enough. In contrast to the second challenge, I contend that the limitations on the ADA's effectiveness are not simply the result of a judicial backlash against the statute. Rather, they are, to a significant extent, built into the antidiscrimination model itself.

17. See, e.g., CHARLTON, *supra* note 13, at 124-27; Timothy M. Cook, *The Americans with Disabilities Act: The Move to Integration*, 64 TEMP. L. REV. 393, 397 (1991); Ann Hubbard, *The Major Life Activity of Belonging*, 39 WAKE FOREST L. REV. 217, 254-64 (2004); Jacobus tenBroek, *The Right To Live in the World: The Disabled in the Law of Torts*, 54 CAL. L. REV. 841, 843 (1966).

18. On employment, see, for example, Bagenstos, *supra* note 4, at 964-65. On community placement, see, for example, Cook, *supra* note 17.

19. The prime example in the legal academic literature is RICHARD A. EPSTEIN, FORBIDDEN GROUNDS: THE CASE AGAINST EMPLOYMENT DISCRIMINATION LAWS 480-94 (1992).

20. The articles collected in BACKLASH AGAINST THE ADA, *supra* note 2, provide the best examples of this legal literature.

The argument in this Article should be of interest to those who think about antidiscrimination and social welfare law more broadly as well. A number of scholars who write about antidiscrimination law (myself among them) have recently challenged the otherwise near-consensus view that accommodation mandates are fundamentally different from and broader than antidiscrimination requirements. These challenges have typically emphasized the breadth of the antidiscrimination principle: They have sought to show that even the supposedly limited antidiscrimination requirement imposes the same sorts of costs—for the same sorts of reasons—as are usually attributed to accommodation requirements.²¹ This Article may be regarded as approaching the same issue from the opposite perspective—by emphasizing the narrowness of accommodation requirements. As I show, especially in Part II, the ADA’s requirement of reasonable accommodation has been consistently interpreted in a way that brings it very close to an antidiscrimination requirement in operation as well as effect. Because even the ADA’s strongest supporters have an ideological interest in narrowly reading the scope of the accommodation requirement, there is little reason to believe that this will ever change. This is a point that has not previously been appreciated in the literature.

Moreover, there are strong parallels between the structural barriers to employment for people with disabilities and the structural barriers to employment faced by poor people more generally.²² Indeed, disability and poverty are closely intertwined: Disability is a frequent cause of poverty, and living in poverty often causes or exacerbates disabling conditions.²³ Because people with disabilities are often perceived as the “deserving poor,” it may be politically easier to obtain enactment of programs to eliminate the structural barriers they face than it is to obtain the enactment of broad antipoverty programs. As I discuss in Part III, however, the goals of community integration and employment for people with disabilities may

21. I tried to do this in Samuel R. Bagenstos, “*Rational Discrimination*,” *Accommodation, and the Politics of (Disability) Civil Rights*, 89 VA. L. REV. 825 (2003). Other examples include Mary A. Crossley, *Reasonable Accommodation as Part and Parcel of the Antidiscrimination Project*, 35 RUTGERS L.J. 861 (2004); Christine Jolls, *Antidiscrimination and Accommodation*, 115 HARV. L. REV. 642 (2001); and Michael Ashley Stein, *Same Struggle, Different Difference: ADA Accommodations as Antidiscrimination*, 153 U. PA. L. REV. (forthcoming Dec. 2004).

22. There is, for example, a strong parallel between the obstacles to employment for people with disabilities who need but cannot obtain personal-assistance services and the obstacles to employment for poor people who need but cannot obtain adequate childcare. See GRAETZ & MASHAW, *supra* note 6, at 239-44; JOEL F. HANDLER & YEHESEKEL HASENFELD, *WE THE POOR PEOPLE: WORK, POVERTY, AND WELFARE* 117-27 (1997).

23. See, e.g., COMM. ON A NAT’L AGENDA FOR THE PREVENTION OF DISABILITIES, INST. OF MED., *DISABILITY IN AMERICA: TOWARD A NATIONAL AGENDA FOR PREVENTION* 47 (Andrew M. Pope & Alvin R. Tarlov eds., 1991) [hereinafter INST. OF MED.] (noting the difficulty of determining how frequently poverty causes disability versus how frequently disability causes poverty).

be best served in the long run by broader antipoverty measures. The political and policy dilemmas that people with disabilities face in devising and advocating favored policies may have lessons for other subgroups of poor people.

I. DISABILITY LAW'S SHIFT FROM WELFARE TO RIGHTS

In this Part, I discuss the shift in the orientation of American disability policy that took place in the 1970s and 1980s—a shift that culminated in the 1990 enactment of the Americans with Disabilities Act. Prior to the 1970s, disability law was effectively nothing more than a subcategory of social welfare law. Disability laws were laws that guaranteed rehabilitation services, cash benefits, and medical care to people with disabilities. As I explain in Section A, many disability rights activists sought to change the social welfare orientation of disability law. Those activists argued that welfare is oppressive and stifling and that antidiscrimination and accommodation requirements would enable people with disabilities to leave the benefits rolls and enter the workforce. Their critique of social welfare responses to disability strongly influenced the passage of the ADA.

Yet, as I explain in Section B, the ADA has not achieved the employment results disability rights activists anticipated. Depending on the measure of “disability” used, employment for people with disabilities has declined or remained stagnant since the statute’s enactment. Although a great deal of controversy surrounds the question whether the ADA has actually harmed the employment prospects of people with disabilities, it seems undeniable that the statute has not significantly improved those prospects. As I argue below in Part II, the ADA’s failure to increase employment among people with disabilities reflects the inherent limitations of an antidiscrimination approach.

A. *Disability Rights Activists Embrace the Antidiscrimination Paradigm*

Since at least the end of the Civil War, welfare benefits (often provided in conjunction with publicly supported rehabilitation services) have been one of the major building blocks of disability policy in America.²⁴ With the

24. For discussions of Civil War pensions, see THEDA SKOCPOL, PROTECTING SOLDIERS AND MOTHERS: THE POLITICAL ORIGINS OF SOCIAL POLICY IN THE UNITED STATES 102-51 (1992); Peter Blanck, *Civil War Pensions and Disability*, 62 OHIO ST. L.J. 109 (2001); and Peter Blanck & Chen Song, “Never Forget What They Did Here”: *Civil War Pensions for Gettysburg Union Army Veterans and Disability in Nineteenth-Century America*, 44 WM. & MARY L. REV. 1109 (2003). For discussions of World War I-era disability benefits programs, see DEBORAH A. STONE, THE DISABLED STATE 75 (1984); and K. Walter Hickel, *Medicine, Bureaucracy, and Social Welfare: The Politics of Disability Compensation for American Veterans of World War I*,

creation of the Aid to the Permanently and Totally Disabled (APTD) program in 1950 and the Social Security Disability Insurance (SSDI) program in 1956—both of which extended cash benefits to people determined to be unable to work because of a disability²⁵—welfare benefits became the central component of federal disability policy.

The disability benefits system remains extensive today, with the overwhelming preponderance of disability welfare spending going to four programs.²⁶ Two are cash benefits programs, SSDI and Supplemental Security Income (SSI); two are health care programs, Medicare and Medicaid. SSDI and Medicare are contributory social-insurance programs, which benefit only those individuals who have worked for a sufficient period of time to become eligible for Social Security. When an eligible individual acquires a “disability” under the Social Security Act’s definition—“inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months”²⁷—SSDI pays a monthly cash benefit that effectively serves as early retirement pay.²⁸ Medicare is the health insurance companion to Social Security; after two years on SSDI, an individual with a disability becomes eligible for Medicare’s standard package of coverage.²⁹ SSI and Medicaid are, broadly speaking, means-

in THE NEW DISABILITY HISTORY: AMERICAN PERSPECTIVES 236 (Paul K. Longmore & Lauri Umansky eds., 2001). For good overviews of the history and administration of the major current disability benefits programs, see EDWARD D. BERKOWITZ, *DISABLED POLICY: AMERICA’S PROGRAMS FOR THE HANDICAPPED* 41-151 (1987); and Richard K. Scotch, *American Disability Policy in the Twentieth Century*, in THE NEW DISABILITY HISTORY, *supra*, at 375.

25. Under the APTD program, the federal government gave grants to states to provide welfare benefits to those who, under state-established criteria, could show that they were “permanently and totally disabled.” Pub. L. No. 87-543, § 141(a), 76 Stat. 172, 197 (1962), *repealed by* Pub. L. No. 92-603, § 301, 86 Stat. 1329, 1465 (1972). The APTD program was eliminated in 1972 and replaced with the Supplemental Security Income (SSI) program—a uniform federal program that provides a cash benefit to poor people with disabilities. *See* 42 U.S.C. §§ 1381-1383d (2000). SSDI is a contributory federal social-insurance program that essentially treats disability as a grounds for early retirement under the Social Security system. *See id.* § 423. For good general descriptions of the disability benefits system, see Diller, *Entitlement and Exclusion*, *supra* note 6; and Weber, *Disability and the Law of Welfare*, *supra* note 6, at 923-30.

26. Richard Scotch reports that, in fiscal year 1995, “[o]f the nearly \$184 billion spent on all [federal] disability programs, over 90 percent went for health care (\$91 billion) and income maintenance (\$78 billion).” Scotch, *supra* note 24, at 386; *see also* BERKOWITZ, *supra* note 24, at 4 (“Simply put, this nation spends most of the money allocated to disability on programs that provide the handicapped with tickets out of the labor force.”).

27. 42 U.S.C. § 423(d)(1)(A).

28. *See, e.g.*, GRAETZ & MASHAW, *supra* note 6, at 88.

29. Medicare was established in the 1965 amendments to the Social Security Act, Pub. L. No. 89-97, 79 Stat. 286 (1965) (codified in scattered sections of 42 U.S.C.). It is an entirely federal program that applies uniformly across the nation. It covers inpatient hospitalization (under Medicare Part A) and, at the recipient’s option, outpatient treatment (under Medicare Part B), for individuals who receive Social Security Old Age, Survivors, or Disability Insurance. For a

tested welfare programs. Any individual—regardless of work history—who satisfies the Social Security Act’s “disability” definition is entitled to a monthly SSI benefit (currently \$552) if his or her income and assets fall below a federal means test.³⁰ In most states, Medicaid coverage is automatic for those who receive SSI.³¹

The disability welfare state remains extensive, but disability rights advocates have sought to change that state of affairs in a number of respects. Although its precursors can be traced back at least to the 1930s,³² the U.S. disability rights movement began to coalesce in earnest in the 1970s.³³ Reacting to society’s then-dominant model, which viewed disability as a medical condition to be cured if possible and viewed people with disabilities as unfortunates who deserved charitable largesse, activists developed distinctive ideas of the nature of disability and the proper social response to it.³⁴ They urged that disability is not an essentially medical condition that inheres in the disabled person; it is a social condition caused by the interaction between a person’s physical or mental traits and social institutions that are structured in a way that makes them inaccessible to people with those traits.³⁵ The proper response to disability, so viewed, is not medical treatment, nor is it charity or welfare. Instead, the proper response is civil rights legislation that prohibits discrimination against and requires accommodation of people with disabilities.³⁶ Disability rights activists in the 1970s were thus explicit in their critique of welfare as the primary response to disability. In terms that in many respects echoed the arguments of the welfare rights movement of the late 1960s and early

discussion of the enactment of the Medicare program, see THEODORE R. MARMOR, *THE POLITICS OF MEDICARE* 45-61 (2d ed. 2000).

30. See 42 U.S.C. § 1382.

31. See *infra* text accompanying notes 134-136. Like Medicare, Medicaid was enacted as part of the 1965 amendments to the Social Security Act. It is a state-federal cooperative program that provides medical benefits of various kinds to needy populations. Participation in Medicaid is entirely a matter of state choice (though all states have chosen to participate), and states have a great deal of flexibility in deciding the populations they will cover and the benefits they will provide. But for so long as a state chooses to participate in Medicaid, the statute sets forth certain populations it *must* cover and certain services it *must* provide. For an overview of the enactment of the Medicaid program, see ROBERT STEVENS & ROSEMARY STEVENS, *WELFARE MEDICINE IN AMERICA: A CASE STUDY OF MEDICAID* 49-61 (Transaction 2003) (1974).

32. See Paul K. Longmore & David Goldberger, *The League of the Physically Handicapped and the Great Depression: A Case Study in the New Disability History*, 87 J. AM. HIST. 888 (2000).

33. Probably the best introduction to the disability rights movement is Joseph Shapiro’s journalistic history, JOSEPH P. SHAPIRO, *NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT* (1993). A good source from an American disability rights activist that puts the United States disability rights movement in global perspective is CHARLTON, *supra* note 13.

34. For a discussion of these ideas, see Bagenstos, *supra* note 14, at 426-32.

35. See *id.* at 426-30.

36. See *id.* at 430-32.

1970s, those activists leveled a number of challenges at the disability benefits system.³⁷

First, those activists developed a critique of the paternalism of the “helping professions.”³⁸ In the context of disability benefits programs, this critique took the form of a challenge to the paternalistic, arbitrary, and oppressive aspects of welfare administration. Receipt of benefits depended on compliance with the dictates of rehabilitation counselors and welfare caseworkers. Influenced by an ideology that led them to believe that they, rather than their clients, knew what was best for the clients themselves,³⁹ caseworkers’ dictates extended to core life decisions. As the great blind scholar-activist Jacobus tenBroek⁴⁰ put it in a classic article he wrote with Floyd Matson,

It is the agency of welfare, not the recipient, who decides what life goals are to be followed, what ambitions may be entertained, what services are appropriate, what wants are to be recognized, what needs may be budgeted, and what funds allocated to each. In short, the recipient is told *what* he wants as well as how much he is wanting.⁴¹

37. My discussion in this Section draws on, but extends significantly, my earlier discussion in Bagenstos, *supra* note 4, at 987-1000. In particular, my discussion here draws out the complex relationship between the disability rights and welfare rights movements in a way that I did not attempt to do in the *Welfare Reform* article.

38. See, e.g., BERKOWITZ, *supra* note 24, at 187-88; Samuel R. Bagenstos, *The Americans with Disabilities Act as Risk Regulation*, 101 COLUM. L. REV. 1479, 1486-87 (2001); Billy Golfus, *The Do-Gooder*, reprinted in *THE RAGGED EDGE: THE DISABILITY EXPERIENCE FROM THE PAGES OF THE FIRST FIFTEEN YEARS OF THE DISABILITY RAG* 165 (Barrett Shaw ed., 1994). For an excellent expression of this critique by an important participant-theorist of the disability rights movement, see Irving Kenneth Zola, *Healthism and Disabling Medicalization*, in IVAN ILLICH ET AL., *DISABLING PROFESSIONS* 41 (1977).

39. See BERKOWITZ, *supra* note 24, at 187-88. For a highly critical discussion of the ideology of rehabilitation professionals, see RUTH O'BRIEN, *CRIPPLED JUSTICE: THE HISTORY OF MODERN DISABILITY POLICY IN THE WORKPLACE* 27-87 (2001).

40. Many legal scholars are probably familiar with Professor tenBroek's important contributions to Fourteenth Amendment scholarship. See JACOBUS TENBROEK, *THE ANTISLAVERY ORIGINS OF THE FOURTEENTH AMENDMENT* (1951); Joseph Tussman & Jacobus tenBroek, *The Equal Protection of the Laws*, 37 CAL. L. REV. 341 (1949). But Professor tenBroek was also exceptionally important as a disability rights activist. He founded and served for twenty-one years as president of the National Federation of the Blind—an organization he accurately described as “an aggressive, militant, activist organization of the blind themselves” that even by the mid-1960s had “achieved a great deal, legislatively and otherwise, and ha[d] always been in the thick of the fight.” tenBroek, *supra* note 17, at 841 n.†; see also Sharon Groch, *Free Spaces: Creating Oppositional Consciousness in the Disability Rights Movement*, in *OPPOSITIONAL CONSCIOUSNESS: THE SUBJECTIVE ROOTS OF SOCIAL PROTEST* 65, 76-77 (Jane Mansbridge & Aldon Morris eds., 2001) (describing aggressive, militant character of the National Federation of the Blind). For a history of the National Federation of the Blind, see generally FLOYD MATSON, *WALKING ALONE AND MARCHING TOGETHER: A HISTORY OF THE ORGANIZED BLIND MOVEMENT IN THE UNITED STATES, 1940-1990* (1990).

41. Jacobus tenBroek & Floyd W. Matson, *The Disabled and the Law of Welfare*, 54 CAL. L. REV. 809, 831 (1966).

To Professors tenBroek and Matson, the alternatives for people with disabilities who receive welfare were stark: “obedience or starvation.”⁴² Other disability rights activists echoed this attack on the administration of disability welfare benefits.⁴³

In that respect, the claims of the disability rights movement were entirely consistent with those of the broader welfare rights movement. That broader movement also highlighted the paternalistic, arbitrary, and oppressive behavior of caseworkers.⁴⁴ Its adherents urged expansive, categorical entitlements to welfare that would eliminate the discretion that empowered caseworkers to engage in such conduct.⁴⁵ Indeed, Professors tenBroek and Matson frequently cast their argument in terms that supported a more general program of welfare rights,⁴⁶ and tenBroek himself was an important legal strategist for the welfare rights movement.⁴⁷

But several aspects of disability rights activists’ thought pushed in exactly the opposite direction. Disability rights activists, unlike welfare rights activists, often framed their critiques of the existing welfare system in

42. *Id.*

43. *See, e.g.*, PAUL K. LONGMORE, *WHY I BURNED MY BOOK AND OTHER ESSAYS ON DISABILITY* 112-14, 234-46 (2003).

44. *See* FRANCES FOX PIVEN & RICHARD A. CLOWARD, *REGULATING THE POOR: THE FUNCTIONS OF PUBLIC WELFARE* 157-59 (1971) (discussing arbitrary terminations); *id.* at 166 (“A central feature of the recipient’s degradation is that she must surrender commonly accepted rights in exchange for aid. AFDC mothers, for example, are often forced to answer questions about their sexual behavior (“When did you last menstruate?”), open their closets to inspection (“Whose pants are those?”), and permit their children to be interrogated (“Do any men visit your mother?”).”); *id.* at 170-71 (discussing “degradation” inherent in submission to welfare agencies’ efforts at vocational rehabilitation); *id.* at 176-77 (discussing paternalistic aspects of social welfare programs). *See generally* Matthew Diller, *The Revolution in Welfare Administration: Rules, Discretion, and Entrepreneurial Government*, 75 N.Y.U. L. REV. 1121, 1137-38 (2000) (discussing welfare rights activists’ attack on discretion of welfare caseworkers).

45. *See* PIVEN & CLOWARD, *supra* note 44, at 348 (“In the absence of fundamental economic reforms, therefore, we take the position that the explosion of the rolls is the true relief reform, that it should be defended, and expanded.”); *see also id.* at 314 (writing that welfare rights litigation “contributed to the collapse of restrictions, partly by overturning major exclusionary statutes, but perhaps more importantly by instituting procedural safeguards that hampered the arbitrary exercise of discretion by relief officials”). For powerful critiques of welfare rights lawyers’ attack on the discretion of caseworkers and their accompanying turn toward rule-oriented proceduralism, *see* William H. Simon, *The Invention and Reinvention of Welfare Rights*, 44 MD. L. REV. 1 (1985); and William H. Simon, *Legality, Bureaucracy, and Class in the Welfare System*, 92 YALE L.J. 1198 (1983).

46. *See, e.g.*, tenBroek & Matson, *supra* note 41, at 837, 836-37 (favorably discussing the idea of “a guaranteed income [for] all Americans” that would provide “a common floor of protection for the needy”).

47. *See* PIVEN & CLOWARD, *supra* note 44, at 306 n.17 (“The legal arguments which underpinned litigation against relief agencies were developed in substantial part by Jacobus ten Broek, a blind professor of political science at the University of California in Berkeley, who spent the better part of his career writing about what he called America’s dual system of justice—one for the affluent, another for the poor.”); *see also* MARTHA F. DAVIS, *BRUTAL NEED: LAWYERS AND THE WELFARE RIGHTS MOVEMENT, 1960-1973*, at 20-21 (1993). For Professor tenBroek’s most important contributions to poverty law scholarship generally, *see* FAMILY LAW AND THE POOR: ESSAYS BY JACOBUS TENBROEK (Joel F. Handler ed., 1971).

terms that attacked the legitimacy of *any* welfare benefits system (or at least any disability-specific welfare benefits system). These fundamental challenges to disability benefits were of three essential sorts, one of which resonated strongly with the rhetoric of the political left, one of which resonated strongly with that of the political right, and one of which was politically ambiguous.

From the left, many disability rights activists contended that disability welfare programs promoted political quiescence among people with disabilities. They argued that disability welfare programs are essentially symbolic government acts that, in the words of one activist, merely “buy off” a potentially troublesome group.⁴⁸ Instead of making fundamental changes to social relations or the built environment that would allow people with disabilities to achieve actual integration and equality in society, the nondisabled majority uses relatively small cash benefits as a means of dulling any urge among people with disabilities to protest existing power arrangements.⁴⁹

From the right, many disability rights activists argued that welfare programs promoted a culture of dependence among people with disabilities. Professors tenBroek and Matson themselves had argued that the existing scheme of administering disability benefits “perpetuate[d] dependency and discourage[d] initiative.”⁵⁰ But, like welfare rights activists generally, they remained sanguine that a welfare scheme could be structured in a way that avoided these problems.⁵¹ Other disability rights activists did not appear so confident, however. To the contrary, they spoke in terms that resonated

48. Cheryl Rogers, *The Employment Dilemma for Disabled Persons*, in *IMAGES OF THE DISABLED, DISABLING IMAGES* 117, 120-21 (Alan Gartner & Tom Joe eds., 1987).

49. See Harlan Hahn, *Civil Rights for Disabled Americans: The Foundations of a Political Agenda*, in *IMAGES OF THE DISABLED, DISABLING IMAGES*, *supra* note 48, at 181, 197; Rogers, *supra* note 48. Even here, one can hear in disability rights activists’ claims the echoes of arguments of welfare rights activists like Frances Fox Piven and Richard Cloward, who contended that public welfare generally serves to blunt lower-class unrest at times of high unemployment and to enforce a regime of low-wage work during more prosperous times. See THEODORE R. MARMOR ET AL., *AMERICA’S MISUNDERSTOOD WELFARE STATE: PERSISTENT MYTHS, ENDURING REALITIES* 13-14 (1990) (discussing left-wing criticism of the welfare state by, inter alia, Piven and Cloward); PIVEN & CLOWARD, *supra* note 44, *passim*; see also *id.* at 286 (“The political circumstances of the 1960’s made it crucial, however, that blacks get something in order to solidify their allegiance to the national Democratic Party, and in order to quiet them. As it turned out, welfare was the system that was made to do most of the giving—partly, perhaps, because black constituents needed money; more importantly, because it was easier to give welfare than to press for concessions that would challenge the interests of other groups in the cities.”). But cf. JOEL F. HANDLER & YEHEKEL HASENFELD, *THE MORAL CONSTRUCTION OF POVERTY: WELFARE REFORM IN AMERICA* 4-5 (1991) (critiquing the Piven and Cloward critique). Piven and Cloward, however, urged broad welfare entitlements. See PIVEN & CLOWARD, *supra* note 44, at 348. Disability rights activists, by contrast, were much more hostile to the idea of disability welfare.

50. tenBroek & Matson, *supra* note 41, at 831.

51. See *id.* at 836-40 (discussing what seemed to be the emerging possibility of a reconstructed welfare system).

quite strongly with critiques of the welfare system that would be articulated by such conservative commentators as Charles Murray.⁵² Ed Roberts, one of the most important founding figures in the 1970s disability rights movement,⁵³ urged that people with disabilities should move away from a dependent “welfare mentality.”⁵⁴ And a group of activists that included Justin Dart, who played the central role in lobbying for the passage of the ADA,⁵⁵ wrote that disability welfare programs “support[ed] large segments of the population in relatively idle dependency.”⁵⁶ They criticized the position they characterized as the “‘give me’ socialist” view “that ‘society’ should and can provide certain benefits to each human with no corresponding obligation on the part of the individuals.”⁵⁷

Both of these fundamental challenges to disability welfare were broadly compatible with another critique asserted by disability rights activists, one that rested on the notion of the double-edged nature of categorical welfare programs in a market society. Many nondisabled people believe that disability benefits programs make disability a *favored* status in society by exempting people with disabilities from the ordinary obligation to work for a living. In that common view, disability welfare is an act of beneficence, one that demonstrates society’s intense concern for people with disabilities. They are the paradigm case of the “deserving” rather than the “undeserving” poor.⁵⁸

But activists sought to challenge the notion that society’s “beneficence” toward people with disabilities was really beneficial. Disability rights advocates have long contended that “superficial indications of sympathy, and even pity, for the plight of disabled persons frequently conceal a deeper sense of discomfort and resistance that has perpetuated the segregation and inequality” of people with disabilities.⁵⁹ Those advocates believed that the

52. See CHARLES MURRAY, *LOSING GROUND: AMERICAN SOCIAL POLICY, 1950-1980* (1984).

53. See SHAPIRO, *supra* note 33, at 41-58.

54. Edward V. Roberts, *A History of the Independent Living Movement: A Founder’s Perspective*, in *PSYCHOSOCIAL INTERVENTIONS WITH PHYSICALLY DISABLED PERSONS* 231, 239 (Bruce W. Heller et al. eds., 1989).

55. For discussions of Dart’s role, see NAT’L COUNCIL ON DISABILITY, *EQUALITY OF OPPORTUNITY: THE MAKING OF THE AMERICANS WITH DISABILITIES ACT 49-59, 72-79* (1997); and SHAPIRO, *supra* note 33, at 108-11.

56. PEG NOSEK ET AL., *A PHILOSOPHICAL FOUNDATION FOR THE INDEPENDENT LIVING AND DISABILITY RIGHTS MOVEMENTS* 11 (1982).

57. *Id.* at 44.

58. See STONE, *supra* note 24, at 29-51 (describing evolution of the disability category in the English Poor Laws); Diller, *Entitlement and Exclusion*, *supra* note 6 (discussing the role of the disability category in the American social welfare system).

59. Harlan Hahn, *Antidiscrimination Laws and Social Research on Disability: The Minority Group Perspective*, 14 *BEHAV. SCI. & L.* 41, 43 (1996); see also MARY JOHNSON, *MAKE THEM GO AWAY: CLINT EASTWOOD, CHRISTOPHER REEVE, AND THE CASE AGAINST DISABILITY RIGHTS* (2003). In developing these arguments, the disability rights movement plainly drew on the

welfare system, which treats disability as an excuse for not working, was a prime example of that phenomenon. To be excused from the social obligations of citizenship, they contended, is also to be excused from the social rights of citizenship.⁶⁰ When persons cannot make their own way—even for fully understandable reasons—then a society that undertakes to care for them will necessarily also undertake to make their decisions for them.⁶¹ Many of the more theoretically inclined disability rights thinkers characterized the role of disability welfare recipients as an extended version of the “sick role” described by the sociologist Talcott Parsons.⁶² The sick person is excused from ordinary social responsibilities for the duration of the illness, but only so long as the sick person submits to the control and direction of professionals who “treat” the condition.⁶³ For people with disabilities, who often cannot expect to be “cured,” the submission to the control of others—and attendant denial of full citizenship—is lifelong.⁶⁴

These interconnected (if not entirely consistent) critiques of disability welfare programs led disability rights activists to urge a fundamental shift in the orientation of disability policy—a shift, captured in the title of Richard Scotch’s important book, “from good will to civil rights.”⁶⁵ Disability rights activists urged that disability policy should promote integration and inclusion in all arenas of political, civic, and social life.⁶⁶ In the realm of employment specifically, they argued that most people with disabilities are willing and able to work, and that hostile attitudes and contingent environmental barriers were the primary reasons for their

feminist movement’s argument that paternalistic policies placed women on a “pedestal” that was in fact a “cage,” *Frontiero v. Richardson*, 411 U.S. 677, 684 (1973) (plurality opinion). See Samuel R. Bagenstos, *Justice Ginsburg and the Judicial Role in Expanding “We the People”: The Disability Rights Cases*, 104 COLUM. L. REV. 49, 50-51, 56 (2004).

60. See, e.g., Gerben DeJong, *Defining and Implementing the Independent Living Concept, in INDEPENDENT LIVING FOR PHYSICALLY DISABLED PEOPLE* 4, 18 (Nancy M. Crewe & Irving Kenneth Zola eds., 1983). The British sociologist T.H. Marshall made the same point about the English Poor Law of 1834. See T.H. MARSHALL, *CITIZENSHIP AND SOCIAL CLASS* 15 (Pluto Press 1992) (1950) (“The Poor Law treated the claims of the poor, not as an integral part of the rights of the citizen, but as an alternative to them—as claims which could be met only if the claimants ceased to be citizens in any true sense of the word.”). Marshall contrasted that effective denial of citizenship with the reaffirmation of citizenship that is implicit in universal social insurance systems. See *id.* at 33.

61. Thus tenBroek and Matson’s observation that “[w]elfare clients, including the blind and the disabled, have been categorically judged incompetent to manage their lives and affairs.” tenBroek & Matson, *supra* note 41, at 831.

62. See TALCOTT PARSONS, *THE SOCIAL SYSTEM* 428-79 (1951).

63. See *id.*

64. See JOHN GLIEDMAN & WILLIAM ROTH, *THE UNEXPECTED MINORITY: HANDICAPPED CHILDREN IN AMERICA* 35-42 (1980); DeJong, *supra* note 60, at 16-18; Hahn, *supra* note 59, at 45.

65. RICHARD K. SCOTCH, *FROM GOOD WILL TO CIVIL RIGHTS: TRANSFORMING FEDERAL DISABILITY POLICY* (2d ed. 2001).

66. See CHARLTON, *supra* note 13, at 124-27; Cook, *supra* note 17; tenBroek, *supra* note 17, at 843.

exclusion from the workforce.⁶⁷ Accordingly, they advocated the adoption of civil rights laws that would prohibit discrimination against and require the provision of accommodations to individuals with disabilities in the workplace.⁶⁸

Some British disability rights activists in the 1970s turned the same sorts of critiques of disability welfare into a thoroughgoing attack on cash benefits programs.⁶⁹ American disability rights activists did not go so far. Many recognized that welfare programs would remain important for a large number of people with disabilities, if only to provide the health insurance benefits they needed to participate in the world.⁷⁰ And grass-roots disability protests preponderantly focused on demands for benefits rather than civil rights.⁷¹ But a number of important grass-roots disability protests did focus on civil rights.⁷² And activists (particularly, although not exclusively, elite activists) did urge a fundamental reorientation of disability policy toward a civil-rights-focused approach. As I have shown in other work, in the campaign to enact the ADA, disability rights activists frequently posed a stark choice between welfare and civil rights approaches. Throughout the legislative process, those activists highlighted the public costs of existing disability welfare programs and argued that dependence on such programs (and the attendant fiscal burden) would be reduced substantially if only civil rights laws existed to open up opportunities for gainful employment.⁷³

67. See, e.g., Hahn, *supra* note 49, at 182.

68. See, e.g., Bagenstos, *supra* note 14, at 430 (discussing goals of the disability rights movement).

69. See MICHAEL OLIVER, UNDERSTANDING DISABILITY: FROM THEORY TO PRACTICE 24-25 (1996) (reprinting an edited version of the Union of the Physically Impaired Against Segregation's 1976 statement of "fundamental principles of disability") ("Benefits' which are not carefully related to the struggle for integrated employment and active social participation will constantly be used to justify our dependence and exclusion from the mainstream of life—the very opposite of what is intended. This is why the . . . appeal to the state for legislation to implement a comprehensive, national disability incomes scheme is in reality nothing so much as a programme to obtain and maintain in perpetuity the historical dependence of physically impaired people on charity.") (omission in original); *id.* at 26 ("Experts begging for state charity on our behalf can do nothing but lower our status, by reinforcing out-of-date attitudes.").

70. See, e.g., LONGMORE, *supra* note 43, at 236; DeJong, *supra* note 60, at 12. To some extent, there may be less of a difference between the positions of British and American disability rights activists on this point than meets the eye. British activists, after all, were operating in a country with universal health care, so the opposition to cash benefits did not entail opposition to all social welfare programs. It is significant, however, that the British National Health Service is a universal, rather than disability-specific, social welfare system. See *infra* Part III.

71. See BARNARTT & SCOTCH, *supra* note 13, at 78, 177.

72. See SHAPIRO, *supra* note 33, at 130-41.

73. See Bagenstos, *supra* note 4, at 957-75.

B. *The Results of the Antidiscrimination Approach*

The enactment of the ADA in 1990 was a major triumph for disability rights advocates, and it seemed to herald the fundamental reorientation of federal disability policy they had long urged. To be sure, the statute made no changes to the existing disability welfare programs; to that extent, disability policy remained “dissonant.”⁷⁴ But the ADA did nonetheless send the strong message that people with disabilities should be expected to work rather than to sit on the welfare rolls. And the statute’s enactment led a number of technocratic analysts to urge that the revamping of disability benefits programs along much more restrictive lines would be the logical next policy step.⁷⁵

But if the ADA’s enactment raised expectations that large numbers of people with disabilities would leave the benefits rolls and enter the workforce, subsequent experience has been a major disappointment. Numerous studies have found that the employment rate for people with disabilities declined or remained stagnant throughout the 1990s—a period that overlapped with both the implementation of the ADA and a booming economy. The variety of possible definitions of “disability” makes it hard to compare numbers across studies,⁷⁶ but the trend is clear. When “disability” is defined as an impairment that imposes limitations on any life activity, the employment rate for working-age people with disabilities declined from 49% in 1990 to 46.6% in 1996, according to the federal government’s National Health Information Survey (NHIS).⁷⁷ When “disability” is defined more broadly—as a diagnosed impairment simpliciter—the employment rate for working-age men with disabilities fell from 84.7% in 1990 to 77.3% in 1996, while the employment rate for working-age women with disabilities stayed relatively stagnant at just over 63% during that period, according to the NHIS.⁷⁸ And when “disability” is defined more narrowly, as an impairment that specifically limits the life activity of working, the

74. See generally Diller, *Dissonant Disability Policies*, *supra* note 6 (discussing tensions between the ADA and disability welfare programs).

75. See Edward D. Berkowitz, *Implications for Income Maintenance Policy*, in IMPLEMENTING THE AMERICANS WITH DISABILITIES ACT 193, 218-23 (Jane West ed., 1996) [hereinafter IMPLEMENTING THE ADA]; Richard V. Burkhauser, *Post-ADA: Are People with Disabilities Expected To Work?*, 549 ANNALS AM. ACAD. POL. & SOC. SCI. 71, 82 (1997); Bonnie O’Day & Monroe Berkowitz, *Disability Benefit Programs: Can We Improve the Return-to-Work Record?*, in HANDBOOK OF DISABILITY STUDIES 633, 639-40 (Gary L. Albrecht et al. eds., 2001).

76. See Richard V. Burkhauser et al., *A User’s Guide to Current Statistics on the Employment of People with Disabilities*, in THE DECLINE IN EMPLOYMENT OF PEOPLE WITH DISABILITIES: A POLICY PUZZLE 23, 29-30 tbl.2.1, 72-73 tbl.2A.3 (David C. Stapleton & Richard V. Burkhauser eds., 2003) [hereinafter DECLINE IN EMPLOYMENT].

77. See H. STEPHEN KAYE, IMPROVED EMPLOYMENT OPPORTUNITIES FOR PEOPLE WITH DISABILITIES 9 & fig. 1 (Disability Statistics Ctr., Disability Statistics Report 17, 2003).

78. See Burkhauser et al., *supra* note 76, at 72-73 tbl.2A.3.

employment rate for working-age men with disabilities fell from 42.1% in 1990 to 33.1% in 2000, according to the federal government's Current Population Survey, which provides data that can be compared across the entire decade; the employment rate for working-age women with disabilities fell from 34.9% to 32.6% over that period, according to the same measure.⁷⁹

More important than any absolute drop in the employment rate, however, is the relative decline in the employment rate for people with disabilities vis-à-vis the nondisabled. Although the employment rates for men and women without disabilities increased with the economic boom of the 1990s, the employment rates for those with disabilities did not. As a result, "in the 1990s the relative employment rates of both men and women with disabilities also declined dramatically."⁸⁰ A 2000 Harris survey of working-age people with disabilities revealed that only 32% reported being employed, as compared with 81% of the comparable population without disabilities.⁸¹

A number of commentators argue that the stubbornly high nonemployment rate for people with disabilities shows that the ADA has not just failed in its effort to improve disability employment; they contend that the statute in fact caused the drop in disability employment in the 1990s. The theory is straightforward: Because accommodations are costly, the ADA gave employers an incentive to refuse to hire people with disabilities; because it is difficult to enforce the statute effectively at the hiring stage, employers were likely to act on that incentive.⁸² A number of empirical studies that attempt to control for other explanations of the employment drop appear to confirm this theory.⁸³

79. *Id.*

80. *Id.* at 41; see also KAYE, *supra* note 77, at 10 (finding "statistically significant upward trends in the employment gap" between those with and without disabilities throughout the 1990s); Nanette Goodman & Timothy Waidmann, *Social Security Disability Insurance and the Recent Decline in the Employment Rate of People with Disabilities*, in *DECLINE IN EMPLOYMENT*, *supra* note 76, at 339, 341 ("[F]or both men and women, the employment rate of people with disabilities was falling relative to that of people without disabilities during the economic expansion of the mid and late 1990s.").

81. NAT'L ORG. ON DISABILITY, 2000 N.O.D./HARRIS SURVEY OF AMERICANS WITH DISABILITIES 27 (2000).

82. See, e.g., Daron Acemoglu & Joshua D. Angrist, *Consequences of Employment Protection? The Case of the Americans with Disabilities Act*, 109 J. POL. ECON. 915, 924 (2001); Thomas DeLeire, *The Wage and Employment Effects of the Americans with Disabilities Act*, 35 J. HUM. RESOURCES 693, 694 (2000); Christine Jolls, *Accommodation Mandates*, 53 STAN. L. REV. 223, 273-76 (2000).

83. See Acemoglu & Angrist, *supra* note 82, at 929-32; DeLeire, *supra* note 82, at 700-08; see also Christine Jolls & J.J. Prescott, *The Effects of "Reasonable Accommodations" Requirements and Firing Costs on the Employment of Individuals with Disabilities* 18-19, 28 (July 2004) (unpublished manuscript, on file with author) (finding disemployment effect in initial years of implementation of the ADA but no statute-specific disemployment effect after 1994).

But the claim that the ADA has harmed the employment prospects of people with disabilities remains controversial. ADA defenders note that the empirical studies finding negative employment effects have used a definition of disability that does not precisely map onto the coverage of the statute. The ADA defines “disability” in relevant part as “a physical or mental impairment that substantially limits one or more of the major life activities of [an] individual.”⁸⁴ But the studies define “disability” as an impairment that limits the kind or amount of work an individual can do.⁸⁵ That definition fails to embrace some individuals the ADA treats as having “disabilities”—those who experience substantial limitations in a major life activity other than working.⁸⁶ ADA defenders argue that when we focus on classes of people with disabilities who, in their view, are likely to be protected by the ADA—people who have impairments that do not limit their ability to work—we find that employment rates have improved since the enactment of the statute.⁸⁷ Defenders also contend that the ADA’s passage may have destigmatized disability and thus encouraged significant numbers of people who were already out of the workforce to newly identify themselves as disabled; if so, the employment decline for people with disabilities may be merely an artifact of measurement.⁸⁸ Finally, ADA

84. 42 U.S.C. § 12102(2)(A) (2000).

85. See Acemoglu & Angrist, *supra* note 82, at 925; DeLeire, *supra* note 82, at 695; Jolls & Prescott, *supra* note 83, at 6.

86. See, e.g., Toyota Motor Mfg., Ky. v. Williams, 534 U.S. 184, 199-203 (2002) (major life activity of performing manual tasks); Bragdon v. Abbott, 524 U.S. 624, 638-39 (1998) (major life activity of reproduction).

87. See KAYE, *supra* note 77, at 15; Peter Blanck et al., *Calibrating the Impact of the ADA’s Employment Provisions*, 14 STAN. L. & POL’Y REV. 267, 275 (2003) [hereinafter Blanck et al., *Calibrating the Impact*]; see also Peter Blanck et al., *Is It Time To Declare the ADA a Failed Law?*, in DECLINE IN EMPLOYMENT, *supra* note 76, at 301, 315-18 [hereinafter Blanck et al., *Is It Time*]; Douglas Kruse & Lisa Schur, *Does the Definition Affect the Outcome? Employment Trends Under Alternative Measures of Disability*, in DECLINE IN EMPLOYMENT, *supra* note 76, at 279, 282-86, 292-96; Susan Schwochau & Peter David Blanck, *The Economics of the Americans with Disabilities Act, Part III: Does the ADA Disable the Disabled?*, 21 BERKELEY J. EMP. & LAB. L. 271, 298-301 (2000); Tom Tolin & Martin Patwell, *A Critique of Economic Analysis of the ADA*, 23 DISABILITY STUD. Q. 130, 133-34 (2003). Cf. Blanck et al., *Is It Time*, *supra*, at 326 (“In light of the flaws identified, we submit that existing empirical research provides little basis on which policymakers can make informed decisions regarding whether the ADA is the cause of employment declines and should thus be amended, repealed, or left untouched.”).

88. See Blanck et al., *Calibrating the Impact*, *supra* note 87, at 278; see also Kruse & Schur, *supra* note 87, at 285 (“Perceptions of increased social acceptability and rights may have encouraged more people to identify themselves as having a disability following the ADA. It is plausible that this effect was greatest among those who were suffering the greatest stigma owing to a lack of employment, and thus increased reports of work limitation would lower the associated employment rate.”); Douglas Kruse & Lisa Schur, *Employment of People with Disabilities Following the ADA*, 42 INDUS. REL. 31, 36 (2003) (“Passage of the ADA may have led more to be willing to identify themselves as having a disability either because it became more socially acceptable to have a disability in general or because the general emphasis on employment of people with disabilities led people with serious impairments to be more likely to say that [they]

defenders argue that the empirical studies do not fully negate an alternative explanation for the employment decline—that the loosening of eligibility standards for SSDI benefits throughout the 1980s made leaving the workforce particularly attractive for people with disabilities when the 1990-1991 recession occurred.⁸⁹

The dispute over whether the ADA has been a negative force in the effort to promote employment among people with disabilities is far from resolved in the literature.⁹⁰ But that dispute—which has preoccupied a number of important legal and economic scholars—is largely beside the point. Even on the view of the data presented by the statute's most optimistic supporters, the employment provisions of the ADA have done absolutely nothing to give jobs to the overwhelming majority of people with disabilities. Unless massive numbers of people with disabilities both became employed and stopped identifying themselves as disabled in the few years following enactment of the ADA, the evidence makes clear that the statute has not significantly improved the employment position of people with disabilities, if it has improved that position at all.

In 1994, 10.7 million people with disabilities (defined here as impairments that limit any life activity) reported that they had jobs, an increase of just over 800,000 from 1990. By contrast, 11.7 million working-age people with disabilities reported that they did not have jobs in 1994, an increase of just over two million from 1990.⁹¹ Assume that we can attribute the entire increase in reported employment to the ADA and that we can

are limited in the kind or amount of work they can do (whereas prior to the ADA they may not have considered employment as an option).”).

89. See David H. Autor & Mark G. Duggan, *The Rise in the Disability Rolls and the Decline in Unemployment*, 118 Q.J. ECON. 157, 162-64, 169-74 (2003); John Bound & Timothy Waidmann, *Accounting for Recent Declines in Employment Rates Among Working-Aged Men and Women with Disabilities*, 37 J. HUM. RESOURCES 231, 240 (2002).

90. I offer my own view of the evidence in Samuel R. Bagenstos, *Has the Americans with Disabilities Act Reduced Employment for People with Disabilities?*, 25 BERKELEY J. EMP. & LAB. L. (forthcoming Nov. 2004), from which some of the discussion in this Section is derived. In brief, I find it hard to disagree with the claim that the ADA imposed at least some negative pressure on disability employment, at least in its early implementation. I find unpersuasive the argument that the extant empirical studies are irrelevant because they employ the “wrong” definition of disability. Although the studies that attempt to disaggregate the ADA’s effects across different classes of people with disabilities show that the statute has improved employment for those people with disabilities least likely to need accommodations—those whose conditions do not limit the kind or amount of work they can do—the overall picture for people with disabilities is one of stagnation at best. I also think it unlikely that the measured decline in employment reflects nothing more than compositional changes in the population that self-reports disability. The SSDI-recession explanation for the employment decline, by contrast, is quite plausible, though it is difficult to disentangle from the effects of the ADA. It seems likely that any negative employment effects of the ADA will be a temporary phenomenon, however, as accommodation costs fall over time. The empirical evidence—particularly the findings of Professors Jolls and Prescott, see Jolls & Prescott, *supra* note 83—seems consistent with that prediction.

91. Figures are derived from KAYE, *supra* note 77, at 9, 21.

attribute the entire increase in reported nonemployment to an increase in reports of disability by people who were already out of the workforce. Even in such a rosy scenario, the most that could be said is that the statute created jobs for 800,000 people with disabilities while doing nothing for the ability of more than nine million other people with disabilities to get jobs.⁹² The ADA plainly has not lived up to disability rights activists' hopes that it would move significant numbers of people from the disability benefits rolls into the workforce.

II. THE LIMITS OF THE ANTIDISCRIMINATION PARADIGM: STRUCTURAL BARRIERS TO EMPLOYMENT

Why, even on the most ADA-friendly reading of the data, has the statute failed to make a significant dent in the nonemployment of people with disabilities? The problem, I suggest, stems from the inherently limited nature of antidiscrimination requirements. Antidiscrimination requirements can prohibit employers from discriminating against qualified people with disabilities who apply for jobs, but they cannot put people with disabilities in a position to apply and be qualified for jobs in the first place. For a large number of people with disabilities, it is not the discriminatory acts of particular employers but instead deep-rooted structural barriers—such as the lack of personal-assistance services, assistive technology, and accessible transportation and, above all, the current setup of our health insurance system—that keep them out of the workforce. Antidiscrimination laws like the ADA are a singularly ineffective means of eliminating such structural barriers.⁹³

One might think that the ADA's requirement of reasonable accommodation could be used to remove these barriers. That requirement, after all, is thought to be the ADA's great innovation, a tool that goes beyond a mere nondiscrimination rule to demand the alteration of societal structures that, however unintentionally, stand in the way of opportunities

92. It is theoretically possible that the statute created jobs for more than 800,000 people with disabilities, if some newly employed individuals stopped reporting themselves as having disabilities. But it seems unlikely that this number is very large, especially given the remarkable increase in the number of people reporting disabilities during the post-ADA period.

93. The argument in this Part elaborates on the suggestion I made in Bagenstos, *supra* note 4, at 1019-22, that the ADA cannot be counted on to increase the employment of people with disabilities significantly. For others who have argued that the ADA cannot carry the weight of disability employment policy, see Diller, *Dissonant Disability Policies*, *supra* note 6, at 1066-75; and Weber, *Beyond the ADA*, *supra* note 6, at 135-38. My argument here goes beyond these accounts by focusing on the doctrinal tools courts have employed to limit the statute's effectiveness in eliminating structural barriers to the employment of people with disabilities.

for people with disabilities.⁹⁴ But although it would certainly be possible as a formal matter to interpret the ADA's accommodation requirement as imposing on individual defendants the obligation to make "reasonable" contributions to undoing broad structural employment barriers, at least two widely accepted doctrines relieve individual defendants of that burden. Through these doctrines—the "job-related" requirement and the access/content distinction—courts and the EEOC have removed entire classes of possible accommodations from the requirement's scope. And they have done so even if the requested accommodations could be provided at "reasonable" cost.

These limitations on the scope of the accommodation requirement are not obvious from the text of the ADA, and their application to particular cases is indeterminate in substantial respects. But their agenda seems clear. They confine the accommodation requirement so that, like a classic antidiscrimination requirement, it simply demands that defendants provide redress for their own wrongful conduct that uniquely disadvantages a protected class. To a large extent, the application of these doctrines is a symptom of a broader reticence—among both skeptics and supporters of the ADA—to read the statute as mandating social welfare benefits. And even if disability rights activists can overcome their more general resistance to a social welfare approach and urge a broad interpretation that would eliminate those structural barriers, it seems very unlikely that courts will read the ADA's broadly phrased accommodation requirement in a way that would force individual employers to bear the burden of bringing people with disabilities into the workforce.

My argument in this Part proceeds as follows. In Section A, I discuss some important deep-rooted structural barriers to employment for people with disabilities. In Section B, I describe the "job-related" and access/content doctrines and show how they deprive the accommodation requirement of significant power to eliminate those barriers. In Section C, I try to show that the "job-related" and access/content doctrines reflect a common agenda of assimilating the accommodation requirement very closely to the classic antidiscrimination model. As part of my argument in that Section, I attempt to show that the doctrines the courts have employed to narrow the accommodation requirement are formally indeterminate. That is, they cannot, as an analytic matter, actually resolve any hard case. To that

94. See, e.g., Pamela S. Karlan & George Rutherglen, *Disabilities, Discrimination, and Reasonable Accommodation*, 46 DUKE L.J. 1, 38, 41 (1996) (noting that the ADA's accommodation requirement "present[s] an opportunity to rethink employment discrimination law more generally," and describing it as a "profound" innovation); Miranda Oshige McGowan, *Reconsidering the Americans with Disabilities Act*, 35 GA. L. REV. 27, 35 (2000) ("[T]he ADA appears to make a revolutionary break with the old ways of thinking about discrimination while charting a new course of affirmative obligations to ensure real equality.").

extent, my argument is a critique of the existing case law.⁹⁵ But my principal project here is more positive than normative. I hope to show that courts have more or less consistently applied the accommodation requirement in a way that deprives it of any significant power to eliminate the significant structural barriers that keep people with disabilities out of the workforce. To attack those barriers effectively, disability rights activists must challenge the resistance to social welfare intervention that animates the limiting doctrines applied by courts. Because it is unlikely that courts will be persuaded to read the accommodation requirement more broadly, activists must look past the ADA if they are to attack structural employment barriers effectively.

A. *Structural Barriers to Employment for People with Disabilities*

1. *Structural Barriers Generally*

Although discrimination is plainly a major problem for people with disabilities,⁹⁶ many individuals with disabilities face significant barriers to employment that operate well before they are ever in a position to be discriminated against by an employer.⁹⁷ Many people with disabilities need personal-assistance services—attendants who assist with personal hygiene and other activities of daily living—to help them get out of bed and get to work.⁹⁸ Many others need assistive technology to perform work-related

95. One could give further content to the critique by noting that the doctrines I discuss seem quite strongly to adopt the “perpetrator perspective” toward discrimination, for they give determinative weight in many cases to the question whether it seems intuitively appropriate to hold the employer morally responsible for the barriers faced by individuals with disabilities rather than the question whether the employer is in a position to overcome those barriers. Cf. Alan D. Freeman, *Legitimizing Racial Discrimination Through Antidiscrimination Law: A Critical Review of Supreme Court Doctrine*, 62 MINN. L. REV. 1049, 1052-57 (1978).

96. See, e.g., Bagenstos, *supra* note 14, at 422-25.

97. One should not underestimate the extent to which discrimination itself also operates as a barrier well before an individual with a disability ever puts himself or herself in a position to be discriminated against. A person with a disability, knowing that he or she is likely to experience discrimination in the workplace, may be discouraged from investing in education, training, or other forms of human capital—and may indeed be discouraged from attempting to enter the workforce at all. See, e.g., *id.* at 464. But even if enforcement of the ADA can eliminate that structural barrier to employment, it leaves many significant structural barriers untouched, as I explain in the text.

98. Stephen Kaye observes that thirty-two percent of people with disabilities who report that they are unable to work also report that they need personal-assistance services. See KAYE, *supra* note 77, at 32-33. Although Kaye’s study does not identify how many of these respondents cannot work without personal-assistance services, there is good reason to believe that it is a very large fraction. The services provided by personal assistants are so basic to any participation in society that an individual who needs those services for any purpose likely needs them to work. For discussions of the importance of personal-assistance services to people with disabilities, see SIMI LITVAK ET AL., ATTENDING TO AMERICA: PERSONAL ASSISTANCE FOR INDEPENDENT LIVING: A REPORT OF THE NATIONAL SURVEY OF ATTENDANT SERVICES PROGRAMS IN THE UNITED

(and other) tasks, as well as structural modifications to their homes to enable them to leave for work in the morning.⁹⁹ And the lack of accessible transportation remains a crucial issue for people with disabilities.¹⁰⁰

2. *The Important Role of Health Insurance*

But far and away the most significant barrier to employment for people with disabilities is the current structure of our health insurance system.¹⁰¹ For two major reasons, health insurance is a matter of especial importance for those who have disabilities. First, because our society's response to disability has historically been so heavily medicalized, many of the services people with disabilities need for independence and labor force participation—personal assistance and assistive technology being the most obvious—are typically regarded as “medical” services for which the health insurance system is responsible. Second, even without considering those services (which might more appropriately be provided in a nonmedical

STATES 1-17 (1987); Andrew I. Batavia et al., *Toward a National Personal Assistance Program: The Independent Living Model of Long-Term Care for Persons with Disabilities*, 16 J. HEALTH POL. POL'Y & L. 523 (1991); Gerben DeJong & Teg Wenker, *Attendant Care*, in INDEPENDENT LIVING FOR PHYSICALLY DISABLED PEOPLE, *supra* note 60, at 157, 157-62; and Margaret A. Nosek & Carol A. Howland, *Personal Assistance Services: The Hub of the Policy Wheel for Community Integration of People with Severe Physical Disabilities*, 21 POL'Y STUD. J. 789, 789-90 (1993).

99. On the importance of assistive technology to the employment prospects of people with disabilities, see Andrew I. Batavia, *Health Care, Personal Assistance and Assistive Technology: Are In-Kind Benefits Key to Independence or Dependence for People with Disabilities?*, in DISABILITY, WORK AND CASH BENEFITS, *supra* note 6, at 389, 402-05; John C. DeWitt, *The Role of Technology in Removing Barriers*, in THE AMERICANS WITH DISABILITIES ACT: FROM POLICY TO PRACTICE 313 (Jane West ed., 1991) [hereinafter FROM POLICY TO PRACTICE]; and Katherine D. Seelman, *Assistive Technology Policy: A Road to Independence for Individuals with Disabilities*, 49 J. SOC. ISSUES 115 (1993).

100. On the lack of accessible transportation as a barrier to employment, see Robert A. Katzmann, *Transportation Policy*, in FROM POLICY TO PRACTICE, *supra* note 99, at 214, 216.

101. See NAT'L COUNCIL ON DISABILITY, REMOVING BARRIERS TO WORK: ACTION PROPOSALS FOR THE 105TH CONGRESS AND BEYOND, at “Barrier: Many People Would Be Worse Off Financially if They Worked and Earned to Their Potential Than if They Did Not Work” (1997) [hereinafter NAT'L COUNCIL ON DISABILITY, REMOVING BARRIERS TO WORK], available at <http://www.ncd.gov/newsroom/publications/1997/barriers.htm> (stating, as the first barrier to work for people with disabilities, that “[p]eople fear, most of all, losing the medical benefits that can literally spell the difference between life and death”); NAT'L COUNCIL ON DISABILITY, SHARING THE RISK AND ENSURING INDEPENDENCE: A DISABILITY PERSPECTIVE ON ACCESS TO HEALTH INSURANCE AND HEALTH-RELATED SERVICES, at “Findings on Barriers to Health Insurance and Health-Related Services” No. 3 (1993) [hereinafter NAT'L COUNCIL ON DISABILITY, SHARING THE RISK], available at <http://www.ncd.gov/newsroom/publications/1993/sharing.htm> (“Without adequate insurance coverage, persons with disabilities are likely to forego employment.”); see also Jerry L. Mashaw & Virginia P. Reno, *Overview*, in DISABILITY, WORK AND CASH BENEFITS, *supra* note 6, at 18.

context), it is nonetheless true that people with disabilities, on average, have greater health needs than do those without disabilities.¹⁰²

In its current form, our health insurance system affirmatively disservices the interest of people with disabilities in moving into the workforce. The problem is not that people with disabilities are disproportionately uninsured; they are not.¹⁰³ The problem is that private insurance—on which most nondisabled people rely for their health needs—fails to cover the services people with disabilities most need for independence and health.¹⁰⁴ And public insurance is saddled with requirements that lock people with disabilities out of the workforce.

a. *Limitations of Private Insurance*

Largely in response to perceived problems of adverse selection,¹⁰⁵ private health insurance often places severe limitations on coverage for

102. See Gerben DeJong & Ian Basnett, *Disability and Health Policy: The Role of Markets in the Delivery of Health Services*, in HANDBOOK OF DISABILITY STUDIES, *supra* note 75, at 610, 612-13; Gerben DeJong et al., *America's Neglected Health Minority: Working-Age Persons with Disabilities*, 67 MILBANK Q. 311, 320-22 (1989); Robert B. Friedland & Alison Evans, *People with Disabilities: Access to Health Care and Related Benefits*, in DISABILITY, WORK AND CASH BENEFITS, *supra* note 6, at 357, 358; Kristina W. Hanson et al., *Uncovering the Health Challenges Facing People with Disabilities: The Role of Health Insurance*, HEALTH AFF., Nov. 19, 2003, at W3-552, W3-555, <http://content.healthaffairs.org/cgi/reprint/hlthaff.w3.552v1.pdf>.

103. A recent GAO report based on government data from 1997 and 1998 found that only 9% of individuals with disabilities reported being uninsured, compared with 15% of individuals in the rest of the working-age population. See GAO, MEDICAID AND TICKET TO WORK: STATES' EARLY EFFORTS TO COVER WORKING INDIVIDUALS WITH DISABILITIES 14-15 (2003); see also INST. OF MED., *supra* note 23, at 253 (reporting 1984 statistics that showed that 10.8% of individuals with a major activity limitation were uninsured, compared with 13.4% of individuals without such a limitation). A nationwide Harris survey conducted for the National Organization on Disability (NOD) in 2000 reported that 90% of respondents with disabilities had health insurance, a number essentially identical to the 89% of respondents without disabilities who had health insurance. See NAT'L ORG. ON DISABILITY, *supra* note 81, at 54.

104. See INST. OF MED., *supra* note 23, at 252; NAT'L COUNCIL ON DISABILITY, SHARING THE RISK, *supra* note 101, at "Findings on Barriers to Health Insurance and Health-Related Services" No. 1; Andrew I. Batavia, *Health Care Reform and People with Disabilities*, HEALTH AFF., Spring 1993, at 40, 43. The 2000 NOD survey found that, although people with disabilities are insured in roughly similar percentages as people without disabilities, those with disabilities were four times more likely "to have special needs that are not covered by their health insurance." NAT'L ORG. ON DISABILITY, *supra* note 81, at 52.

105. See Andrew I. Batavia & Gerben DeJong, *Disability, Chronic Illness, and Risk Selection*, 82 ARCHIVES PHYSICAL MED. & REHABILITATION 546, 546 (2001). For a general discussion of the economic forces that operate on such insurance classification decisions, see KENNETH S. ABRAHAM, DISTRIBUTING RISK: INSURANCE, LEGAL THEORY, AND PUBLIC POLICY 64-100 (1986). For a strong theoretical and empirical claim that the likelihood of adverse selection in insurance markets is overstated, see Peter Siegelman, *Adverse Selection in Insurance Markets: An Exaggerated Threat*, 113 YALE L.J. 1223 (2004). For a claim that health insurance ought not to exclude "bad risks," see Deborah A. Stone, *The Struggle for the Soul of Health Insurance*, 18 J. HEALTH POL. POL'Y & L. 287 (1993).

disabling conditions.¹⁰⁶ Insurers frequently offer policies that are subject to “exclusion waivers,” which bar reimbursement for any treatment for particular named conditions.¹⁰⁷ When they do not exclude coverage altogether, insurers often impose annual or lifetime caps on the permitted reimbursement for specific conditions or classes of conditions. These caps frequently are set far below the amount that would be necessary to pay for even minimally sufficient care for the targeted conditions.¹⁰⁸

The limitations many insurers place on coverage for mental health conditions—limitations that are often substantially more restrictive than those placed on coverage for physical illness—have also been a major subject of public debate and litigation.¹⁰⁹ The Mental Health Parity Act of

106. In the past, a common technique for imposing such a limitation was the preexisting condition exclusion. *See, e.g.*, NAT’L COUNCIL ON DISABILITY, MAKING HEALTH CARE REFORM WORK FOR AMERICANS WITH DISABILITIES: SUMMARY INFORMATION ON FIVE “TOWN MEETINGS” ON HEALTH CARE REFORM 8-9 (1994); NAT’L COUNCIL ON DISABILITY, SHARING THE RISK, *supra* note 101, at “Findings on Barriers to Health Insurance and Health-Related Services” No. 1; Batavia, *supra* note 104, at 43. But the Health Insurance Portability and Accountability Act (HIPAA) of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified in scattered sections of 18, 26, 29, and 42 U.S.C.), has made preexisting condition exclusions relatively less important than are the condition- and treatment-specific exclusions discussed in text.

107. *See, e.g.*, Krauel v. Iowa Methodist Med. Ctr., 95 F.3d 674, 675 (8th Cir. 1996) (infertility treatment); Templet v. Blue Cross/Blue Shield of La., No. 99-1400, 2000 WL 1568219, at *1 (E.D. La. Oct. 20, 2000) (obesity); Morgenthal *ex rel.* Morgenthal v. AT&T, No. 97 CIV. 6443 DAB, 1999 WL 187055, at *1 (S.D.N.Y. Apr. 6, 1999) (developmental disorders); Conner v. Colony Lake Lure, No. 4:97CV01, 1997 WL 816511, at *3-4 (W.D.N.C. Sept. 4, 1997) (Treacher Collins Syndrome, a disorder marked by significant deformities of the head and face); *see also* GAO, PRIVATE HEALTH INSURANCE: MILLIONS RELYING ON INDIVIDUAL MARKET FACE COST AND COVERAGE TRADE-OFFS 43 (1996) (listing, *inter alia*, asthma, cleft palate, and glaucoma as conditions for which insurers often exclude coverage); INST. OF MED., *supra* note 23, at 255 (listing, *inter alia*, cataracts, pelvic inflammatory disease, and spine/back disorders as conditions for which insurers often exclude coverage).

108. There are dozens of examples in the case law and the secondary literature. *See, e.g.*, NAT’L COUNCIL ON DISABILITY, *supra* note 106, at 9 (“The insurance company at my husband’s new employer . . . would only cover my lupus to a lifetime limit of \$10,000. When you’re spending over \$300 per month on drugs and hundreds more each year on physician care and laboratory work, that amount wouldn’t last very long. One—even one very brief—hospital stay would use it all.”); Bonnie Poitras Tucker, *Access to Health Care for Individuals with Hearing Impairments*, 37 HOUS. L. REV. 1101, 1153 n.365 (2000) (noting that the EEOC settled litigation against an employer whose insurance coverage imposed an annual cap of \$150 on treatment for hearing loss). Extremely low caps placed on reimbursement for treatment of HIV- or AIDS-related illnesses have been a frequent target of litigation. *See, e.g.*, McNeil v. Time Ins. Co., 205 F.3d 179, 182 (5th Cir. 2000) (\$10,000 limit on coverage for AIDS or AIDS-related complex during first two years of the policy); Doe v. Mut. of Omaha Ins. Co., 179 F.3d 557, 558 (7th Cir. 1999) (two policies, one with a lifetime limit of \$25,000 for AIDS or AIDS-related conditions, the other with a lifetime limit of \$100,000 for those conditions, both with \$1 million lifetime limit for coverage for all conditions); McGann v. H&H Music Co., 946 F.2d 401, 403 (5th Cir. 1991) (\$5000 lifetime limit for AIDS-related conditions). Recent estimates of the average lifetime health care costs for AIDS-related illnesses in the United States exceed \$155,000 for each individual with the condition. *See* Nancy R. Mansfield, *Evolving Limitations on Coverage for AIDS: Implications for Health Insurers and Employers Under the ADA and ERISA*, 35 TORT & INS. L.J. 117, 117 (1999).

109. *See, e.g.*, S. REP. NO. 107-61 (2001) (reporting the proposed Mental Health Equitable Treatment Act of 2001 to address this problem); Brian D. Shannon, *Paving the Path to Parity in*

1996—which was recently extended through December 2004¹¹⁰—prohibits insurers from imposing annual or lifetime dollar limits on mental health coverage that are less than those imposed on physical illness coverage.¹¹¹ But the statute has a number of loopholes.¹¹² As a result, “because of [the statute’s] narrow scope and reductions in mental health benefits that the employers have made to offset the required enhancements, compliance may have little effect on employees’ access to mental health services.”¹¹³ Many state mental-health-parity laws aim to close some of these loopholes,¹¹⁴ but those laws typically do not apply to insurance offered on the individual market,¹¹⁵ nor do they apply to insurance offered by employers through self-funded plans.¹¹⁶

Although the exclusion and capping of coverage for particular conditions is a major problem for individuals with disabilities, it may not be the most important way in which private health insurance policies fail to meet their needs. For even when private health insurance contains no limitations on the conditions for which individuals may be treated, it

Health Insurance Coverage for Mental Illness: New Law or Merely Good Intentions?, 68 U. COLO. L. REV. 63 (1997); Beth Mellen Harrison, Note, *Mental Health Parity*, 39 HARV. J. ON LEGIS. 255 (2002) (discussing recent legislative developments relating to the issue); Richard G. Frank et al., *The Politics and Economics of Mental Health ‘Parity’ Laws*, HEALTH AFF., July/Aug. 1997, at 108. For case law, see *Moddero v. King*, 82 F.3d 1059, 1060 (D.C. Cir. 1996) (\$75,000 lifetime cap on mental health care benefits, in a policy with no cap for physical illnesses); *Kunin v. Benefit Trust Life Insurance Co.*, 910 F.2d 534, 535 (9th Cir. 1990) (\$10,000 annual limit for “mental illness or nervous disorders,” which the insurer applied to limit coverage for autism); and *Fermin v. Conseco Direct Life Insurance Co.*, No. SA-98-CA-0943 NN, 2001 WL 685903, at *7 (W.D. Tex. May 1, 2001) (190-day lifetime cap on coverage for hospitalization to treat “mental, psychoneurotic or personality disorders,” in a policy with no similar cap for hospitalization to treat physical illnesses).

110. See Pub. L. No. 108-197, 117 Stat. 2998 (2003).

111. See 29 U.S.C. § 1185a (2000); 42 U.S.C. § 300gg-5 (2000).

112. It applies only to group health plans, not health plans offered directly by insurers to individual policyholders. See 29 U.S.C. § 1185a(a)(1)-(2); 42 U.S.C. § 300gg-5(a)(1)-(2). Even then, it applies only to group health plans offered by employers with more than fifty employees. See 29 U.S.C. § 1185a(c); 42 U.S.C. § 300gg-5(c). And it applies only to (annual or lifetime) dollar limitations placed on mental health coverage; the statute specifically permits covered insurers to impose “cost sharing, limits on numbers of visits or days of coverage, and requirements relating to medical necessity,” on mental health coverage—even if it does not impose such restrictions on physical illness coverage. 29 U.S.C. § 1185a(b)(2); 42 U.S.C. § 300gg-5(b)(2). Indeed, the statute even permits insurers to decline to offer any mental health coverage at all. See § 29 U.S.C. 1185a(b)(1); 42 U.S.C. § 300gg-5(b)(1).

113. GAO, MENTAL HEALTH PARITY ACT: DESPITE NEW FEDERAL STANDARDS, MENTAL HEALTH BENEFITS REMAIN LIMITED 5 (2000).

114. See *id.* at 8 (reporting that twenty-nine states have adopted laws that “are more comprehensive than the federal parity law by requiring parity not only in dollar limits but also in service limits or cost-sharing provisions”).

115. See GAO, PRIVATE HEALTH INSURANCE: ACCESS TO INDIVIDUAL MARKET COVERAGE MAY BE RESTRICTED FOR APPLICANTS WITH MENTAL DISORDERS 8 (2002).

116. See S. REP. NO. 107-61, at 4 (2001) (explaining that ERISA preemption bars states from applying coverage mandates to self-insured employer plans); Shannon, *supra* note 109, at 77 (same).

typically imposes strict limitations on the specific treatments and other interventions for which it will pay. Those treatment-specific limitations formally affect all policyholders—disabled and nondisabled alike. But they often fall most heavily in practice on individuals with disabilities. Two aspects of private insurance largely account for this effect: (1) the tilt of insurance policies toward acute, as opposed to chronic, care;¹¹⁷ and (2) the typical requirement that covered treatments be “medically necessary.”¹¹⁸ These aspects are intertwined, because insurance policies’ definitions of medical necessity often incorporate an acute-care bias by “requir[ing] evidence that a service will significantly improve a person’s health status” and not merely “maintain [that person’s] functional capacity.”¹¹⁹

The acute-care orientation of private health insurance creates a number of gaps in coverage that have a significant effect on individuals with disabilities. Individuals who experience disabling injuries or strokes, for example, typically find that their insurance does not cover the rehabilitative

117. See, e.g., INST. OF MED., *supra* note 23, at 227; NAT’L COUNCIL ON DISABILITY, SHARING THE RISK, *supra* note 101, at “Findings on Barriers to Health Insurance and Health-Related Services” No. 4; DeJong et al., *supra* note 102, at 335. For a general critique of the American health system’s acute-care bias, see DANIEL M. FOX, POWER AND ILLNESS: THE FAILURE AND FUTURE OF AMERICAN HEALTH CARE POLICY (1993).

118. See, e.g., HENRY T. IREYS ET AL., DEFINING MEDICAL NECESSITY: STRATEGIES FOR PROMOTING ACCESS TO QUALITY CARE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES, MENTAL RETARDATION, AND OTHER SPECIAL HEALTH CARE NEEDS 1-2 (1999); NAT’L COUNCIL ON DISABILITY, SHARING THE RISK, *supra* note 101, at “Findings on Barriers to Health Insurance and Health-Related Services” No. 4. Insurers’ imposition and application of “medical necessity” criteria are frequently discussed in the legal and health policy literature. For discussions in the legal literature, see Einer Elhauge, *The Limited Regulatory Potential of Medical Technology Assessment*, 82 VA. L. REV. 1525 (1996); Mark A. Hall & Gerard F. Anderson, *Health Insurers’ Assessment of Medical Necessity*, 140 U. PA. L. REV. 1637 (1992); and Timothy Stoltzfus Jost, *The American Difference in Health Care Costs: Is There a Problem? Is Medical Necessity the Solution?*, 43 ST. LOUIS U. L.J. 1 (1999). For discussions in the health policy literature, see David M. Eddy, *Benefit Language: Criteria That Will Improve Quality While Reducing Costs*, 275 JAMA 650 (1996); Peter D. Jacobson et al., *Defining and Implementing Medical Necessity in Washington State and Oregon*, 34 INQUIRY 143 (1997); Sara Rosenbaum et al., *Who Should Determine When Health Care Is Medically Necessary?*, 340 NEW ENG. J. MED. 229 (1999); and Linda A. Bergthold, *Medical Necessity: Do We Need It?*, HEALTH AFF., Winter 1995, at 180. See also *Medical Necessity: From Theory to Practice: Hearing Before the Senate Comm. on Health, Educ., Labor, and Pensions*, 106th Cong. (1999). Although people with disabilities and those who focus on disability certainly understand the connection between prevailing definitions of “medical necessity” and the inadequacy of private health insurance for people with disabilities, the point is largely absent from the general legal or health policy literature on medical-necessity requirements. Virtually none of that literature focuses on the way in which the acute-care bias of medical-necessity definitions—and their focus on what one analyst calls the “truly medical,” Eddy, *supra*, at 652—limits the coverage people with disabilities most need. For a rare hint at this issue, see Jacobson et al., *supra*, at 151-52 (“[M]edical necessity is not well-suited for the severely disabled or the chronic care populations, where problems often deal with social necessity, such as keeping people independent.”).

119. IREYS ET AL., *supra* note 118, at 2. *But cf. id.* at 17 (noting that definitions “vary widely”).

therapy they need.¹²⁰ Individuals with disabilities who need other forms of ongoing therapy—such as those with hearing impairments who need speech therapy—have a similar experience. Private insurers will pay for such therapy when it is a short-term response to an acute condition, but not when it is a continuing response to a chronic condition.¹²¹

Similarly, private insurers often do not cover, or do not adequately cover, durable medical equipment and assistive technologies.¹²² The failure of private insurers to cover the costs of hearing aids is widely documented.¹²³ Individuals with limb amputations also frequently have difficulty obtaining coverage for their prostheses.¹²⁴ Insurers often invoke the “medical necessity” concept to refuse to pay for more advanced (and more functional) prostheses where less expensive (and less functional) prostheses are available.¹²⁵ The same “medical necessity” issue often arises

120. See, e.g., LISA I. IEZZONI, WHEN WALKING FAILS: MOBILITY PROBLEMS OF ADULTS WITH CHRONIC CONDITIONS 241 (2003); INST. OF MED., *supra* note 23, at 255; NAT’L COUNCIL ON DISABILITY, SHARING THE RISK, *supra* note 101, at “Findings on Barriers to Health Insurance and Health-Related Services” No. 5; Batavia, *supra* note 104, at 43.

121. See, e.g., Micek v. City of Chicago, No. 98-C-6757, 1999 WL 966970, at *6 n.12 (N.D. Ill. Oct. 4, 1999) (stating that plaintiff born with a hearing impairment was denied coverage for speech therapy “because his condition was chronic and significant improvement could not be shown within sixty days”); see also Johns Hopkins Hosp. v. Pepper, 697 A.2d 1358, 1370 (Md. 1997) (noting that plaintiffs’ insurance did not cover “long-term (*i.e.*, lasting more than sixty days) physical, speech or occupational therapies”).

122. See, e.g., IEZZONI, *supra* note 120, at 249-50; INST. OF MED., *supra* note 23, at 227; NAT’L COUNCIL ON DISABILITY, SHARING THE RISK, *supra* note 101, at “Findings on Barriers to Health Insurance and Health-Related Services” No. 5; SHAPIRO, *supra* note 33, at 231; Batavia, *supra* note 104, at 43-44; see also IEZZONI, *supra* note 120, at 254-55 (noting that even when insurers pay for mobility aids, they often fail to pay for necessary adjustments and repairs).

123. See, e.g., Tucker, *supra* note 108, at 1147; Steven B. Adams, Comment, *Who Will Hear? An Examination of the Regulation of Hearing Aids*, 11 J. CONTEMP. HEALTH L. & POL’Y 505, 509 (1995); Christine M. Tomko, Note, *The Economically Disadvantaged and the ADA: Why Economic Need Should Factor into the Mitigating Measures Disability Analysis*, 52 CASE W. RES. L. REV. 1033, 1035 (2002); see also Ellen A. Rhoades, *Hearing Aids for Children: Who Pays?*, VOLTA VOICES, Mar.-Apr. 2002, at 5, 5 (“It is widely known that effective hearing prostheses are critical to the well-being of these children. And yet, this is the one piece of equipment that is often the most expensive and the most difficult for parents to secure.”).

124. For that reason, the Amputee Coalition of America, in its publication on “adapting to limb loss,” includes articles with titles such as *Have You Read Your Insurance Policy Lately?*, *When Your Insurance Claim Is Denied*, and *In Search of Funding*. See NAT’L LIMB LOSS INFO. CTR., FIRST STEP: A GUIDE FOR ADAPTING TO LIMB LOSS 46-54 (2003). Such titles are, in fact, commonplace in publications geared toward parents of children with disabilities. See, e.g., Tricia Luker & Calvin Luker, *What Do You Mean It’s Not Covered?*, EXCEPTIONAL PARENT, Aug. 1998, at 42.

125. See, e.g., Cynthia Myers, *The Future of Amputee Rehabilitation*, REHAB MGMT., Oct./Nov. 1998, at 50, 51. For a discussion of the functional benefits of technologically advanced prostheses, see SHAPIRO, *supra* note 33, at 222-23. For relevant case law, see *EEOC v. Hinsdale Hospital*, No. 98-C-3482, 1999 WL 495480, at *1 (N.D. Ill. June 30, 1999) (noting that insurer refused to pay for myoelectric arm prosthesis that would eliminate neck strain caused by complainant’s existing mechanical prosthesis); *Palmer v. Superior Court*, 127 Cal. Rptr. 2d 252, 256 (Ct. App. 2002) (noting that, although plaintiff’s prosthetist believed that more expensive ultralight prostheses would be more functional for his active lifestyle, only the basic prosthesis satisfied the insurer’s “medical necessity” criterion).

when individuals with mobility impairments seek reimbursements for wheelchairs.¹²⁶

b. *Limitations of Public Insurance*

The foregoing limitations on private insurance coverage have driven people with disabilities into the public health care system, primarily Medicare and Medicaid. But the public health insurance programs themselves impose serious impediments to the participation of people with disabilities in the labor force. Most notably, they incorporate restrictive eligibility criteria that create both psychological and economic disincentives to working.

To receive Medicare, a working-age individual with a disability generally must first become eligible for Social Security Disability Insurance (SSDI) by showing that he or she is unable to do any “substantial gainful work which exists in the national economy.”¹²⁷ SSDI recipients must then wait two years before receiving Medicare.¹²⁸ Although the administrative eligibility rules sweep in a large number of people who in fact could work,¹²⁹ the need to prove that one cannot work to obtain SSDI, combined with the need to remain idle during the two-year waiting period to obtain health coverage, gives disabled Medicare recipients a significant psychological investment in the notion that they are unable to work. That psychological investment makes it hard to leave the SSDI rolls,¹³⁰ as does the fear of losing Medicare benefits entirely.

SSDI contains a work-incentive provision that allows people with disabilities who leave the rolls to retain Medicare eligibility for a substantial length of time (eight-and-a-half years, thanks to the 1999 enactment of the Ticket to Work and Work Incentives Improvement Act (TWWIA), discussed *infra* Part III).¹³¹ But benefits recipients who reach the end of that work-incentive period abruptly lose their Medicare

126. An extensive discussion of this issue appears in IEZZONI, *supra* note 120, at 223-59.

127. 42 U.S.C. § 423(d)(2)(A) (2000).

128. *See id.* § 426(b).

129. For a discussion of this issue, see *Cleveland v. Policy Management Systems Corp.*, 526 U.S. 795, 804 (1999) (noting that administrative rules governing SSDI eligibility “inevitably simplify, eliminating consideration of many differences potentially relevant to an individual’s ability to perform a particular job” and therefore that an individual might qualify for SSDI under these rules yet still be able to work). *See generally* Heckler v. Campbell, 461 U.S. 458 (1983) (describing and upholding the administrative scheme, which relies on categorical rules, for determining whether individuals are able to work for purposes of SSDI).

130. *See* DeJong et al., *supra* note 102, at 334-35; Walter Y. Oi, *Employment and Benefits for People with Diverse Disabilities*, in *DISABILITY, WORK AND CASH BENEFITS*, *supra* note 6, at 103, 121.

131. *See* 42 U.S.C. § 426(b).

eligibility.¹³² And SSDI recipients have long feared that if they return to the workforce for any period, the Social Security Administration will declare them no longer disabled and thereby eliminate their eligibility for any benefits.¹³³

Medicaid contains similar—though not quite identical—work disincentives. Although the rules governing Medicaid eligibility are complicated and vary significantly across states, roughly seventy-eight percent of disabled Medicaid beneficiaries are entitled to coverage because they receive Supplemental Security Income (SSI).¹³⁴ (With the exception of states that have invoked the so-called “209(b) option,”¹³⁵ states are required to provide Medicaid coverage to all SSI recipients.¹³⁶) To receive SSI, applicants must establish both that they have a “disability” and that they earn and own less than a statutory income and resource threshold.¹³⁷ Because the SSI program’s definition of disability is the same inability-to-perform-substantial-gainful-activity definition as the one that applies under the SSDI program, the same structural work deterrent appears in both: To establish eligibility, an applicant must make a substantial investment (psychological and otherwise) in the proposition that he or she is simply unable to work.¹³⁸

SSI (and the accompanying entitlement to Medicaid) does contain a work-incentive provision: If an SSI recipient with a disability returns to work, medical benefits will not be cut off until the recipient’s monthly income exceeds the sum of (1) the monthly SSI cash benefit (currently \$552) plus any supplemental payment provided by the state; (2) the

132. See GAO, SSA DISABILITY: PROGRAM REDESIGN NECESSARY TO ENCOURAGE RETURN TO WORK 44-47 (1996).

133. See NAT’L COUNCIL ON DISABILITY, REMOVING BARRIERS TO WORK, *supra* note 101. TWWIIA substantially alleviates this fear. See *infra* Subsection III.A.2.

134. See KAISER COMM’N ON MEDICAID & THE UNINSURED, MEDICAID’S ROLE FOR PEOPLE WITH DISABILITIES 12 (2003).

135. This option, codified at 42 U.S.C. § 1396a(f), was created during the 1972 change from a cooperative state-federal program of aid to the Aged, Blind, and Disabled (ABD) to an entirely federal SSI program. A number of states applied more restrictive eligibility criteria to their ABD programs than the federal government ultimately applied to SSI. The 209(b) option permits those states to use their more restrictive pre-1972 ABD eligibility standards, rather than the federal government’s relatively more generous post-1972 SSI eligibility standards, to govern access to Medicaid. Eleven states—Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia—currently use the 209(b) option. See KAISER COMM’N ON MEDICAID & THE UNINSURED, *supra* note 134, at 13.

136. See 42 U.S.C. § 1396a(a)(10)(A)(i)(II).

137. See *id.* § 1382.

138. SSI recipients face no waiting period before receiving Medicaid. In this respect, they are quite unlike SSDI recipients, who must wait two years before receiving Medicare. But even though SSI-Medicaid recipients do not face the two years of forced idleness that SSDI-Medicare recipients do, they still must remain idle while their SSI applications are being considered. And because SSI is not a contributory social-insurance program like SSDI, SSI recipients are far less likely than SSDI recipients to have had any significant prior workforce attachment.

recipient's impairment-related work expenses; and (3) the monthly cost of Medicaid benefits and publicly funded attendant-care services previously paid to the recipient.¹³⁹ Unlike the work-incentive provision under SSDI, this provision has no time limit, but it still has not moved significant numbers of people with disabilities into the workforce.¹⁴⁰ The initial investment in idleness that attends the receipt of SSI benefits, the lack of understanding by SSI recipients of the complex structure of the work-incentive provision, and the relatively low income levels at which Medicaid eligibility phases out under that provision are likely explanations.¹⁴¹

3. Summary

The foregoing discussion should demonstrate that people with disabilities face an array of deep-rooted structural barriers to work. These barriers—the lack of access to personal-assistance services, accessible technology, home modifications, and accessible transportation, together with the structure of our health care system—operate to keep many people with disabilities out of the workforce well before any individual employer has an opportunity to discriminate against them. An antidiscrimination model thus does not appear to be a promising means of attacking those barriers.

B. *The Accommodation Requirement's Ineffectiveness in Eliminating Structural Barriers to Employment*

The ADA might, at first glance, appear to be a more promising vehicle for eliminating deep structural barriers to employment than other antidiscrimination statutes. The ADA's innovation, after all, was that it placed the requirement of "reasonable accommodation" front and center.¹⁴² Because the existing physical and social environment is structured in a way

139. See 42 U.S.C. § 1382h(b); 20 C.F.R. §§ 416.260-.269 (2004).

140. See, e.g., GAO, MAJOR MANAGEMENT CHALLENGES AND PROGRAM RISKS: SOCIAL SECURITY ADMINISTRATION 10-11 (2003).

141. For a good discussion of some likely reasons the work incentives have been so ineffective, see GAO, *supra* note 132, at 39-47. See also Friedland & Evans, *supra* note 102, at 369 ("Current Medicaid policy addresses some of the employment disincentives for individuals leaving SSI rolls and returning to work. It does not, however, address the motivation to go on Medicaid in the first place. This incentive arises because employer-based coverage is unavailable or inadequate and because Medicaid's income test effectively requires that one stop working to become eligible.").

142. See 42 U.S.C. § 12111(8) (defining "qualified individual with a disability" to mean "an individual with a disability who, with or without reasonable accommodation, can perform the essential functions of the employment position that such individual holds or desires"); *id.* § 12112(b)(5)(A) (requiring employers to "mak[e] reasonable accommodations to the known physical or mental limitations of an otherwise qualified individual with a disability").

that often excludes people with disabilities simply by failing to take them into account, the ADA's drafters insisted that any disability discrimination law must include a requirement that employers make changes to (physical and social) structures that were designed without people with disabilities in mind.¹⁴³ The accommodation requirement might in principle serve as a means of attacking the deep-rooted structural obstacles to employment for people with disabilities.¹⁴⁴

As I show in this Section, however, it has not worked out that way. By deploying two doctrines—the “job-related” rule, which I discuss in Subsection 1, and the access/content distinction, which I discuss in Subsection 2—courts have drained the accommodation requirement of significant power to eliminate those deep-rooted barriers. These doctrines categorically exclude certain classes of accommodation from the purview of the ADA—even if the requested accommodations could be provided reasonably and without undue hardship. Unfortunately, the types of accommodation excluded by these doctrines are precisely those that are necessary to eliminate broad structural barriers to employment for people with disabilities.

1. *The “Job-Related” Rule*

One aspect of ADA doctrine quite directly relieves employers of responsibility for alleviating broad structural barriers to the employment of people with disabilities. It is well accepted, both by the EEOC and by the courts, that an ADA accommodation must be “job-related” rather than a “personal item.”¹⁴⁵ Under this rule, an employer might be required to provide a disabled individual with an accommodation that “specifically assists the individual in performing the duties of a particular job” (so long as the accommodation is reasonable and can be provided without undue hardship).¹⁴⁶ But the employer will never be required to provide “an

143. See, e.g., Robert L. Burgdorf Jr., *The Americans with Disabilities Act: Analysis and Implications of a Second-Generation Civil Rights Statute*, 26 HARV. C.R.-C.L. L. REV. 413, 460-61 (1991); see also SCOTCH, *supra* note 65, at 70-72 (describing how drafters of the regulations implementing section 504 of the Rehabilitation Act recognized the need for an accommodation requirement).

144. Cf. Karlan & Rutherglen, *supra* note 94, at 39-41 (suggesting that a race discrimination regime modeled on the ADA's reasonable accommodation requirement might provide a means for attacking structural employment problems among racial minorities).

145. 29 C.F.R. pt. 1630 app. § 1630.9 (2004). This doctrine draws directly from a statement in the House Education and Labor Committee's report on the proposed ADA. See H.R. REP. NO. 101-485, pt. 2, at 64 (1990).

146. 29 C.F.R. pt. 1630 app. § 1630.9.

adjustment or modification [that] assists the individual throughout his or her daily activities, on and off the job.”¹⁴⁷

The “job-related” rule plainly rules out a number of accommodations that could be provided at reasonable cost and without undue hardship and that, while necessary to enable many individuals to work, also provide off-the-job benefits. For example, the rule excuses employers from any obligation to provide assistive technology that people with disabilities need to get to work—at least if that technology also helps them outside of the workplace.¹⁴⁸ Nor need employers provide medical treatment or rehabilitation that would make an individual with a disability able to work,¹⁴⁹ paid leave to attend training for a new service animal that would enable an individual with a disability to come to work,¹⁵⁰ or training that would enable an individual to perform a new job when she has become unable to perform her old job because of a disability.¹⁵¹ In all of these cases, the accommodation might enable an individual with a disability to work, and it might be provided at “reasonable” cost and without “undue hardship.” But because the accommodation would also provide benefits that extend beyond the individual’s relationship with her particular employer, the “job-related” rule excludes it from the ADA’s requirements.

By similar logic, the statute does not require employers to provide the home-based personal assistance that many individuals with disabilities need to get out of bed and ready for work, because such assistance also enhances those individuals’ independence more generally.¹⁵² It bears emphasis that the problem here is not the expense or burden of personal-assistance services, which might be relatively cheap. The problem is that such services help the disabled individual off the job as well as on. When an individual with a disability needs the assistance of an aide in performing on-the-job tasks, an employer might well be required to provide it.¹⁵³ That may be true

147. *Id.*

148. See EEOC, A TECHNICAL ASSISTANCE MANUAL ON THE EMPLOYMENT PROVISIONS (TITLE I) OF THE AMERICANS WITH DISABILITIES ACT § 3.4 (1992) (“Equipment or devices that assist a person in daily activities on and off the job are considered personal items that an employer is not required to provide.”).

149. See *Brookins v. Indianapolis Power & Light Co.*, 90 F. Supp. 2d 993, 1003-04 (S.D. Ind. 2000); *Burnett v. W. Res., Inc.*, 929 F. Supp. 1349, 1358 (D. Kan. 1996).

150. See *Nelson v. Ryan*, 860 F. Supp. 76, 82-83 (W.D.N.Y. 1994).

151. See *Williams v. United Ins. Co.*, 253 F.3d 280, 282-83 (7th Cir. 2001).

152. For discussion of the difficulty with using the ADA as a tool to obtain personal assistance services, see Simi Litvak, *Personal Assistance Services*, in IMPLEMENTING THE ADA, *supra* note 75, at 365, 370-74.

153. See, e.g., 42 U.S.C. § 12111(9)(B) (2000) (providing that “reasonable accommodation” includes “provision of qualified readers or interpreters”); *Borkowski v. Valley Cent. Sch. Dist.*, 63 F.3d 131, 141-42 (2d Cir. 1995) (Calabresi, J.) (holding that full-time aide to assist plaintiff teacher in classroom management might be a reasonable accommodation); *Nelson v. Thornburgh*, 567 F. Supp. 369, 382 (E.D. Pa. 1983) (Pollak, J.) (holding that hiring readers to assist blind employees with on-the-job tasks is reasonable accommodation).

even if the cost is substantial.¹⁵⁴ But an employer will never be required to provide aides who offer off-the-job help, no matter how inexpensive.

The EEOC and at least one lower court have gone even further and concluded that an employer's accommodation obligation does not even begin until the individual with a disability arrives at the workplace. Accordingly, the employer need not provide transportation to help the individual get to the workplace in the first instance.¹⁵⁵ The case law is not uniform on this issue, however.¹⁵⁶ But whether it affects access to transportation or not, the "job-related" rule represents a significant limitation on the accommodation requirement's power to disestablish deep-rooted structural obstacles to employment for people with disabilities.

2. *The Access/Content Distinction*

In addition to applying the "job-related" rule, courts have consistently employed what I will call the access/content distinction in adjudicating accommodation claims under all three substantive titles of the ADA: Title I, which prohibits discrimination in private employment; Title II, which prohibits discrimination by state and local governments; and Title III, which prohibits discrimination by places of public accommodation. These courts have held that an accommodation can be required only if it provides people with disabilities "access" to the same benefit received by nondisabled individuals; an accommodation that would alter the "content" of the benefit will not be required, even if it can be provided at reasonable cost and without undue hardship. In practice, this distinction has largely drained the statute of effectiveness in attacking what may be the single most significant employment barrier faced by people with disabilities as a group—the current structure of our health insurance system.¹⁵⁷

154. See, e.g., *Nelson*, 567 F. Supp. at 376 (noting that readers would cost approximately half of plaintiffs' salary, or roughly \$6638 per plaintiff per year in 1983 dollars).

155. See *Wade v. Gen. Motors Corp.*, No. 97-3378, 1998 WL 639162, at *2 (6th Cir. Sept. 10, 1998) (holding employer not required to provide transportation to and from work); *LORI A. BOWMAN ET AL., EMPLOYMENT LAW YEARBOOK* § 9:7.7 (2003) (reporting the EEOC's position that "barriers outside the workplace, such as a difficulty in getting to work, are not 'workplace created barriers'" subject to the accommodation obligation).

156. See *Lyons v. Legal Aid Soc'y*, 68 F.3d 1512, 1516-17 (2d Cir. 1995) (holding that employer may be required to provide paid parking space as accommodation for employee whose disability makes her unable to take public transportation to work); *Smallwood v. Witco Corp.*, No. 94 CIV. 7766 (LMM), 1995 WL 716745, at *1 (S.D.N.Y. Dec. 6, 1995) ("There is nothing inherently unreasonable in requiring an employe[r] to furnish an otherwise qualified disabled employee with assistance related to her ability to get to work.").

157. Professor Melissa Cole argues that the cases that have applied an access/content distinction in the context of insurance have really applied a status/conduct distinction because they prohibit discrimination on the basis of disability status but permit discrimination based on the conduct of using particular medical services. See Melissa Cole, *In/Ensuring Disability*, 77 TUL. L. REV. 839, 873 (2003). Without denying the force of Professor Cole's argument, my sense is that

In the fourteen years the ADA has been on the books, it has proven an ineffective tool to force structural reforms in our health insurance system. In particular, courts have consistently read the statute as *not* reaching the condition- and treatment-specific coverage limitations that impose severe burdens on people with disabilities. At first glance, this result may not be surprising, for the ADA includes a specific safe harbor provision for certain risk classification and administration decisions by insurers. That provision states that the statute “shall not be construed to prohibit or restrict”:

(1) an insurer, hospital or medical service company, health maintenance organization, or any agent, or entity that administers benefit plans, or similar organizations from underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State law; or

(2) a person or organization covered by this chapter from establishing, sponsoring, observing or administering the terms of a bona fide benefit plan that are based on underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State law; or

(3) a person or organization covered by this chapter from establishing, sponsoring, observing or administering the terms of a bona fide benefit plan that is not subject to State laws that regulate insurance.¹⁵⁸

This language seems to authorize insurers to discriminate against people with disabilities in all acts of risk underwriting, classification, and administration. But the same provision goes on to say that the foregoing paragraphs “shall not be used as a subterfuge to evade the purposes of subchapter[s] I and III of this chapter.”¹⁵⁹ Although the details of this provision are nearly inscrutable—particularly its “subterfuge” coda¹⁶⁰—it

analysis of ADA accommodation doctrine is best advanced by thinking of these cases as applying what they straightforwardly purport to apply—an access/content distinction.

158. 42 U.S.C. § 12201(c).

159. *Id.* (footnote omitted).

160. Consider the futile efforts of one esteemed judge to make sense of the provision. Suggesting that insurance companies insisted on the inclusion of the safe harbor provision because they feared “being sued under [the ADA’s public accommodations provisions] for refusing to sell an insurance policy to a disabled person,” then-Chief Judge Posner contended that the provision might protect such insurers when their refusal to deal rested on sound actuarial principles as required by state law:

For Mutual of Omaha to take the position that people with AIDS are so unhealthy that it won’t sell them health insurance would be a prima facie violation of [the ADA’s public accommodations provisions]. But the insurance company just might be able to steer into the safe harbor provided by [42 U.S.C. § 12201(c)], provided it didn’t run afoul of the “subterfuge” limitation, as it would do if, for example, it had adopted the AIDS caps to deter people who know they are HIV positive from buying the policies at all.

“is obviously intended for the benefit of insurance companies.”¹⁶¹ One might therefore expect that it is the insurance-specific safe harbor provision that made the ADA an ineffective tool for forcing change in private insurance practices that serve to limit the independence of people with disabilities.

What is striking, however, is that the cases that have rejected ADA challenges to condition- and treatment-specific exclusions and caps have not, for the most part, relied on the safe harbor provision. Judge Posner’s leading decision in *Doe v. Mutual of Omaha Insurance Co.*¹⁶² is exemplary. The plaintiff, who had HIV, challenged AIDS caps that Mutual of Omaha had imposed on its health insurance policies. Defending the caps, the insurer made no effort to claim the protection of the safe harbor provision. To the contrary, it “conceded itself out of relying on [42 U.S.C. § 12201(c)’s] safe harbor by stipulating that it cannot show that its AIDS caps are based on sound actuarial principles or claims experience or are consistent with state law.”¹⁶³ Despite that concession, the court rejected the plaintiff’s ADA claim on the basis of the access/content distinction. Because Mutual of Omaha offered people with HIV the same product it offered everyone else (health insurance with an AIDS cap), the court concluded that it had not denied the plaintiffs *access* to the goods or services it offered and therefore could not be liable under the statute.¹⁶⁴ In seeking to lift the AIDS caps, the court held, the plaintiff impermissibly sought to change the *content* of the insurance policies Mutual of Omaha offered.¹⁶⁵

Judge Posner made clear that the access/content distinction was not an insurance-specific doctrine. Rather, it reflected a general limitation on the ADA’s accommodation requirement:

The common sense of the statute is that the content of the goods or services offered by a place of public accommodation is not

Doe v. Mut. of Omaha Ins. Co., 179 F.3d 557, 562 (7th Cir. 1999). As Judge Posner describes it, the “subterfuge” language takes back the entire benefit that insurance companies expected to get from the safe harbor provision. The whole premise of his argument is that the safe harbor protects insurers in at least some cases in which they refuse to sell policies to individuals because of their disabilities. But if an insurer’s action is treated as “subterfuge” whenever the insurer aims to keep a class of people with disabilities from buying its policies, how can the safe harbor ever protect an insurer who refuses to deal with an individual with a disability? For a good discussion of the confusing nature of the safe harbor’s “subterfuge” provision, see Jeffrey S. Manning, Comment, *Are Insurance Companies Liable Under the Americans with Disabilities Act?*, 88 CAL. L. REV. 607, 639-43 (2000).

161. *Doe*, 179 F.3d at 562. For a discussion of the legislative history of the insurance safe harbor provision, see Chai R. Feldblum, *The Employment Sector*, in IMPLEMENTING THE ADA, *supra* note 75, at 81, 111-18.

162. 179 F.3d 557.

163. *Id.* at 562.

164. *See id.* at 559.

165. *See id.* at 560.

regulated. A camera store may not refuse to sell cameras to a disabled person, but it is not required to stock cameras specially designed for such persons.¹⁶⁶

Like Judge Posner, courts adjudicating ADA cases frequently say that an accommodation may be required only if it provides a disabled individual access to the same opportunity provided to others (the same job in the employment context, the same government benefit in the public services context, or the same good or service in the public accommodations context). If an accommodation provides nothing more than such access, then the defendant must provide it to the extent reasonable. But no accommodation will be required—no matter how reasonable—if it would alter the content of the opportunity the defendant offers generally.¹⁶⁷

Although the insurer does not usually stipulate itself out of the ADA's safe harbor, *Doe's* analysis is typical of the case law in this area. The cases have consistently rejected challenges to disability-related caps or exclusions, and they have typically done so on access/content grounds: So long as the insurer offers people with disabilities the opportunity to purchase policies on the same terms as everyone else, it has not denied them access to the benefit received by the nondisabled. That is true even if the policy terms cap or exclude coverage for specific disabling conditions, or for specific treatments that only people with disabilities can use. Courts

166. *Id.*

167. See *US Airways v. Barnett*, 535 U.S. 391, 397 (2002) (employment case) (“The Act requires preferences in the form of ‘reasonable accommodations’ that are needed for those with disabilities to obtain the *same* workplace opportunities that those without disabilities automatically enjoy.”); *PGA Tour v. Martin*, 532 U.S. 661, 683 n.37 (2001) (public accommodations case) (“The statute seeks to assure that a disabled person’s disability will not deny him *equal access* to (among other things) competitive sporting events” (quoting *id.* at 703 (Scalia, J., dissenting))); *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597, 603 n.14 (1999) (public services case) (holding that states might be required to create community placements for individuals with mental disabilities, but rejecting characterization of that holding as requiring states to provide different services to individuals with disabilities than are provided to others, while holding that “States must adhere to the ADA’s nondiscrimination requirement with regard to the services they in fact provide”); *Alexander v. Choate*, 469 U.S. 287, 301, 303 (1985) (public services case) (holding under the Rehabilitation Act—the predecessor to the ADA—that “an otherwise qualified handicapped individual must be provided with meaningful access to the benefit that the grantee offers,” but that the statute “does not require the State to alter [its] definition of the benefit being offered simply to meet the reality that the handicapped have greater medical needs”). The ADA’s access/content distinction finds an imperfect parallel in jurisprudence under the Individuals with Disabilities Education Act (IDEA) and its predecessor statute, the Education for All Handicapped Children Act. The Supreme Court has held that the IDEA imposes a non-cost-qualified requirement that school districts provide services necessary for individuals with disabilities to obtain access to the classroom. See, e.g., *Cedar Rapids Cmty. Sch. Dist. v. Garret F. ex rel. Charlene F.*, 526 U.S. 66, 77-79 (1999). But it has also held that school districts have a much more limited obligation under the statute to alter the content of the instruction provided. See *Bd. of Educ. v. Rowley*, 458 U.S. 176, 198-204 (1982).

have applied this analysis in cases involving both condition-specific¹⁶⁸ and treatment-specific¹⁶⁹ limitations on insurance coverage. With only a few exceptions, they have not found it necessary to rely on the safe harbor provision.¹⁷⁰ In short, the ADA has proven ineffective in challenging the limits on private health insurance for people with disabilities, and the access/content distinction has been largely responsible for that result.

168. See, e.g., *McNeil v. Time Ins. Co.*, 205 F.3d 179, 189, 188-89 (5th Cir. 2000) (rejecting challenge to AIDS cap in health insurance policy and stating that, “[b]ecause Title III does not reach so far as to regulate the content of goods and services, and because it is undisputed this limitation for AIDS is part of the content of the good that Time offered, Mr. McNeil’s Title III claim must fail”); *Doe*, 179 F.3d at 559-60; *Moddero v. King*, 82 F.3d 1059, 1062 (D.C. Cir. 1996) (rejecting challenge to insurance plan’s \$75,000 lifetime cap on mental health benefits—a cap not paralleled by any similar limitation on benefits for physical conditions—essentially on access/content grounds). *But cf.* *Carparts Distrib. Ctr. v. Auto. Wholesaler’s Ass’n*, 37 F.3d 12, 19 (1st Cir. 1994) (stating that “a sharp distinction between” access and content may be “illusory”). For a general discussion of the case law, see Mary Crossley, *Becoming Visible: The ADA’s Impact on Health Care for Persons with Disabilities*, 52 ALA. L. REV. 51, 80 (2000) (“Although some courts have been willing to scrutinize insurance practices to protect the interests of people with disabilities, the trend of the case law over the past several years has been for courts to take a fairly hands-off approach . . .”).

169. See, e.g., *Bythway v. Principal Health Care of Del.*, Nos. CIV. A. 97-435-GMS & CIV. A. 97-600-GMS, 1999 WL 33220042, at *2-3 (D. Del. Sept. 29, 1999) (bone marrow transplant covered for aplastic anemia and acute leukemia but not Hodgkin’s disease); *Rome v. MTA/N.Y. City Transit*, No. 97-CV-2945 (JG), 1997 WL 1048908, at *4 (E.D.N.Y. Nov. 18, 1997) (speech therapy covered for some conditions but not for autism); *Hilliard v. BellSouth Med. Assistance Plan*, 918 F. Supp. 1016, 1026-27 (S.D. Miss. 1995) (high-dose chemotherapy covered for some cancers but not multiple myeloma); *Pokorney v. Miami Valley Career Tech. Ctr. Sch. Dist.*, No. C-3-94-247, 1995 WL 1671909 (S.D. Ohio July 14, 1995) (Taxol rejected as “experimental” treatment for lung cancer when it was covered for other cancers). *But see* *Henderson v. Bodine Aluminum*, 70 F.3d 958, 960-61 (8th Cir. 1995) (granting preliminary injunction to woman with breast cancer who challenged insurance policy’s refusal to cover high-dose chemotherapy treatment (HDCT) for breast cancer when it covered HDCT for some other cancers).

170. Although a number of cases discuss the safe harbor provision, they tend to do so only as additional support for their decisions or to rebut the contention that the safe harbor provision is itself evidence of an intent that the statute regulate the content of insurance policies. See *Rogers v. Dep’t of Health & Envtl. Control*, 174 F.3d 431, 435-37 (4th Cir. 1999); *Ford v. Schering-Plough Corp.*, 145 F.3d 601, 610-12 (3d Cir. 1998); *Parker v. Met. Life Ins. Co.*, 121 F.3d 1006, 1012-13 (6th Cir. 1997); *Moddero*, 82 F.3d at 1063-65. Some courts and judges, to be sure, have relied primarily on the safe harbor provision in such cases, but they are a distinct minority. See, e.g., *Ford*, 145 F.3d at 614-15 (Alito, J., concurring in the judgment); cf. *Leonard F. v. Isr. Disc. Bank of N.Y.*, 199 F.3d 99, 106 (2d Cir. 1999) (stating, in challenge to long-term disability policy that capped coverage for mental conditions, that “we agree with the district court that, if MetLife’s LTD policy is consistent with state law and was adopted prior to the passage of the ADA, it is exempt from regulation under the Act pursuant to the safe harbor provision,” but vacating judgment against the plaintiff (footnote omitted)). In Rachel Schneller Ziegler, Note, *Safe, but Not Sound: Limiting Safe Harbor Immunity for Health and Disability Insurers and Self-Insured Employers Under the Americans with Disabilities Act*, 101 MICH. L. REV. 840, 856-61 (2002), many decisions are erroneously attributed to reliance on the safe harbor provision; that attribution leads the author to conclude that the safe harbor provision has a much greater effect than it actually does.

C. *Treating Accommodation as Antidiscrimination*

As I have shown, courts have read the ADA's accommodation requirement in a way that rules out of bounds any significant challenge to the deep-rooted structural barriers to employment for people with disabilities. In this Section, I explore the possible agenda behind the "job-related" and access/content doctrines that have achieved that effect. In Subsection 1, I argue that neither doctrine is especially compelling as an analytic matter. The "job-related" rule rests on an implicit act/omission distinction, with all the baseline problems to which such distinctions often succumb. And the application of the access/content distinction turns crucially on the level of generality at which the benefit offered by the defendant is defined—a matter on which the distinction itself provides no guidance. As I argue in Subsection 2, however, the "job-related" and access/content rules do serve a discernible agenda. Both operate to assimilate the accommodation requirement very closely to a classic antidiscrimination requirement. I hope to show that it is not just accommodation skeptics and judges engaged in a backlash against the ADA who have a stake in this agenda; disability rights advocates may see an ideological interest in it as well.

1. *The Analytic Failure of the "Job-Related" and Access/Content Doctrines*

a. *The "Job-Related" Rule*

Neither the courts nor the EEOC have offered any explicit defense of the "job-related" rule. But the rule seems to rest on a rough-and-ready notion of corrective justice. Under this view, an employer can be held responsible only for the obstacles it erects to the employment of people with disabilities; if an individual with a disability cannot come to work because of factors that go beyond any particular employer's workplace or work rules, no individual employer can rightly be held responsible for those factors. In essence, the rule imposes a kind of act/omission distinction: Employers are responsible for their own acts, and they must take "reasonable" care to assure that those acts "accommodate" employees with disabilities. But employers are not responsible for simply failing to help employees with disabilities overcome obstacles that stem from the government's failure to extend social provision. Indeed, the people who interjected the "job-related" concept into the congressional deliberations surrounding the ADA's accommodation requirement—lobbyists for hotel and small-business employer groups—appear to have had precisely this

kind of act/omission distinction in mind. Urging that employers not be required to provide accommodations whose usefulness extended outside of the workplace, they contended that such accommodations were the responsibility of the social welfare system rather than individual employers.¹⁷¹

Like all act/omission distinctions, the “job-related” rule is subject to serious critique.¹⁷² The mere fact that an accommodation removes an obstacle that the employer did not impose cannot be determinative, for ADA-mandated accommodations always require employers to alleviate disadvantages that are caused by the interaction between conditions the employer created and conditions the employer played no role in creating.¹⁷³ That is true even of core accommodations. When an employer provides a ramp in a building that formerly had only stairs, for example, it removes an obstacle that results from the interaction between the design of its facilities (facilities the employer either created or chose to move in to) and the inability of people who use wheelchairs to climb stairs (an inability the employer played no role in creating). If wheelchair users could climb stairs, the lack of a ramp would not be an obstacle. And when an employer modifies work schedules for an individual with diabetes, it removes an obstacle that results from the interaction between its general work schedules (schedules the employer created) and the need of people with diabetes to take unusually frequent breaks for self-monitoring and medication (a need the employer played no role in creating).

There appear to be two principal distinctions between these core accommodations and accommodations that fail the “job-related” test, but neither seems to identify any relevant difference. First, under existing property law arrangements, the employer is the only party that can put a wheelchair ramp into its facilities or change its work schedules. By contrast, the state could itself provide a disabled employee with personal assistance to get out of bed or transportation to get to work. Requiring employers to provide those non-job-specific accommodations thus seems to

171. See *Americans with Disabilities Act: Hearing Before the House Comm. on Small Bus.*, 101st Cong. 96 (1990) (statement of David Pinkus on behalf of National Small Business United) (giving as example of a proper accommodation requirement a North Carolina statute that relieved employers of the obligation to “[p]rovide accommodations of a personal nature, including, but not limited to, eyeglasses, hearing aids, or prostheses, except under the same terms and conditions as such items are provided to the employer’s employees generally”); *Americans with Disabilities Act of 1989: Hearings on H.R. 2273 Before the House Comm. on the Judiciary and Subcomm. on Civil and Constitutional Rights*, 101st Cong. 128 (1989) (statement of James A. DiLuigi on behalf of the American Hotel and Motel Association) (stating that “some of the items mentioned earlier as to employment issues, such as personal attendance and readers” are “sort of . . . a social service”).

172. See, e.g., Bagenstos, *supra* note 21, at 864-65.

173. See, e.g., Bagenstos, *supra* note 14, at 428-29.

force employers to bear the costs of the state's broader policy decision not to provide them itself. But one could make the same point about the core "job-related" accommodations: The state could pay the costs of installing wheelchair ramps or modifying work schedules for individuals with disabilities, but it requires employers to pay. It thus forces employers to bear the costs of the state's broader policy decision not to pay for those accommodations itself.

Second, the employer does not realize all of the benefits of an accommodation that aids an individual with a disability off the job as well as on. By contrast, a core "job-related" accommodation seems to be devoted entirely to making the individual with a disability a more productive worker for the employer. On reflection, however, "job-related" accommodations do not seem to be any different from non-"job-related" accommodations in this regard. The principal point of requiring employers to accommodate individuals with disabilities cannot be that *employers* will benefit; we can expect employers to do a fairly good job of pursuing their own self-interest even without such a requirement. The point of an accommodation mandate thus must be that individuals with disabilities and society as a whole will benefit. Even in the core "job-related" accommodation case, an employer cannot fully appropriate these benefits to itself, for it cannot lower the wages of newly employed people with disabilities to compensate for the higher intrinsic value employment has for them.¹⁷⁴

These points suggest that there is substantial indeterminacy in the "job-related" rule. For example, I have treated as a core "job-related" accommodation the modification of an employer's break rules to permit an employee with diabetes to engage in periodic self-monitoring and self-medication. In that respect, I have simply followed the case law, which occasionally finds such additional breaks "unreasonable," but never (to my knowledge) finds them to be "personal" rather than "job-related."¹⁷⁵ But additional breaks for self-monitoring and self-medication seem plainly to fit the EEOC's definition of an accommodation that is *not* "job-related": "an adjustment or modification [that] assists the individual throughout his or her daily activities, on and off the job."¹⁷⁶ After all, such breaks are designed to

174. See 42 U.S.C. § 12112(a) (2000) (prohibiting discrimination in, inter alia, "employee compensation"). Employers can appropriate to themselves the societal benefits of accommodations to some extent by taking advantage of the various tax subsidies that defray accommodation costs. See GAO, BUSINESS TAX INCENTIVES: INCENTIVES TO EMPLOY WORKERS WITH DISABILITIES RECEIVE LIMITED USE AND HAVE AN UNCERTAIN IMPACT (2002). But those subsidies are equally available whether the accommodation is "job-related" or not.

175. Cf. *US Airways v. Barnett*, 535 U.S. 391, 398 (2002) (implying that "accommodation of an individual who needs additional breaks from work, perhaps to permit medical visits" could be a reasonable accommodation mandated by the ADA).

176. 29 C.F.R. pt. 1630 app. § 1630.9 (2004).

help the employee keep from falling into insulin shock, a condition that has both on- and off-the-job effects. That such break-in-work accommodations are universally treated as “job-related” suggests that the formal statement of the “job-related” rule is not really doing the important work in these cases. Rather, what is at work seems to be a set of unarticulated assumptions about what kinds of accommodations ought to be the responsibility of employers and what kinds ought to be the responsibilities of individuals with disabilities or the government. Unless these assumptions are articulated and defended, it is difficult to justify the “job-related” rule as it has been formulated and applied.

b. *The Access/Content Distinction*

The access/content distinction does not appear to stand up to close analysis either. Application of that distinction depends entirely on the level of generality at which the “content” of the relevant benefit is described. And the access/content distinction itself has nothing to say about what level of generality is appropriate.

Consider Judge Posner’s leading opinion in *Doe*. The court’s analysis in that case depended crucially on a largely undefended decision to define the “content” of the benefit provided by Mutual of Omaha at a quite low level of generality—the offer to enter into a contract containing precisely the same terms as those offered to the nondisabled.¹⁷⁷ Considered at that level of generality, the access/content distinction virtually transforms the accommodation rule into a classic antidiscrimination requirement: Only if the insurer provides people with disabilities something different than it provides similarly situated nondisabled persons can the insurer be found liable.

But it is equally possible to view the issue from a higher level of generality: Under a policy with an AIDS cap, people without AIDS can expect to “have all their medically necessary care fully covered” up to the relatively high general lifetime limits imposed by the policy, while people with that condition “will have care for their most necessary, life-prolonging care limited to a fraction of that amount.”¹⁷⁸ If the “content” of the policy is

177. See *Doe v. Mut. of Omaha Ins. Co.*, 179 F.3d 557, 560 (7th Cir. 1999) (“An insurance policy is a product, and a policy with a \$25,000 limit is a different product from one with a \$1 million limit, just as a wheelchair is a different product from an armchair. A furniture store that does not stock wheelchairs knows that it is making its services less valuable to disabled than to nondisabled people, but the Americans with Disabilities Act has not been understood to require furniture stores to stock wheelchairs.”).

178. Crossley, *supra* note 168, at 82; see also Jennifer S. Geetter, *Coding for Change: The Power of the Human Genome To Transform the American Health Insurance System*, 28 AM. J.L. & MED. 1, 38 (2002) (describing the view that “for the ‘privilege’ of health insurance to be equal for the disabled and the non-disabled, the insurance coverage must be equally likely to be able to

described at that level of generality, AIDS caps do deny people with that condition access to the same benefit that is offered to the nondisabled. But the access/content distinction cannot tell us whether that perspective or the perspective adopted by most courts is the correct one.¹⁷⁹

The indeterminacy of the access/content distinction comes into full view when one examines the Supreme Court's decisions applying that distinction to demands for disability accommodations. The Court first endorsed the access/content doctrine in *Alexander v. Choate*,¹⁸⁰ which applied the Rehabilitation Act, the predecessor statute to the ADA.¹⁸¹ The plaintiffs, a class of Tennessee Medicaid recipients with disabilities, challenged the state's decision to cut back its annual Medicaid coverage of inpatient hospitalization from twenty to fourteen days.¹⁸² Because the fourteen-day cap had a disproportionate impact on people with disabilities, and because the state failed to explore alternatives that would have achieved the same cost savings as the cap but without such an impact, the plaintiffs contended that it violated the Rehabilitation Act.¹⁸³

In a unanimous opinion by Justice Marshall, the Supreme Court rejected that contention. And the access/content distinction was the principal tool the Court employed to reach that result. The essential requirement of the disability discrimination laws, the Court concluded, is "that an otherwise qualified handicapped individual must be provided with meaningful access to the benefit that the grantee offers."¹⁸⁴ The Court recognized that "reasonable accommodations . . . may have to be made" in order "to assure meaningful access," but it emphasized that access is all that

cover their medical expenses; and an express exclusion for a disability clearly violates this vision of equality").

179. This point strongly parallels an important critique of the formal notion of equality: We cannot decide whether two people are treated unequally unless we have a way of determining whether they are similarly situated. But to decide whether two people are similarly situated requires a normative theory that the formal notion of equality cannot itself provide (and may in fact obscure). For a classic statement of this critique, see Peter Westen, *The Empty Idea of Equality*, 95 HARV. L. REV. 537 (1982). It should not be surprising that the access/content distinction, which assimilates the accommodation requirement closely to a formal rule of nondiscrimination, is subject to a similar critique. For a judicial recognition that a formal nondiscrimination approach can lead one in either direction here, see *EEOC v. Staten Island Savings Bank*, 207 F.3d 144, 149 (2d Cir. 2000).

180. 469 U.S. 287 (1985).

181. Congress specifically directed courts to look to the Rehabilitation Act in construing the ADA, though the Rehabilitation Act sets only a floor, not a ceiling, of protection. See 42 U.S.C. § 12201(a) (2000) ("Except as otherwise provided in this chapter, nothing in this chapter shall be construed to apply a lesser standard than the standards applied under title V of the Rehabilitation Act of 1973 (29 U.S.C. 790 et seq.) or the regulations issued by Federal agencies pursuant to such title.").

182. See *Choate*, 469 U.S. at 289.

183. See *id.* at 306.

184. *Id.* at 301.

the statute requires.¹⁸⁵ Applying that principle, the Court ruled that “[t]he 14-day limitation will not deny respondents meaningful access to Tennessee Medicaid services or exclude them from those services.”¹⁸⁶ The Court argued that “[t]he reduction in inpatient coverage will leave both handicapped and nonhandicapped Medicaid users with identical and effective hospital services fully available for their use, with both classes of users subject to the same durational limitation.”¹⁸⁷

Just as in the private insurance cases, the Court’s conclusion in *Choate* turned entirely on the decision to define the relevant opportunity as the precise package of coverage the defendant offered. If that is the only opportunity to which the state must provide access, then any package of health care services—no matter how poorly it serves the needs of people with disabilities—will comply with disability discrimination law, so long as that package is offered to everyone.¹⁸⁸ The *Choate* Court was explicit on this point. It rejected the notion that the benefit provided by Tennessee’s Medicaid program is “adequate health care” or “that level of health care precisely tailored to [the recipient’s] particular needs”:

Instead, the benefit provided through Medicaid is a particular package of health care services, such as 14 days of inpatient coverage. That package of services has the general aim of assuring that individuals will receive necessary medical care, but the benefit provided remains the individual services offered—not “adequate health care.”¹⁸⁹

The opportunity provided by the Tennessee Medicaid program obviously need not be described at that level of generality, however, and the *Choate* Court provided little reason for doing so.¹⁹⁰ Indeed, it is apparent that the relevant opportunity could be defined at a higher or lower level of generality than the one at which the Court defined it. The state does not provide the package of services that it does because there is anything magical in that particular bundle of services, but because the package meets some basic needs of members of the target population at an affordable cost.

185. *Id.*

186. *Id.* at 302.

187. *Id.*

188. For a rare case in which a state formally excluded individuals with disabilities from a package of health care benefits that were offered to the public more generally, see *Burns-Vidlak ex rel. Burns v. Chandler*, 939 F. Supp. 765, 771 (D. Haw. 1996) (holding that excluding aged, blind, and disabled individuals from an expanded Medicaid managed care plan violated ADA Title II).

189. *Choate*, 469 U.S. at 303.

190. The Court noted that the federal Medicaid statute gave the state “substantial discretion to choose the proper mix of amount, scope, and duration limitations on coverage.” *Id.* But of course the fact that the Medicaid Act gives states broad power to set the benefits they provide says nothing about the restrictions the disability discrimination laws place on that power.

Viewed at that level of generality, people whose basic needs are more extensive because of disability (such as those who, because of their disability, need more hospital care than the average person) should have those basic needs satisfied to the same extent as the average person.

The Court appears to have rejected that higher level of generality out of a reluctance to second-guess the state's resource allocation decisions.¹⁹¹ But that same reluctance could in fact lead us to take the level of generality even lower. For example, why define the opportunity provided by the Tennessee Medicaid program as the opportunity to receive fourteen days of inpatient hospitalization? Why not define it as the opportunity to receive fourteen days of inpatient hospitalization as provided by the particular delivery system the state has set up? Medical care under the Tennessee Medicaid program may be provided in inaccessible buildings, and Medicaid recipients may be required to file forms that blind people cannot use.¹⁹² But making those aspects of the delivery system accessible may draw significant resources away from other state priorities.¹⁹³

The Court's decision in *Choate* thus rests on a definition of the relevant opportunity that, though plausible, is highly contestable. And in the subsequent decision of *Olmstead v. L.C. ex rel. Zimring*,¹⁹⁴ the Court took a broader view of the "content" of the opportunity provided by a state defendant. In *Olmstead*, the Court held that states that institutionalize individuals with disabilities have an obligation to place those individuals in community settings

when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably

191. See *id.* at 307 ("[N]othing in the pre- or post-1973 legislative discussion of § 504 suggests that Congress desired to make major inroads on the States' longstanding discretion to choose the proper mix of amount, scope, and duration limitations on services covered by state Medicaid . . .").

192. See, e.g., *Anderson v. Pa. Dep't of Pub. Welfare*, 1 F. Supp. 2d 456 (E.D. Pa. 1998) (finding triable issue regarding whether state Medicaid HMO program violated Title II by using doctors with physically inaccessible offices and providing handbooks in formats that were not accessible to people with vision impairments); *Tugg v. Towey*, 864 F. Supp. 1201 (S.D. Fla. 1994) (granting preliminary injunction to deaf plaintiffs who argued that state violated ADA Title II by providing mental health counseling services through a sign language interpreter rather than by providing mental health counselors who themselves speak sign language).

193. See, e.g., *Tugg*, 864 F. Supp. at 1203-04 (noting that the state planned to cancel its program of providing sign-language-speaking mental health counselors a month after the federal grant that supported the program expired); *id.* at 1210 (noting state's argument that "there is no way to provide funding for the services sought by the Plaintiffs without undergoing a significant budget reallocation" but concluding that the burden on the state "is a necessary consequence of any agency's compliance with the ADA law").

194. 527 U.S. 581 (1999).

accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.¹⁹⁵

Such an obligation, the Court concluded, flowed from ADA Title II's proscription of disability-based discrimination, as given content by two regulations promulgated by the Attorney General: the "integration regulation," which provides that "[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities";¹⁹⁶ and the "reasonable modifications regulation," which provides that "[a] public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity."¹⁹⁷

The state had argued, and Justice Thomas's dissent emphasized, that a requirement to move institutionalized persons into community placements would overturn the difficult resource allocation decisions the state had made in setting up its program of care for people with disabilities. By requiring it to move people with disabilities into community placements that did not exist, the state argued, the Court's reading of the ADA would do more than simply provide access to the state's program of care; it would alter the content of that program.¹⁹⁸ But Justice Ginsburg's majority opinion dismissed that argument in a footnote:

We do not in this opinion hold that the ADA imposes on the States a "standard of care" for whatever medical services they render, or that the ADA requires States to "provide a certain level of benefits to individuals with disabilities." We do hold, however, that States must adhere to the ADA's nondiscrimination requirement with regard to the services *they in fact provide*.¹⁹⁹

The majority thus argued that its decision was entirely in keeping with *Choate's* access/content distinction.

Justice Thomas had a point, however. If the *Olmstead* Court had defined the relevant services at the same level of generality as did the *Choate* Court, it would have been much harder to defend the ultimate conclusion that community placement was required. At the time the *Olmstead* plaintiffs filed their suit, the "particular package of health care

195. *Id.* at 587.

196. 28 C.F.R. § 35.130(d) (2004).

197. *Id.* § 35.130(b)(7).

198. *Olmstead*, 527 U.S. at 624-25 (Thomas, J., dissenting).

199. *Id.* at 603 n.14 (majority opinion) (emphasis added) (citation omitted).

services”²⁰⁰ offered by the State of Georgia included, in relevant part, mental health treatment in an available bed in a state hospital or one of the community treatment settings the state provided. The *Olmstead* plaintiffs were not denied access to that package of services, and there was no reason to believe that they would be “unable to benefit meaningfully”²⁰¹ from the services they did receive. The problem, as in *Choate*, was simply that the services the state offered were not “tailored to [the plaintiffs’] particular needs.”²⁰²

My point is not that *Choate* was right and *Olmstead* was wrong, or vice versa.²⁰³ My point is that the access/content distinction cannot resolve the issues in those cases. In each case, it was the Court’s largely undefended choice of the level of generality at which to describe the “content” of the relevant benefit, and not the access/content distinction itself, that was determinative.

2. *The Agenda of the “Job-Related” and Access/Content Doctrines*

Although the “job-related” and access/content doctrines fail as an analytic matter, they serve a discernible agenda. Each doctrine operates, in its own way, to confine the reach of the ADA’s accommodation requirement to something very close to that of a classic antidiscrimination requirement. It should be obvious why such an agenda might appeal to skeptics of the accommodation requirement—and the burgeoning literature describing a “backlash” against the ADA suggests that there are many such skeptics in influential positions.²⁰⁴ It is now fairly conventional wisdom that the Supreme Court has limited the reach of the ADA’s protected “disability” class because of concerns about the broad, redistributive nature of the statute.²⁰⁵ But the commentators who have articulated this conventional wisdom have failed to appreciate that accommodation supporters may themselves feel a stake in limiting the scope of that requirement.²⁰⁶

200. *Alexander v. Choate*, 469 U.S. 287, 303 (1985).

201. *Id.* at 302.

202. *Id.* at 303.

203. For what it’s worth, I am on record as a fan of the *Olmstead* majority opinion. See Bagenstos, *supra* note 59, at 54-59.

204. See generally BACKLASH AGAINST THE ADA, *supra* note 2.

205. See Samuel Issacharoff & Justin Nelson, *Discrimination with a Difference: Can Employment Discrimination Law Accommodate the Americans with Disabilities Act?*, 79 N.C. L. REV. 307, 357-58 (2001); Krieger, *supra* note 6, at 503-20.

206. Indeed, it is notable that people and institutions generally supportive of disability rights have been central to the development of both the “job-related” rule and the access/content distinction. It is the EEOC, after all, that has most fully elaborated the “job-related” rule. See 29 C.F.R. pt. 1630 app. § 1630.9 (2004); EEOC, *supra* note 148, § 3.4. And Justice Marshall introduced the access/content distinction into reasonable accommodation law in *Choate*—an

It is easy to see why accommodation skeptics might be concerned about reading the ADA to require employers to undo deep-rooted structural barriers to employment. In the dominant conception, antidiscrimination requirements provide a remedy for the defendant's own wrongful conduct rather than for the defendant's failure to redress a broader societal wrong.²⁰⁷ When employers intentionally discriminate on the basis of race, for example, they have committed an act that is "intrinsically immoral."²⁰⁸ They are held liable for that conduct not because they are convenient scapegoats for a broader societal problem but because they violated the moral and legal injunction to treat people equally without regard to race. Even disparate impact discrimination can be made to fit this account. When an employer implements a practice that has a disproportionately harmful impact on groups that have traditionally suffered intentional discrimination, and that practice lacks a strong business justification, an inference logically arises that the employer adopted the practice for a discriminatory purpose.²⁰⁹

But the accommodation requirement seems to take us far beyond that conception of antidiscrimination. It demands that an employer bear a "reasonable" cost to alter its facilities and routines to promote the participation of people with disabilities—even if the employer clearly had a sound business reason for not making those alterations in the first place.²¹⁰ It may still be easy to see how the employer might have acted wrongfully when it failed to provide something like a wheelchair ramp that both is necessary to permit many people with disabilities to work at the employer's facilities and is something that only the employer is in a position to provide. But if an employer is required to provide personal-assistance services or transportation to enable an employee with a disability to get to work, or health insurance coverage that meets the employee's particular needs, the accommodation requirement seems much more like a requirement that the employer do something to "make up for" the disadvantage that people with disabilities experience because of broader societal decisions about the allocation of social services.²¹¹

opinion issued in the same year that he vigorously defended disability rights in his separate opinion in *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432, 461-64 (1985) (Marshall, J., concurring in the judgment in part and dissenting in part).

207. I describe and critique that conception in Bagenstos, *supra* note 21, at 839-59.

208. Larry Alexander, *What Makes Wrongful Discrimination Wrong? Biases, Preferences, Stereotypes, and Proxies*, 141 U. PA. L. REV. 149, 192 (1992).

209. See George Rutherglen, *Disparate Impact Under Title VII: An Objective Theory of Discrimination*, 73 VA. L. REV. 1297, 1309-11 (1987).

210. This is the core of Professor Mark Kelman's critique of the accommodation requirement. See Mark Kelman, *Market Discrimination and Groups*, 53 STAN. L. REV. 833 (2001). I tried to challenge that critique in Bagenstos, *supra* note 21, at 870-98.

211. *US Airways v. Barnett*, 535 U.S. 391, 413 (2002) (Scalia, J., dissenting).

Accommodation skeptics could readily see such a broad reading as presenting in particularly dramatic terms two of the basic challenges they have leveled against the requirement in general. First, such a reading requires an employer to bear a financial burden not because of any particular fault on its part, but simply because of the fortuity that this particular worker with a disability applied for one of its positions.²¹² Second, such a reading threatens to turn the accommodation requirement into an essentially standardless vehicle for ad hoc wealth redistribution to individuals with disabilities.²¹³

Perhaps counterintuitively, disability rights advocates might feel pressure to reject the broader reading of the accommodation requirement as well. As I discussed in Part I, disability rights activists in the 1970s and 1980s explicitly and emphatically rejected charity and welfare as responses to disability. They argued that it was only a denial of civil rights, and not the lack of charitable largesse, that kept people with disabilities out of the workforce.²¹⁴ But the more that individual employers are required to counteract broad structural obstacles that they did not themselves create, the more it looks like they are being required to provide charity.²¹⁵ Even disability rights activists, then, might have an ideological interest in reading the accommodation requirement to mandate that an individual employer take steps to remove only those barriers that the employer itself played a part in creating.

212. See Issacharoff & Nelson, *supra* note 205, at 344-45.

213. Justice Scalia has particularly emphasized this point in dissents that accuse the Court of disregarding the limitations that he believes properly apply to the accommodation requirement. See *US Airways*, 535 U.S. at 413-14 (Scalia, J., dissenting) (“When one departs from this understanding [of accommodation as removing a ‘disability-related obstacle’ to the specific opportunities offered by the defendant], the ADA’s accommodation provision becomes a standardless grab bag—leaving it to the courts to decide which workplace preferences (higher salary, longer vacations, reassignment to positions to which others are entitled) can be deemed ‘reasonable’ to ‘make up for’ the particular employee’s disability.”); *PGA Tour v. Martin*, 532 U.S. 661, 691 (2001) (Scalia, J., dissenting) (criticizing the majority’s interpretation of the reasonable accommodation requirement for “exercis[ing] a benevolent compassion that the law does not place it within our power to impose”). As I argue in this Subsection, it is not just Justice Scalia who seeks to limit the scope of the accommodation requirement—support for limitations seems to be widespread.

214. See *supra* notes 50-57 and accompanying text.

215. Deans Stewart Schwab and Steven Willborn make a similar point in explaining the general rule under the ADA that employers need not accommodate the lesser productivity of a worker with a disability. Although accommodations that remove obstacles to disabled workers who are as productive as nondisabled workers seem “consistent with our meritocratic ideal that jobs should go to the most qualified applicant,” they contend, disability advocates may recognize that “[t]he argument that less productive workers with lesser costs are functionally equivalent to more productive, greater cost workers may fail to persuade politically.” Stewart J. Schwab & Steven L. Willborn, *Reasonable Accommodation of Workplace Disabilities*, 44 WM. & MARY L. REV. 1197, 1233 (2003).

Both the “job-related” rule and the access/content distinction appear to respond to these concerns by limiting the reach of the accommodation requirement to circumstances in which the traditional justifications for antidiscrimination rules apply. As I argued in the previous Subsection, the “job-related” rule rests on an implicit act/omission distinction in which employers can be held responsible for their “own” choices but cannot be required to make up for broader failures of social provision. Although that act/omission distinction is not especially convincing analytically, it is precisely the same kind of distinction that seems to underlie the requirement of intentional discrimination in equal protection cases.²¹⁶

The access/content distinction seems to serve a similar function. As the Court made clear in *Choate*, the distinction serves to “keep [the accommodation requirement] within manageable bounds.”²¹⁷ It limits required accommodations to those cases in which the defendant has imposed an obstacle that prevents people with disabilities from availing themselves of the same opportunities open to the nondisabled. Like the “job-related” rule, it assimilates the accommodation requirement very closely to an antidiscrimination requirement.

The ADA’s accommodation requirement has been regarded as a “profound” innovation²¹⁸ that represents an effort to shift the baseline against which we measure “discrimination.”²¹⁹ But the doctrines I have discussed show that the differences are ones of degree and not of kind. The accommodation requirement does shift the baseline of analysis somewhat, for it does not limit its scrutiny to those acts taken with an intent to discriminate; taking a wider view, the requirement asks whether an employer has reasonably accounted in its actions for potential employees with disabilities. But the “job-related” and access/content doctrines make the accommodation requirement similar to an antidiscrimination requirement in two key respects: The “job-related” rule, like the intentional discrimination requirement, focuses attention on the responsibility of the individual defendant as opposed to that of society as a whole, and the access/content distinction, like a formal nondiscrimination rule, asks whether people with disabilities have been denied access to the same opportunities as similarly situated nondisabled persons.

216. See, e.g., LOUIS MICHAEL SEIDMAN & MARK V. TUSHNET, REMNANTS OF BELIEF: CONTEMPORARY CONSTITUTIONAL ISSUES 110-15 (1996); Cass R. Sunstein, *Lochner’s Legacy*, 87 COLUM. L. REV. 873, 897-98 (1987).

217. *Alexander v. Choate*, 469 U.S. 287, 299 (1985) (employing the access/content distinction in interpreting the reasonable accommodation requirement imposed by section 504 of the Rehabilitation Act of 1973).

218. Karlan & Rutherglen, *supra* note 94, at 41.

219. See Bagenstos, *supra* note 14, at 435.

As I argued in Subsection 1, the “job-related” and access/content doctrines are formally indeterminate in substantial respects. Courts and advocates committed to broader social welfare provision for people with disabilities could easily read those doctrines in a way that would require employers to dismantle structural barriers to employment for people with disabilities. But the courts’ current applications of these doctrines suggest that efforts to achieve social welfare redistribution through the ADA—a statute that bills itself as an antidiscrimination measure—will meet with substantial resistance. The accommodation requirement has the potential to serve as an open-ended tool of redistribution to people with disabilities, and courts naturally look for some principle to constrain and guide their application of that requirement. The current case law shows that courts have, equally naturally, looked to settled tools of antidiscrimination law—including notions of employer fault and disparate treatment—for such a principle. So long as courts interpreting the accommodation requirement feel compelled to focus on the fault of individual employers, as opposed to that of society as a whole, that requirement will lack significant power to undo the deep-rooted structural barriers to employment for people with disabilities.²²⁰ And so long as courts interpreting the accommodation requirement feel compelled to limit the statute’s redistributive potential by employing the access/content distinction, the same desire to limit the ADA’s sweep will likely lead them to continue to define the “content” of the relevant opportunity at a low level of generality. If they do, the ADA will remain virtually useless as a means of attacking the private insurance limitations that impose the greatest practical burden on many people with disabilities.

III. THE FUTURE OF DISABILITY LAW: FROM ANTIDISCRIMINATION TO SOCIAL WELFARE LAW

In the previous Parts, I have argued that the antidiscrimination model faces significant limitations in its power to enhance employment and integration for people with disabilities. People with disabilities will not move into the workforce in more significant numbers unless the law addresses deep-rooted barriers to employment such as the unavailability of personal-assistance services, assistive technology, and accessible transportation, as well as the current structure of our health care system. But an antidiscrimination approach cannot effectively attack those barriers, and

220. *Cf.* MARK KELMAN, A GUIDE TO CRITICAL LEGAL STUDIES 279-80 (1987) (arguing that our legal culture’s focus on individual duties makes it hard to envision rights to societal provision).

the ADA's requirement of reasonable accommodation is (in practice) little different from a classic antidiscrimination rule in that respect. Solving the problem requires a social welfare approach—that is, sustained and direct government intervention through such means as public funding and provision of services.

In this Part, I argue that disability rights advocates “on the ground” have begun to recognize the importance of social welfare interventions to address the deep-rooted barriers to employment of people with disabilities. Thus, as I show in Section A, both the litigation dockets and legislative priorities of disability rights organizations have increasingly focused on social welfare rather than antidiscrimination laws. Disability rights advocates now frequently bring cases under social welfare laws like the Medicaid Act as well as under antidiscrimination laws like the ADA, and they lobby for changes in public health-insurance programs that would enhance the integration and employability of people with disabilities. To a far greater extent than commentators have appreciated, the disability rights movement has turned (back) to a social welfare approach to disability law.

But in returning to social welfare strategies to enhance employment opportunities and integration of people with disabilities, advocates should not forget their own earlier critique of a social welfare response to disability. In some ways, the new social welfare initiatives promise to avoid the pitfalls the disability rights movement identified in an earlier generation of welfare programs. In other respects, however, the new initiatives seem to be subject to the same challenges as the earlier programs. As social welfare strategies return to the forefront of disability policy, the important task for disability rights advocates will be to identify ways of reconstructing the disability welfare system so that it avoids the paternalism, arbitrariness, and oppression that those advocates so cogently described in earlier programs. In Section B, I discuss some key dilemmas disability rights advocates must confront in this regard.

And there is yet a broader issue—the coherence and viability of the disability rights movement as a movement. Opposition to social welfare law reflected more than a simple policy preference for disability rights activists in the 1970s and 1980s; it also had the important instrumental function of bringing together disparate people with disparate impairments into a more or less unified disability rights movement. As disability rights advocates begin cautiously to embrace social welfare strategies again, they must find some way to avoid the tendency of such strategies to fragment the movement. In Section C, I offer some initial thoughts about this problem.

A. *The Move (Back) to Social Welfare*

In this Section, I describe a number of areas in which disability rights activists have endorsed social-welfare-law means of achieving the goals of employment and community integration for people with disabilities. I first discuss litigation to enforce the Medicaid Act, which is an increasingly important part of the docket of disability rights organizations. I then discuss activists' efforts, through legislative advocacy, to expand public health-insurance programs. Those efforts fall into two categories: efforts to provide coverage to working people with disabilities and efforts to provide reimbursement for services such as personal assistance that make it possible for people with disabilities to participate in community life, including in employment. In each of these areas, disability rights advocates have begun to achieve some success.

1. *Litigation To Enforce the Medicaid Act*

Even if disability rights advocates have increasingly turned toward efforts to enact social welfare legislation, one might expect that disability rights litigation would continue to be dominated by the ADA. To a large extent, that is true—especially in the individual-plaintiff lawsuits that make up the vast majority of disability rights cases.²²¹ But in the systemic-reform dockets of disability rights organizations, there is a notable trend toward a social welfare approach. In dozens of recent cases, those organizations have filed suits to enforce provisions of the Medicaid Act (Title XIX of the Social Security Act).²²² Rather than merely demanding an end to

221. The diversity of disabilities embraced by the ADA's protected-class definition, combined with the individualized nature of the "reasonable accommodation" determination, makes it difficult to bring class action suits under the ADA. See Ruth Colker, *ADA Title III: A Fragile Compromise*, 21 BERKELEY J. EMP. & LAB. L. 377, 379 n.19 (2000) (noting that "it is difficult to file class action remedies" under the ADA's public accommodations title because "the community of individuals with disabilities is quite diverse"); Karlan & Rutherglen, *supra* note 94, at 19 (noting that "[f]ew of the cases brought under the ADA are class actions" because "[l]itigation under the ADA . . . responds to the complexities in the inherently unique circumstances of many disabled individuals"). The point holds particularly true for cases under the employment discrimination title of the ADA, which has been the primary engine of litigation under the statute. Of course, the overwhelming preponderance of individual over class action litigation is not unique to the ADA; to the contrary, as Professors John Donohue and Peter Siegelman showed in their influential article, employment discrimination litigation generally follows a similar pattern. See John J. Donohue III & Peter Siegelman, *The Changing Nature of Employment Discrimination Litigation*, 43 STAN. L. REV. 983, 1019-21 (1991).

222. GARY A. SMITH, HUMAN SERVS. RESEARCH INST., STATUS REPORT: LITIGATION CONCERNING HOME AND COMMUNITY SERVICES FOR PEOPLE WITH DISABILITIES 5-31 (2004), available at <http://www.hsri.org/docs/litigation041804.pdf>, lists Medicaid cases brought by disability rights organizations such as People First, various state chapters of the ARC (formerly the Association of Retarded Citizens), and various state protection and advocacy agencies.

discrimination or seeking an accommodation under the ADA or the Rehabilitation Act, these suits demand specific benefits to which the plaintiffs claim entitlement under the federal Medicaid statute.

Disability rights organizations have not been indiscriminate in the benefits they have sought through litigation. Rather, they have focused on those Medicaid benefits—like community placements and personal-assistance services—that enhance opportunities for people with disabilities to participate in community life (and particularly in employment). They have tended to bring Medicaid suits that address one of two kinds of problems. First, many people with disabilities have been forced to remain on waiting lists for community-based services to which they are entitled under their states' Medicaid plans because the states have refused to provide those services in a timely manner to all who are eligible.²²³ Disability rights organizations have frequently brought class action suits that contend, *inter alia*, that such waiting lists violate various requirements of the Medicaid Act.²²⁴ Plaintiffs in these cases have obtained a number of favorable rulings from courts, and they have received significant relief in settlements.²²⁵

223. See JANE PERKINS & MANJU KULKARNI, ADDRESSING HOME AND COMMUNITY-BASED WAIVER WAITING LISTS THROUGH THE MEDICAID PROGRAM 1 (2000), available at http://www.healthlaw.org/docs/200005FactSheet_hcbw.pdf; SMITH, *supra* note 222. For a comprehensive overview of state waiting lists for services for people with mental retardation and developmental disabilities, see RESEARCH & TRAINING CTR. ON CMTY. LIVING, POLICIES AND RESOURCES RELATING TO WAITING LISTS OF PERSONS WITH MENTAL RETARDATION AND RELATED DEVELOPMENTAL DISABILITIES (2002), available at <http://rtc.umn.edu/pdf/waitlist2002.pdf>.

224. See, *e.g.*, SMITH, *supra* note 222, at 5 (“As of February 2004, lawsuits seeking community services for people with developmental disabilities had been filed in twenty-five states.”). These lawsuits contend that the waiting lists violate such statutory directives as the statute’s “reasonable promptness” provision, 42 U.S.C. § 1396a(a)(8) (2000) (requiring that a state’s Medicaid plan “provide that all individuals wishing to make application for medical assistance under the plan shall have opportunity to do so, and that such assistance shall be furnished with reasonable promptness to all eligible individuals”); the statute’s “comparability” provision, *id.* § 1396a(a)(10)(B) (requiring that medical assistance provided to any eligible individual “shall not be less in amount, duration, or scope than the medical assistance made available to any other such individual”); the statute’s “best interests” provision, *id.* § 1396a(a)(19) (requiring that services be provided “in a manner consistent with simplicity of administration and the best interests of the recipients”); and the statute’s “free choice” provision, *id.* § 1396n(c)(2)(C) (requiring, under the statute’s home- and community-based waiver provision, that beneficiaries be “informed of the feasible alternatives, if available under the waiver, at the choice of such individuals, to the provision of inpatient hospital services, nursing facility services, or services in an intermediate care facility for the mentally retarded”).

225. See *Bryson v. Shumway*, 308 F.3d 79, 88 (1st Cir. 2002) (stating that failure to fill available home- and community-based waiver slots can violate “reasonable promptness” provision but remanding for a determination whether the defendants had in fact violated that provision); *Lewis v. N.M. Dep’t of Health*, 275 F. Supp. 2d 1319, 1345 (D.N.M. 2003) (stating that failure to provide home- and community-based services to individuals eligible for open home and community-based waiver slots violates “reasonable promptness” provision); *Boulet v. Cellucci*, 107 F. Supp. 2d 61, 76-80 (D. Mass. 2000) (holding that waiting list for residential placements for individuals receiving services under state’s home- and community-based waiver

Second, some state Medicaid policies, such as low reimbursement rates for personal assistance and other services, can make it impossible in practice for individuals with disabilities to obtain adequate community-based services even if the state does not place those individuals on a waiting list.²²⁶ Disability rights organizations have challenged these policies under the adequate-payment provision of the Medicaid Act. That provision requires states to “assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area.”²²⁷ These suits have been less successful than the waiting-list suits. No court has yet granted final relief to plaintiffs with disabilities who challenge inadequate reimbursement rates for community services providers, and some courts have ruled against these plaintiffs, though a number of cases are still pending.²²⁸

Litigation to enforce the Medicaid Act plainly has serious limitations as a tool to achieve community integration for people with disabilities. Such litigation can be only as effective in achieving those goals as the Medicaid statute itself.²²⁹ To be sure, Medicaid covers an array of services that are important to people with disabilities—potentially including, at each individual state’s option, services such as durable medical equipment and

program violates “reasonable promptness” and “freedom of choice” provisions); Benjamin H. v. Ohl, No. 3:99-0338, 1999 U.S. Dist. LEXIS 22469, at *39-43, *44-45 (S.D. W. Va. July 15, 1999) (granting preliminary injunction on basis of claim that waiting lists violate “reasonable promptness” and “freedom of choice” requirements). For examples of settlements, see *Rancourt v. Concannon*, No. 01-CV-159 (D. Me. July 9, 2003), available at <http://www.drcme.org/rancourt.html> (agreement settling litigation challenging Maine’s denial of timely Medicaid services to adults with mental retardation); *Makin v. Hawaii*, No. CV 98-00997 DAE, slip op. at 2 (D. Haw. Apr. 25, 2000) (agreement settling litigation challenging waiting list for home- and community-based services in Hawaii); and *Hawaii Disability Rights Center v. Hawaii*, No. 03-00524 HG-KSC (D. Haw. filed Oct. 21, 2003), available at [http://www.hawaiidisabilityrights.org/Forms/SMComplaint10.01.03\(web\).doc](http://www.hawaiidisabilityrights.org/Forms/SMComplaint10.01.03(web).doc) (complaint alleging lack of compliance with the *Makin* settlement and renewing challenge to Hawaii waiting list).

226. See, e.g., Sandra L. Yue, *A Return to Institutionalization Despite Olmstead v. L.C.? The Inadequacy of Medicaid Provider Reimbursement in Minnesota and the Failure To Deliver Home- and Community-Based Waiver Services*, 19 LAW & INEQ. 307, 330-37 (2001).

227. 42 U.S.C. § 1396a(a)(30)(A).

228. See *Sanchez v. Johnson*, 301 F. Supp. 2d 1060, 1062-65 (N.D. Cal. 2004) (dismissing challenge to low rates of payment for community services providers on the ground that, per *Gonzaga University v. Doe*, 536 U.S. 273, 279-90 (2002), the adequate-payment provision does not create judicially enforceable rights); *Mandy R. v. Owens*, No. 00-M-1609 (BNB) (D. Colo. filed Aug. 14, 2000) (marking the intervention of Colorado Association of Community Centered Boards as plaintiff challenging adequacy of state’s payments for community services); *Ball v. Biedess*, No. CIV 00-67 TUC ACM (D. Ariz. filed Jan. 27, 2000) (challenging Arizona Medicaid program’s reimbursement rates for home-care workers).

229. Even when the Medicaid statute contains sufficient *substantive* requirements, moreover, many of those requirements may be held not to be judicially enforceable under the § 1983 doctrine most recently articulated in *Gonzaga*. See, e.g., *Sanchez*, 301 F. Supp. 2d at 1062-65.

prosthetics.²³⁰ Also at state option, Medicaid may provide home- and community-based services, including personal assistance, for many people with disabilities.²³¹ But in two significant respects, Medicaid is a flawed tool.

First, the wide discretion accorded to states in the structuring of Medicaid benefits²³² makes the program a less than sure means of promoting the interests of people with disabilities. Although Medicaid currently provides a great deal to people with disabilities, in most cases (accounting for two-thirds of overall program spending on people with disabilities) it does so because states have chosen to cover optional populations and to provide optional services.²³³ Roughly twenty-two percent of disabled Medicaid recipients qualify because their states have chosen to participate in an optional eligibility pathway authorized by the Medicaid statute.²³⁴ The most important of these pathways is the so-called “medically needy” option. That option permits states to extend coverage to people with disabilities whose incomes and assets are too high to satisfy the requirements for SSI eligibility but who “spend down” to a “medically needy income limit” set by the state.²³⁵ Thirty-five states participate in the “medically needy” option, with a median income limit of fifty-five percent of the federal poverty line.²³⁶ And even when individuals with disabilities are part of a mandatorily covered population—as when they receive SSI—the decision to provide services that promote integration and employment

230. For durable medical equipment, see 42 U.S.C. § 1396d(a)(7) (authorizing states to cover home health services); and 42 C.F.R. § 440.70(b)(3) (2003) (defining home health services to include the provision of medical equipment). For prosthetics, see 42 U.S.C. § 1396d(a)(12) (authorizing states to cover “prosthetic devices”). See KAISER COMM’N ON MEDICAID & THE UNINSURED, *supra* note 134, at 2 (“Medicaid is unique among public and private insurance programs, in that it provides a comprehensive set of acute and long-term care benefits to meet the needs of people with disabilities.”); Jane Perkins, *Medicaid: Past Successes and Future Challenges*, 12 HEALTH MATRIX 7, 24 (2002) (“Medicaid has provided essential services for people with disabilities that are not generally available through private health insurance coverage. . . . [T]he benefits package offered by Medicaid includes coverage of long-term care services and services which help maximize functioning, such as home health services, durable medical equipment, prosthetic devices, and personal care attendant services.”); Sandra Tanenbaum, *Medicaid and Disability: The Unlikely Entitlement*, 67 MILBANK Q. 288, 295-96 (1989).

231. See Letter from Timothy Westmoreland, Dir., Ctr. for Medicaid & State Operations, Health Care Fin. Admin., to State Medicaid Directors attachment 3-g (July 25, 2000), available at <http://www.cms.hhs.gov/states/letters/smd725a0.asp>.

232. See *Beal v. Doe*, 432 U.S. 438, 444 (1977) (concluding that the Medicaid statute “confers broad discretion on the States to adopt standards for determining the extent of medical assistance”).

233. See KAISER COMM’N ON MEDICAID & THE UNINSURED, *supra* note 134, at 36.

234. See *id.* at 12-16.

235. See KAISER COMM’N ON MEDICAID & THE UNINSURED, MEDICAID MEDICALLY NEEDED PROGRAMS: AN IMPORTANT SOURCE OF MEDICAID COVERAGE (2003); KAISER COMM’N ON MEDICAID & THE UNINSURED, *supra* note 134, at 15.

236. See KAISER COMM’N ON MEDICAID & THE UNINSURED, *supra* note 134, at 15.

opportunities (such as durable medical equipment and personal care) is one that rests almost entirely with the state.²³⁷

With states facing severe budget crises, optional Medicaid benefits for people with disabilities are prime targets for cuts. “Forty-nine states and the District of Columbia implemented Medicaid cuts in FY 2003 and 32 states that enacted Medicaid reductions earlier in the year[] revisited the Medicaid budget and made cuts a second time in the year.”²³⁸ And states are considering even deeper reductions, including elimination of their “medically needy” programs and restrictions on long-term-care spending.²³⁹ Even with fiscal pressures easing as the economy improves, a number of states are continuing to implement new Medicaid cost containment strategies.²⁴⁰ The Bush Administration’s Health Insurance Flexibility and Accountability Initiative (HIFA)²⁴¹ only adds to these budgetary pressures. HIFA encourages states to finance expansions of coverage of the uninsured population through cuts in the optional services they currently provide.²⁴² And the Administration has proposed to go farther and move Medicaid to a block-grant model more generally.²⁴³ Medicaid recipients with disabilities, who incur a disproportionate share of the program’s costs, are likely to be particularly vulnerable to the service-cutting incentives created by these initiatives.²⁴⁴

237. See 42 U.S.C. § 1396a(a)(10)(A) (2000) (mandating only that states cover inpatient and outpatient hospital and health center services; laboratory services; nursing facility services for adults; early and periodic screening, diagnosis, and treatment for children; family planning services for individuals of childbearing age; medical services provided by physicians and dentists; nurse-midwife services; and services of a pediatric nurse practitioner).

238. KAISER COMM’N ON MEDICAID & THE UNINSURED, *supra* note 134, at 35. For additional discussion of the budgetary pressures on state Medicaid programs, see Perkins, *supra* note 230, at 27. For a recent example of how these cuts affect people with disabilities, see Bob Herbert, Op-Ed, *Punishing the Poor*, N.Y. TIMES, June 11, 2004, at A27 (describing recent Mississippi cuts that “will end Medicaid eligibility for some 65,000 low-income senior citizens and people with severe disabilities”).

239. See KAISER COMM’N ON MEDICAID & THE UNINSURED, *supra* note 134, at 35.

240. See KAISER COMM’N ON MEDICAID & THE UNINSURED, STATES RESPOND TO FISCAL PRESSURE: A 50-STATE UPDATE OF STATE MEDICAID SPENDING GROWTH AND COST CONTAINMENT ACTIONS 3 (2004) (noting that eighteen states had initiated new mid-year Medicaid cost-containment strategies in fiscal year 2004).

241. See CTRS. FOR MEDICARE & MEDICAID SERVS., GUIDELINES FOR STATES INTERESTED IN APPLYING FOR A HIFA DEMONSTRATION, <http://www.cms.hhs.gov/hifa/hifagde.asp> (last modified Sept. 16, 2004).

242. See KAISER COMM’N ON MEDICAID & THE UNINSURED, *supra* note 134, at 34; Jennifer Mathis, *Community Integration of Individuals with Disabilities: An Update on Olmstead Implementation*, 35 CLEARINGHOUSE REV. 395, 409-10 (2001); Perkins, *supra* note 230, at 29-30.

243. For a discussion of recent jousting between the Bush Administration and state governments over Medicaid financing, see Robert Pear, *U.S. Nears Clash with Governors on Medicaid Cost*, N.Y. TIMES, Feb. 16, 2004, at A1.

244. See KAISER COMM’N ON MEDICAID & THE UNINSURED, *supra* note 134, at 21 (noting that people with disabilities account for sixteen percent of the Medicaid population but forty-three percent of Medicaid expenditures).

Second, the structure of the Medicaid program itself imposes significant obstacles to the ability of people with disabilities to live and work in the community. Foremost among these is Medicaid's strong institutional bias.²⁴⁵ Nursing-home care is a mandatory service under the Medicaid program,²⁴⁶ but home-based services are not.²⁴⁷ Although thirty-one states have invoked the statute's personal-care option to provide benefits for individuals in the community, "[i]n most states, the personal care benefit is less comprehensive than nursing home care and is targeted to beneficiaries who are less disabled than nursing home residents."²⁴⁸ And although forty-nine states have received waivers from the Secretary of Health and Human Services to provide home- and community-based services to a subset of Medicaid recipients with disabilities,²⁴⁹ the statutory provision that authorizes such waivers permits states to limit the number of beneficiaries eligible for community placements²⁵⁰—limitations that states are forbidden to impose for institutional placements. States have aggressively taken advantage of their authority to limit the number of waiver slots; waiting lists for home- and community-based Medicaid services can be caused by these permissible limitations, rather than any violation of the Medicaid Act.²⁵¹ And the statutory waiver provision also requires states to provide assurance to the Secretary that the average cost of serving an individual under the waiver program will not exceed the cost of serving that individual in an institution.²⁵² When states seek to provide institutional placements, the statute requires no comparable assurance that

245. See *id.* at 31; NAT'L COUNCIL ON DISABILITY, SHARING THE RISK, *supra* note 101, at "Findings on Barriers to Health Insurance and Health-Related Services" No. 2 ("Medicaid has an inherent institutional bias whereby certain services are covered only in inpatient hospital or institutional settings.").

246. See 42 U.S.C. § 1396a(10)(A) (2000); *id.* § 1396d(a)(4)(A).

247. See *id.* § 1396a(a)(10)(A) (mandatory services); *id.* § 1396d(a)(8) (optional private duty nursing services); *id.* § 1396d(a)(19) (optional case-management services); *id.* § 1396d(a)(22) (optional home and community care for disabled elderly individuals); *id.* § 1396d(a)(23) (optional community-supported living-arrangement services); *id.* § 1396d(a)(24) (optional home- and community-based personal care services). The Medicaid statute does, however, require that states provide "for the inclusion of home health services for any individual who, under the State plan, is entitled to nursing facility services." *Id.* § 1396a(10)(D). But "home health services" do not include the important community services described in this footnote.

248. Loretta Williams, Note, *Long Term Care After Olmstead v. L.C.: Will the Potential of the ADA's Integration Mandate Be Achieved?*, 17 J. CONTEMP. HEALTH L. & POL'Y 205, 212 (2000).

249. KAISER COMM'N ON MEDICAID & THE UNINSURED, *supra* note 134, at 31.

250. See 42 U.S.C. § 1396n(c)(3).

251. See, e.g., Jane Perkins & Randolph T. Boyle, *Addressing Long Waits for Home and Community-Based Care Through Medicaid and the ADA*, 45 ST. LOUIS U. L.J. 117, 120-21, 130 (2001); Sara Rosenbaum et al., *Olmstead v. L.C.: Implications for Medicaid and Other Publicly Funded Health Services*, 12 HEALTH MATRIX 93, 129-30 (2002).

252. See 42 U.S.C. § 1396n(c)(2)(D); KAISER COMM'N ON MEDICAID & THE UNINSURED, *supra* note 134, at 31-32.

community placements are at least as expensive. As a result of all of these provisions that skew Medicaid coverage toward institutionalization, “persons with disabilities are often institutionalized, rather than kept in the community, in order to receive necessary health care services.”²⁵³

Other limitations include significant restrictions on Medicaid coverage of durable medical equipment. Because Medicaid covers such equipment only as a form of “home health services,”²⁵⁴ it will be reimbursed only if it is “suitable for use in the home.”²⁵⁵ As a result, Medicaid recipients are denied reimbursement for multiple-terrain wheelchairs “that would enable them to get out of their house, and travel independently” but that are not necessary for use in the home.²⁵⁶ And “Medicaid often denies mobility aids, describing them as ‘non-essential,’ or pays only for obsolete equipment.”²⁵⁷ As the National Council on Disability reported, “the refusal of Medicaid to cover appropriate wheelchairs for people with physical disabilities borders on the legendary.”²⁵⁸

At best, then, Medicaid litigation can force states to comply with their own earlier decisions to provide optional services. If states respond to that litigation by amending their Medicaid plans to cut back on the services they promise to provide, there is nothing in the statute to stop them.²⁵⁹ Successes in Medicaid litigation thus may become Pyrrhic victories for disability rights advocates.

But the rise in Medicaid litigation by disability rights advocates is important nonetheless. Despite its limitations, it represents a recognition that antidiscrimination strategies alone cannot achieve employment and community integration for people with disabilities. These goals can be achieved only through state-provided services—core social-welfare-law interventions. As I discuss in the next two Subsections, disability rights advocates are increasingly focusing their legislative advocacy on efforts to alter the aspects of existing Medicaid law that limit the program’s power to achieve these goals.

253. NAT’L COUNCIL ON DISABILITY, SHARING THE RISK, *supra* note 101, at “Findings on Barriers to Health Insurance and Health-Related Services” No. 2.

254. *See* 42 C.F.R. § 440.70(b)(3) (2003); *see also* 42 U.S.C. § 1396d(a)(7) (permitting states, at their option, to provide Medicaid coverage for home health services).

255. 42 C.F.R. § 440.70(b)(3).

256. KAISER COMM’N ON MEDICAID & THE UNINSURED, *supra* note 134, at 28-29.

257. IEZZONI, *supra* note 120, at 249.

258. NAT’L COUNCIL ON DISABILITY, *supra* note 106, at 4.

259. This may be an area where the ADA’s accommodation approach can do a great deal of good. The statute’s integration mandate, as interpreted in *Olmstead*, might well prevent a state from cutting back on integration-enhancing services that are optional under the Medicaid law. As I noted in Part II, however, the access/content distinction significantly limits the usefulness of the ADA in this respect.

2. *Expanding Eligibility for Public Health Insurance*

As I discussed above, the most significant aspects of our current health insurance system that limit work opportunities for people with disabilities are the powerful work disincentives built into the major public health-insurance programs, Medicare and Medicaid. To obtain coverage under these programs, people with disabilities must generally show that they are unable to work. In the past, recipients who returned to work often lost their Medicare and Medicaid eligibility as a result. Because private health insurance will not provide the services many people with disabilities need, these eligibility rules effectively lock them out of the workforce.²⁶⁰ Any effort to move substantial numbers of people with disabilities into jobs must address disincentives like these. In particular, such an effort must sever the link between cash benefits and public health insurance and thereby make work no longer a disqualifying factor for the receipt of Medicare and Medicaid.

Recognizing this point, disability rights advocates in recent years have devoted substantial energy to lobbying for legislation that would extend eligibility for Medicare and Medicaid to a larger number of working people with disabilities. Disability rights advocates were among those who successfully pushed for the passage of the Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999.²⁶¹ Among other things, TWWIIA extends Medicare coverage for a full eight-and-a-half years to individuals with disabilities who leave the SSDI rolls to return to work.²⁶² The statute provides for expedited reinstatement to the SSDI-Medicare or SSI-Medicaid rolls for former recipients who, after a period of time back in the labor force, become unable to work once again.²⁶³ It also limits the degree to which work activity can be used as evidence that a former

260. See *supra* notes 127-141 and accompanying text.

261. Pub. L. No. 106-170, 113 Stat. 1860 (codified in scattered sections of 26 and 42 U.S.C.). For discussion of the role of disability rights advocates in drafting and lobbying for TWWIIA, see 145 CONG. REC. S14,981 (daily ed. Nov. 19, 1999) (statement of Sen. Jeffords) (“In addition to staff, we received countless hours of assistance and advice from the Work Incentives Task Force of the Consortium for Citizens with Disabilities. These individuals worked tirelessly to educate Members of Congress about the need for and the effects of this legislation.”); 145 CONG. REC. S7060-61 (daily ed. June 16, 1999) (statement of Sen. Dodd) (“In support of this important legislation are the Consortium for Citizens with Disabilities, the ARC, Easter Seals, the National Alliance for the Mentally Ill, the Paralyzed Veterans of America, the United Cerebral Palsy Association, and the National Education Association.”); Susan Page, *Clinton Aims To Help Disabled Workers*, USA TODAY, Jan. 13, 1999, at 12A (noting Justin Dart’s support of the statute that became TWWIIA); and Joshua Harris Prager, *Back to Work: Loss of Health Benefits No Longer Threatens Disabled Job-Seekers*, WALL ST. J., Oct. 22, 1999, at A1 (“In December 1996, several advocacy groups for the disabled convened in Washington, D.C., and Oakland, Calif., to push the idea of Medicaid buy-in programs.”).

262. See § 202(a) (codified at 42 U.S.C. § 426(b) (2000)).

263. See *id.* § 112 (codified at 42 U.S.C. §§ 423(i), 1383(p) (2000)).

recipient no longer has a disability.²⁶⁴ These provisions address a significant fear held by many SSDI recipients: If they leave the benefits rolls to return to work, they will lose their SSDI eligibility—and hence their entitlement to Medicare—once and for all, even if they later cannot find adequate work or private health insurance.

But TWWIA's extension of Medicare coverage to individuals who leave the SSDI rolls has a number of significant limitations. Although the statute extends Medicare coverage to individuals for a longer period of time after they leave the SSDI rolls, it does not make Medicare available to those who have not yet joined those rolls. To become eligible for Medicare in the first place, individuals with disabilities must still establish that they are unable to work, and they must remain unemployed through the lengthy disability-determination process. As a result, Medicare recipients with disabilities continue to develop a significant psychological investment in the proposition that they cannot work, and they continue to experience long periods of separation from the workforce that make them less employable.²⁶⁵ A truly effective effort to improve the employment rate of people with disabilities must also focus on individuals who are currently employed but whose attachment to the workforce is shaky.²⁶⁶

Moreover, an extension of Medicare benefits may not be sufficient to eliminate disincentives to work. Medicare was designed for a nonworking elderly population and does not well serve the interest of people with disabilities in community integration and access to the labor market.²⁶⁷ For one thing, the program uses a "medical necessity" standard similar to that employed by private insurers.²⁶⁸ As the Institute of Medicine has pointed

264. See *id.* § 111(a) (codified at 42 U.S.C. § 421(m) (2000)).

265. See GAO, *supra* note 140, at 10-11; GAO, SOCIAL SECURITY ADMINISTRATION: STATUS OF ACHIEVING KEY OUTCOMES AND ADDRESSING MAJOR MANAGEMENT CHALLENGES 19-20 (2001).

266. See GAO, DISABILITY PROGRAMS LAG IN PROMOTING RETURN TO WORK 19 (1997); Richard V. Burkhauser & Mary C. Daly, *Employment and Economic Well-Being Following the Onset of a Disability*, in DISABILITY, WORK AND CASH BENEFITS, *supra* note 6, at 59, 77-85; O'Day & Berkowitz, *supra* note 75, at 636-38.

267. See MARMOR, *supra* note 29, at 153 ("[T]he structure of the benefits themselves, providing acute hospital care and intermittent physician treatment, was not tightly linked to the special circumstances of the elderly as a group. Left out were provisions that addressed the particular problems of the chronically sick elderly: medical conditions that would not dramatically improve and the need to maintain independent function rather than triumph over discrete illness and injury.").

268. See INST. OF MED., *supra* note 23, at 227; see also 42 U.S.C. § 1395y(a)(1)(A) (2000) (limiting reimbursement to items or services that are "reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member"); *id.* § 1395y(a)(6) (barring reimbursement for "personal comfort items"). For critical discussion of the Medicare medical necessity determination process, see Timothy P. Blanchard, "Medical Necessity" Denials as a Medicare Part B Cost-Containment Strategy: Two Wrongs Don't Make It Right or Rational, 34 ST. LOUIS U. L.J. 939 (1990); and Timothy P. Blanchard, *Medicare Medical*

out, under that standard, “assistive technologies are likely to be dismissed as ‘not primarily medical in nature’ or as ‘convenience items.’”²⁶⁹ And Medicare denies reimbursement for mobility aids and power wheelchairs to recipients who can move around in their homes without them; if a recipient needs such equipment for purposes of traveling outside the home only, the equipment is deemed to be an uncovered “convenience item.”²⁷⁰ In the guise of preventing fraud, the Centers for Medicare and Medicaid Services (CMS) recently promised to enforce the “medical necessity” requirement particularly stringently when individuals seek Medicare reimbursement for power wheelchairs; although CMS ultimately withdrew the “guidance” document containing that promise, the agency insists that its policy remains unchanged.²⁷¹ Services essential to participation in community life, such as augmentative communication or personal assistance, often fail to satisfy Medicare’s medical necessity criteria as well.²⁷²

When Medicare does provide services that could be used to promote integration of people with disabilities in the life of the community, it frequently imposes a restriction that defeats a major purpose of those services: Recipients must become, in effect, “prisoners in their own homes.”²⁷³ Under Medicare’s “homebound rule,” a person who receives “home health services” (a term that includes such important services as personal assistance, physical and occupational therapy, and speech and language pathology²⁷⁴) must be “confined to his home.”²⁷⁵ The statute elaborates that “[w]hile an individual does not have to be bedridden to be considered ‘confined to his home’, the condition of the individual should be such that there exists a normal inability to leave home and that leaving

Necessity Determinations Revisited: Abuse of Discretion and Abuse of Process in the War Against Medicare Fraud and Abuse, 43 ST. LOUIS U. L.J. 91, 100-04 (1999).

269. INST. OF MED., *supra* note 23, at 227; *see also* IEZZONI, *supra* note 120, at 232 (“The prohibition against ‘convenience’ items, in particular, compromises efforts to obtain assistive technologies and other devices.”); Bruce C. Vladeck et al., *Confronting the Ambivalence of Disability Policy: Has Push Come to Shove?*, in *DISABILITY: CHALLENGES*, *supra* note 6, at 83, 95 (“Assistive technology addresses a range of needs that go well beyond the scope of Medicare’s currently stated purposes and benefits.”).

270. *See* IEZZONI, *supra* note 120, at 250; *see also* 42 U.S.C. § 1395x(n) (providing coverage for durable medical equipment only when it is “used in the patient’s home”).

271. *See* CTRS. FOR MEDICARE & MEDICAID SERVS., DEP’T OF HEALTH & HUMAN SERVS., PUB. 100-02, CMS MANUAL SYSTEM: BENEFIT POLICY (2003), *available at* www.cms.hhs.gov/manuals/pm_trans/R2BP.pdf; Michael Janofsky, *Costs and Savings in Medicare Change on Wheelchairs*, N.Y. TIMES, Jan. 30, 2004, at A13; *Payment for Power Wheelchairs: CMS Rescinds Latest Policy Change, but Confusion Is Likely To Remain*, 27 REP. ON DISABILITY PROGRAMS (Bus. Publishers, Inc., Silver Spring, Md.), Apr. 1, 2004, at 49, 49-50.

272. *See* INST. OF MED., *supra* note 23, at 257.

273. DEP’T OF HEALTH & HUMAN SERVS., DELIVERING ON THE PROMISE: U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES SELF-EVALUATION TO PROMOTE COMMUNITY LIVING FOR PEOPLE WITH DISABILITIES app. A at 58 (2002) (internal quotation marks omitted).

274. *See* 42 U.S.C. § 1395x(m).

275. *Id.* § 1395f(a)(2)(C); *accord id.* § 1395n(a)(2)(A).

home requires a considerable and taxing effort by the individual.”²⁷⁶ This provision was recently amended to clarify that absences from the home to receive health care treatment or adult day care do not compromise a recipient’s homebound status, nor do other absences “of infrequent or of relatively short duration.”²⁷⁷ But because the permitted trips must still be infrequent and require “considerable and taxing effort,” the changes in the homebound definition do not alter the fundamental problem: As soon as an individual with a disability becomes able to leave the house and participate in the community, the individual will lose Medicare home health services. In a classic Catch-22, an individual will lose home services even if those very services remain essential to the individual’s continued ability to leave the house.²⁷⁸

Other provisions of TWWIIA attempt to address these limitations of the Medicare extension. Section 201 of the statute authorizes states, at their option, to create Medicaid buy-in programs for working people with disabilities.²⁷⁹ Even if individuals with disabilities earn too much to qualify for Medicaid under the statute’s general work-incentive provisions,²⁸⁰ states may permit them to obtain Medicaid by “pay[ing] premiums or other cost-sharing charges set on a sliding scale based on income.”²⁸¹ States have broad flexibility in setting those premiums, as well as in setting income and asset limits for eligibility.²⁸² But enrollees whose income does not exceed 450% of the federal poverty line may not be charged a premium that amounts to more than 7.5% of their income.²⁸³ And section 204 authorizes a “demonstration project” in which states may provide Medicaid coverage for state-identified classes of individuals with impairments who currently work but whose conditions are “reasonably expected” to become work-

276. *Id.* § 1395f(a); *accord id.* § 1395n(a).

277. *Id.* § 1395f(a), amended by Medicare, Medicaid, and SCHIP Benefits Improvement and Protection Act of 2000, Pub. L. No. 106-554, § 507, 114 Stat. 2763, 2763 app. F 2763A-532 to -533. The amended statute provides that “any absence for the purpose of attending a religious service” shall be conclusively presumed to be infrequent or of relatively short duration.

278. See IEZZONI, *supra* note 120, at 239-40.

279. Section 201 is codified at 42 U.S.C. § 1396a(a)(10)(A)(ii)(XV). Disability rights activists have also been major supporters of the proposed Family Opportunity Act of 2003, S. 622, 108th Cong. (2003), which would authorize states to allow parents of children with disabilities to buy into the Medicaid program, *see* S. REP. NO. 108-157, at 5-7 (2003).

280. See *supra* Section II.A (discussing the operation of those provisions).

281. 42 U.S.C. § 1396o(g)(1)(A) (added by TWWIIA, Pub. L. No. 106-170, § 201(a)(3), 113 Stat. 1860, 1893 (1999)).

282. See 42 U.S.C. §§ 1396a(a)(10)(A)(ii)(XV), (XVI), 1396o(g)(1)(A).

283. See *id.* § 1396o(g)(1)(B). This provision builds on an earlier statute, the Balanced Budget Act of 1997, Pub. L. No. 105-33, § 4733, 111 Stat. 251, 522, which authorized states to establish Medicaid buy-in programs for people with disabilities who earn up to 250% of the federal poverty level. TWWIIA eliminates the 250% income cap on eligibility, though it permits states to impose income caps of their own.

prohibiting disabilities if those individuals do not receive Medicaid services.²⁸⁴

These efforts to expand Medicaid eligibility are themselves quite limited. Neither the general buy-in authority under section 201 nor the targeted demonstration-project authority under section 204 is mandatory for states. Given the substantial budgetary pressures on states to limit optional categories of Medicaid spending,²⁸⁵ it is unlikely that TWWIIA's eligibility expansions will ever be fully implemented. Indeed, only twenty-eight states have chosen to implement Medicaid buy-in programs for workers with disabilities.²⁸⁶ As of September 2003, these programs covered approximately 56,000 people.²⁸⁷ And nearly all of them limit eligibility to workers whose income is less than three times the federal poverty line.²⁸⁸ Moreover, the TWWIIA provision for workers at risk of falling out of the workforce is a mere demonstration, which is expected to reach selected populations in no more than eight states and the District of Columbia by the end of fiscal year 2004.²⁸⁹

Despite these limitations, TWWIIA marks a major step forward in promoting independence and work for people with disabilities. And the involvement of disability rights activists in lobbying for the statute marked a major advance as well, for it reflected a recognition that social welfare interventions can be crucial in empowering people with disabilities.

3. *Expanding the Services Covered by Public Health Insurance*

Even if disability rights activists succeed in expanding eligibility for public health insurance, significant structural barriers to employment will

284. TWWIIA, Pub. L. No. 106-170, § 204(b)(1)(B), 113 Stat. 1860, 1898 (1999).

285. *See supra* Subsection III.A.1.

286. *See* CTRS. FOR MEDICARE & MEDICAID SERVS., DEP'T OF HEALTH & HUMAN SERVS., CURRENT ENROLLMENTS IN THE MEDICAID BUY-IN AS OF MARCH 31, 2003, <http://cms.hhs.gov/twwiia/enrollmentperstate.pdf>. For discussions of the implementation of the buy-in program, *see* DEP'T OF HEALTH & HUMAN SERVS., THE MEDICAID BUY-IN PROGRAM: LESSONS LEARNED FROM NINE "EARLY IMPLEMENTER" STATES (2002), *available at* <http://aspe.hhs.gov/daltcp/reports/Eilesson.htm>; GAO, *supra* note 103; and HENRY T. IREYS ET AL., THE MEDICAID BUY-IN PROGRAM: QUANTITATIVE MEASURES OF ENROLLMENT TRENDS AND PARTICIPANT CHARACTERISTICS IN 2002, PRELIMINARY REPORT (2003), *available at* <http://www.cms.hhs.gov/twwiia/mathrpt1003.pdf>.

287. *See* CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 286.

288. The GAO reported that only three of the twenty-four states that had Medicaid buy-in programs in December 2002 extended eligibility to those who earned more than three times the poverty line. Minnesota has no income eligibility limit, New Hampshire limits eligibility to those who earn less than 450% of the federal poverty level, and Indiana limits eligibility to those who earn less than 350% of the federal poverty level. *See* GAO, *supra* note 103, at 17.

289. *See* General Services Administration, Catalog of Federal Domestic Assistance, *available at* http://12.46.245.173/pls/portal30/SYSTEM.PROGRAM_TEXT_RPT.SHOW?p_arg_names=prog_nbr&p_arg_values=93.769 (last visited Sept. 24, 2004).

remain. As I discussed above, the coverage formulas for both Medicare and (to a lesser but still important extent) Medicaid give short shrift to those services that would enable people with disabilities to live and work in the community. Under Medicare, the homebound rule limits home health services to those who are “confined to [their] home[s].”²⁹⁰ If home services enable an individual to leave his or her home routinely, the individual will lose coverage for those services.²⁹¹ And Medicaid’s “institutional bias” means that home-based personal-assistance services—perhaps the most important tool for people with disabilities to achieve integration in the community—are often not covered.²⁹²

Disability rights activists have increasingly turned their attention to attacking these limitations on Medicare and Medicaid benefits. Indeed, passage of the so-called MiCASSA law—the Medicaid Community-Based Attendant Services and Supports Act²⁹³—is probably the most significant legislative priority for disability rights activists.²⁹⁴ MiCASSA would eliminate Medicaid’s institutional bias by mandating that states cover personal-assistance services for recipients with disabilities.²⁹⁵ The bill would give eligible individuals the choice between receiving community-based attendant services and receiving services in an institutional setting, and it would guarantee persons with disabilities the power personally to hire, fire, and manage their assistants.²⁹⁶

290. 42 U.S.C. §§ 1395f(a)(2)(C), 1395n(a)(2)(A) (2000).

291. *See supra* Subsection III.A.2.

292. *See supra* Subsection III.A.1.

293. H.R. 2032, 108th Cong. (2003); S. 971, 108th Cong. (2003).

294. *See* Harriet McBryde Johnson & Lesly Bowers, *Civil Rights and Long-Term Care: Advocacy in the Wake of Olmstead v. L.C. ex rel. Zimring*, 10 ELDER L.J. 453, 457-58 (2002) (“Passing MiCassa is now the single national goal for American Disabled for Attendant Programs Today (ADAPT), the grassroots organization that effectively applied direct action, including civil disobedience, in its successful, twenty-year fight for accessible public transportation.”); ADAPT, *A Community-Based Alternative to Nursing Homes and Institutions for People with Disabilities*, <http://www.adapt.org/casaintr.htm> (last visited Sept. 24, 2004) (describing ADAPT’s support for MiCASSA); ADAPT, *List of Supporters*, <http://www.adapt.org/casa/supporters.htm> (last updated Jan. 13, 2004) (listing organizations that have endorsed MiCASSA, including disability rights groups such as ADA Watch, the American Association of People with Disabilities, the Bazelon Center for Mental Health Law, the Disability Rights Center, the Disability Rights Education and Defense Fund, and Justice for All). In September 2003, ADAPT led a fourteen-day march from the Liberty Bell in Philadelphia to the Capitol in Washington, D.C., to draw attention to MiCASSA. For the website devoted to that “Free Our People March,” *see* ADAPT, *Free Our People!*, <http://www.adapt.org/freeourpeople> (last visited Sept. 24, 2004). At a congressional hearing in March 1998, both ADAPT leader Michael Auberger and Justin Dart, one of the key disability rights advocates in the effort to obtain passage of the ADA, offered strong testimony in support of MiCASSA. *See Community-Based Care for Americans with Disabilities: Hearing Before the Subcomm. on Health and the Env’t of the House Comm. on Commerce*, 105th Cong. 21-24, 78-87 (1998) [hereinafter *Community-Based Care Hearing*].

295. In particular, the bill would require that states cover “community-based attendant services and supports” for any Medicaid-eligible individual who meets the criteria for institutional care. H.R. 2032 § 101.

296. *See id.*

The disability rights community has also begun to mobilize against Medicare's homebound rule. Disability rights organizations have supported legislation that would eliminate the homebound restriction.²⁹⁷ In response to these efforts, a provision in the 2003 Medicare reform law established a pilot project, limited to three states and 15,000 participants, that effectively eliminates the homebound requirement for certain individuals with permanent and severe disabilities.²⁹⁸

The homebound demonstration aside, disability rights activists' efforts to expand the services covered by public health insurance have not yet borne significant fruit. MiCASSA has now been introduced in five successive Congresses without ever making it out of committee.²⁹⁹ The nursing-home lobby, which carries a great deal of clout on Capitol Hill,³⁰⁰ understandably is strenuously opposed to the bill.³⁰¹ If passed, after all, MiCASSA would likely result in large numbers of people moving from nursing homes to home- and community-based settings. Some groups of parents of people with disabilities, such as Voice of the Retarded, also oppose the bill. The parents in these groups fear that their (now-grown) children will not receive appropriate care in community settings.³⁰²

Even if MiCASSA can navigate these legislative shoals, it will not be a panacea for people with disabilities. As I discuss below, the bill could easily leave people with disabilities at the mercy of private home-health-care agencies, which may subordinate the independence of their clients to their own profit-maximizing objectives. And MiCASSA is limited to personal-assistance services; it does nothing to assure access to such important services as assistive technology or home modifications for people with disabilities. Nonetheless, the fact that disability rights activists have placed such a high priority on the enactment of legislation expanding the

297. See H.R. 1874, 108th Cong. (2003); S. 598, 108th Cong. (2003). For the list of supporters—including disability rights groups American Association of People with Disabilities (AAPD) and Justice for All—see Nat'l Coalition To Amend the Medicare Homebound Restriction for Ams. with Significant Illness, Endorsements, <http://www.amendhomeboundpolicy.homestead.com/endorse.html> (last visited Sept. 24, 2004).

298. See Medicare Prescription Drug, Improvement, and Modernization Act of 2003, Pub. L. No. 108-173, § 702, 117 Stat. 2066, 2335-36.

299. See H.R. 2032; S. 971, 108th Cong. (2003); H.R. 3612, 107th Cong. (2002); S. 1298, 107th Cong. (2001); H.R. 4416, 106th Cong. (2000); S. 1935, 106th Cong. (1999); H.R. 2020, 105th Cong. (1997); H.R. 4250, 104th Cong. (1996).

300. On the power of the nursing home lobby, see BRUCE C. VLADECK, UNLOVING CARE: THE NURSING HOME TRAGEDY 192-201 (1980). See generally Batavia et al., *supra* note 98, at 531-32 (discussing opposition to personal assistance policies from entrenched interests).

301. See, for example, the MiCASSA issue paper on the website of the American Health Care Association, probably the leading nursing home trade association; that paper "strongly calls upon Congress to oppose MiCASSA legislation." AM. HEALTH CARE ASS'N, ISSUE BRIEF: MiCASSA LEGISLATION 2 (2004), available at http://www.ahca.org/brief/ib_micassa.pdf.

302. See, e.g., *Community-Based Care Hearing*, *supra* note 294, at 13 (statement of Rep. Brown); *id.* at 52-57 (statement of Polly Spare).

Medicaid program is itself telling. It reflects a recognition by disability rights activists that the ADA alone is not sufficient to achieve community integration for people with disabilities. Social welfare law remains important as well.

B. *Emerging Dilemmas*

As the previous Section demonstrates, disability rights activists have increasingly recognized the limitations of the antidiscrimination approach of the ADA. But as those activists turn toward social welfare strategies, new dilemmas will arise—or rather, old dilemmas will reassert themselves. Although social welfare strategies are essential to achieving the goals of disability rights activists, the disability rights movement's 1970s-era critique of the social welfare system remains powerful. But a number of the new social welfare initiatives potentially raise the same sorts of concerns that disability rights activists voiced in the 1970s. Any return to social welfare law must seek to address those concerns.

In this Section, I discuss two broad questions disability rights advocates will face as they embrace social welfare strategies for achieving their goals. First, they must choose whether to advocate universal social insurance benefits or targeted disability-specific interventions. The choice between universalism and targeting is one that appears throughout social welfare law, but, as I show in Subsection 1, the disability rights movement's critique of welfare gives the choice an unusual character in the disability context. Second, disability rights advocates' critique of professional domination of people with disabilities makes it particularly important that renewed social welfare interventions reduce the medicalization of disability benefits and guarantee consumer control. At the same time, these interventions must do so without placing people with disabilities at risk of receiving inferior services. I discuss these matters in Subsection 2. These two examples hardly exhaust the issues that disability rights advocates will face in relying on social welfare strategies, but they illustrate the kinds of dilemmas with which those advocates must grapple.

1. *Universal Versus Targeted Approaches*

In social welfare policy generally, policymakers are often said to face a tradeoff between targeted and universal interventions.³⁰³ Targeted

303. See, e.g., NEIL GILBERT, TRANSFORMATION OF THE WELFARE STATE: THE SILENT SURRENDER OF PUBLIC RESPONSIBILITY 135 (2002) ("Since the birth of the welfare state, policymakers have debated the defining principles that guide the allocation of social benefits. The classic line of this debate draws the distinction between universalism and selectivity.").

programs—those that focus benefits on a particular needy group—may more efficiently achieve the goal of alleviating suffering. But universal programs—social insurance programs that provide benefits to broad classes such as all workers or all citizens—are generally thought to be more politically stable. “Programs for the poor are poor programs,” the cliché goes.³⁰⁴

Looking at the history of the American welfare state in general, there seems to be a great deal of evidence to support the notion that broad social insurance programs fare better politically than do more targeted interventions.³⁰⁵ In this regard, one need only compare the history of the Social Security program with that of the major means-tested welfare program, Aid to Families with Dependent Children (AFDC) (which became Temporary Assistance to Needy Families (TANF) after passage of the 1996 welfare law). Social Security’s universal coverage has largely masked the program’s redistributive character, and political support for the program has remained sufficiently strong to scare off—at least so far—any effort to change it fundamentally.³⁰⁶ Welfare, by contrast, has long been a political target, and efforts to limit and condition the benefits it provides have not stopped with the passage of the 1996 reform law, which eliminated the federal entitlement to welfare.³⁰⁷ When the issue is viewed in a comparative perspective across industrial democracies, the evidence remains strong that

304. The saying is variously credited to Richard Titmuss and to Wilbur Cohen, one of the founding fathers of Social Security. For examples of commentators noting the political advantages to framing social welfare programs as universal social-insurance entitlements, see GRAETZ & MASHAW, *supra* note 6, at 288-89; THEDA SKOCPOL, *SOCIAL POLICY IN THE UNITED STATES: FUTURE POSSIBILITIES IN HISTORICAL PERSPECTIVE* 250-72 (1995); and WILLIAM JULIUS WILSON, *THE TRULY DISADVANTAGED: THE INNER CITY, THE UNDERCLASS, AND PUBLIC POLICY* 118 (1987). See also JACOB S. HACKER, *THE DIVIDED WELFARE STATE: THE BATTLE OVER PUBLIC AND PRIVATE SOCIAL BENEFITS IN THE UNITED STATES* 40 (2002) (calling this claim “ubiquitous”). There also may be efficiency advantages to universalism, which can circumvent adverse selection and moral hazard problems. See, e.g., GRAETZ & MASHAW, *supra* note 6, at 38-39.

305. For a contrary view, see PAUL PIERSON, *DISMANTLING THE WELFARE STATE? REAGAN, THATCHER, AND THE POLITICS OF RETRENCHMENT* 103, 101-03, 128 (1994) (explaining that “the biggest programmatic losers in the 1980s were often universal programs” and “the biggest winners were in fact targeted ones”).

306. See, e.g., GRAETZ & MASHAW, *supra* note 6, at 285-86; SKOCPOL, *supra* note 304, at 263-66.

307. Professor Theda Skocpol explicitly draws the comparison between Social Security and welfare in Theda Skocpol, *The Limits of the New Deal System and the Roots of Contemporary Welfare Dilemmas*, in *THE POLITICS OF SOCIAL POLICY IN THE UNITED STATES* 293, 295-98 (Margaret Weir et al. eds., 1988). See also SKOCPOL, *supra* note 304, at 255-59. For good pre-welfare-reform discussions of the American politics of welfare, see THOMAS BYRNE EDSALL & MARY D. EDSALL, *CHAIN REACTION: THE IMPACT OF RACE, RIGHTS, AND TAXES ON AMERICAN POLITICS* (1991); and HANDLER & HASENFELD, *supra* note 49, at 82-131. For good post-1996 treatments, see generally R. KENT WEAVER, *ENDING WELFARE AS WE KNOW IT* (2000); HAROLD L. WILENSKY, *RICH DEMOCRACIES: POLITICAL ECONOMY, PUBLIC POLICY, AND PERFORMANCE* 223-24 (2002); and Hugh Hecl, *The Politics of Welfare Reform*, in *THE NEW WORLD OF WELFARE* 169 (Rebecca M. Blank & Ron Haskins eds., 2001).

welfare programs based on broad universal entitlements have a political advantage over more targeted interventions.³⁰⁸

In the disability context, however, it might appear that there is no such tradeoff between universal and targeted approaches. People with disabilities, after all, have long been considered to be the “deserving poor.”³⁰⁹ A social welfare program targeted to poor people in general might well be politically vulnerable, but a social welfare program targeted to people with disabilities—toward whom the general public has a charitable disposition—will likely be much stronger politically.³¹⁰ As they turn back to social welfare strategies, disability rights activists might well be tempted to seek enactment of targeted programs that will provide enhanced benefits for people with disabilities only. Indeed, all of the legislative proposals discussed in Section A were disability-specific initiatives.³¹¹ At a time when significant retrenchment in domestic spending seems all but inevitable, the successful passage of the TWWIA statute and the relatively favorable reception the other disability-specific initiatives have received may suggest that such targeted proposals are politically viable in a way that broader social insurance proposals are not.

308. See WILENSKY, *supra* note 307, at 363-97; Bo Rothstein, *The Universal Welfare State as a Social Dilemma*, in *RESTRUCTURING THE WELFARE STATE: POLITICAL INSTITUTIONS AND POLICY CHANGE 206* (Bo Rothstein & Sven Steinmo eds., 2002); Duane Swank, *Political Institutions and Welfare State Restructuring: The Impact of Institutions on Social Policy Change in Developed Democracies*, in *THE NEW POLITICS OF THE WELFARE STATE 197, 213-14, 232-33* (Paul Pierson ed., 2001).

309. See *supra* text accompanying note 58.

310. See, e.g., Jonathan Zasloff, *Children, Families, and Bureaucrats: A Prehistory of Welfare Reform*, 14 J.L. & POL. 225, 308 n.259 (1998) (arguing that the means-tested SSI program has fared well politically, notwithstanding its targeted nature, because the program’s beneficiaries—including, inter alia, people with disabilities—have “substantial political support among the general public”). Indeed, Professor Jerry Mashaw suggests that public attitudes toward disability are sufficiently positive to make politically possible a regime in which private employers would be required to satisfy employment quotas for people with disabilities. See Jerry L. Mashaw, *Against First Principles*, 31 SAN DIEGO L. REV. 211, 233 (1994) (“Quotas simply do not have the same ideological loading in this context that they have in others.”). I am dubious about that political judgment and find it striking that disability-employment quotas have not been seriously proposed in any political forum in the United States in at least two decades. See STEPHEN L. PERCY, *DISABILITY, CIVIL RIGHTS, AND PUBLIC POLICY: THE POLITICS OF IMPLEMENTATION 207* (1989) (describing the Carter Administration’s decision *not* to impose numerical goals for disability employment on federal contractors under section 503 of the Rehabilitation Act, even though the government had imposed numerical goals for race and gender on federal contractors under Executive Order No. 11,246, 30 Fed. Reg. 12,319 (Sept. 24, 1965), the model for section 503).

311. Another disability-specific program frequently discussed in the literature is a “Disabled Worker Tax Credit,” which would be modeled on the Earned Income Tax Credit and provide a refundable tax credit to working individuals with disabilities. See, e.g., Burkhauser & Daly, *supra* note 266, at 87; Hilary Williamson Hoynes & Robert Moffitt, *The Effectiveness of Financial Work Incentives in Social Security Disability Insurance and Supplemental Security Income*, in *DISABILITY, WORK AND CASH BENEFITS*, *supra* note 6, at 189, 214; Weber, *Disability and the Law of Welfare*, *supra* note 6, at 947-50.

But targeted disability-specific social welfare programs have a downside as well. As disability rights activists made clear in the 1970s, one reason disability welfare programs have broad political support is that much of the public holds attitudes that are inconsistent with recognizing people with disabilities as full citizens.³¹² Many believe that people with disabilities are especially deserving of charity and public largesse precisely because they believe that people with disabilities are not capable of providing for themselves. If disability rights activists rely on and cater to those attitudes to gain support for disability-specific social welfare initiatives, they may end up reinforcing those attitudes in a way that is extremely damaging to the movement's broader goals.³¹³

This point suggests that disability rights activists should, whenever possible, seek to achieve their social welfare goals through "universal policies that recognize that the entire population is 'at risk' for the concomitants of chronic illness and disability."³¹⁴ For this reason, I think that job set-asides for people with disabilities, an approach favored by a number of commentators,³¹⁵ ought properly to be a nonstarter. Indeed, it is notable that European countries that have historically maintained quota systems are now moving—largely at the insistence of politically activated people with disabilities—to abolish them.³¹⁶ There is good reason to doubt that such systems have been especially effective in promoting employment and integration for people with disabilities in any event.³¹⁷

312. See *supra* notes 59-64 and accompanying text.

313. This is a classic example of what Professor Martha Minow has labeled the "dilemma of difference," in which "[t]he stigma of difference may be recreated both by ignoring and by focusing on it." MARTHA MINOW, *MAKING ALL THE DIFFERENCE: INCLUSION, EXCLUSION, AND AMERICAN LAW* 20 (1990).

314. Irving Kenneth Zola, *Toward the Necessary Universalizing of a Disability Policy*, 67 *MILBANK Q.* 401, 401 (1989).

315. See, e.g., Issacharoff & Nelson, *supra* note 205, at 355-57; Mashaw, *supra* note 310, at 231-37; Weber, *Beyond the ADA*, *supra* note 6, at 159-74.

316. See Lisa Waddington, *Reassessing the Employment of People with Disabilities in Europe: From Quotas to Anti-Discrimination Laws*, 18 *COMP. LAB. L.J.* 62, 81-99 (1996).

317. As Professor Lisa Waddington concludes,

[M]ore than fifty years' experience with the quota system has revealed that systems which are not effectively enforced have little or no effect in terms of generating employment, while those which are based on the levy-grant system are incapable of meeting the set targets in this period of high unemployment, at least where the levy is set at a low level. The political will does not exist to enforce quota systems, or to set a high levy, and it cannot be expected that the performance records of quotas will improve.

Id. at 100; see also Katharina C. Heyer, *The ADA on the Road: Disability Rights in Germany*, 27 *LAW & SOC. INQUIRY* 723, 729 (2002) (stating that the German quota system "remains highly segregated and continues to isolate people with severe, learning, or developmental disabilities," and that it has not improved the employment position of people with disabilities); Katharina Heyer, *From Special Needs to Equal Rights: Japanese Disability Law*, 1 *ASIAN-PAC. L. & POL'Y J.* 7:1, :8 (2000), <http://www.hawaii.edu/aplpj/pdfs/07-heyer.pdf> (stating that Japan has never met its 1.8% employment quota for people with disabilities, and that the quota system has resulted in

Health policy seems an extremely promising area in which to take a universalist approach. Until the 1990s, American disability rights activists were quite averse to urging a broadening of guaranteed health coverage. The movement had “worked so hard for so long to separate the issues of health and disability” that demands for broader health coverage would seem to “resurrect[] harmful stereotypes.”³¹⁸ Three events led disability rights activists to recognize their important stake in health reform debates: the Oregon Health Plan controversy of 1992,³¹⁹ the flurry of activity surrounding President Clinton’s proposed Health Security Act in 1993 and 1994,³²⁰ and the rise of managed care in the mid- to late 1990s.³²¹ But if disability rights activists restrict their goals to disability-specific expansions of health insurance such as those embodied in TWWIIA and MiCASSA, their actions risk “reviving the stereotype that all people with disabilities are sick and should be viewed as patients.”³²²

If disability rights advocates place a greater focus on urging enactment of a universal health care system, though, they may help to blunt that stereotype. For many of the reasons discussed in Part II, people with disabilities would disproportionately benefit from a universal guarantee of health insurance.³²³ Most notably, such a guarantee would eliminate the fear of the loss of coverage that is the most significant barrier to employment for people with disabilities. But a universal health care system would likely not be seen as a disability-oriented program, because it would provide benefits to everyone. Advocacy for and enactment of such a system would not send the message that people with disabilities are uniquely in need of caretaking; it would send the message that we all need insurance against contingencies in life.³²⁴

“de facto re-segregation into separate workplaces” as companies have “compl[ie]d with the quota by establishing special ‘barrier-free’ subsidiary companies”).

318. Sara D. Watson, *An Alliance at Risk: The Disability Movement and Health Care Reform*, AM. PROSPECT, Winter 1993, at 60, 63, available at <http://www.prospect.org/print/V4/12/watson-s.html>; see also DeJong & Basnett, *supra* note 102, at 614 (discussing American disability rights activists’ reticence to participate in health policy debates until the 1990s).

319. See DeJong & Basnett, *supra* note 102, at 614-15; Watson, *supra* note 318. For a general discussion of the Oregon Health Plan controversy, see Bagenstos, *supra* note 38, at 1507-09.

320. See DeJong & Basnett, *supra* note 102, at 615. For good discussions of the failure of the Clinton health proposal, see HAYNES JOHNSON & DAVID S. BRODER, *THE SYSTEM: THE AMERICAN WAY OF POLITICS AT THE BREAKING POINT* (1996); and THEDA SKOCPOL, *BOOMERANG: CLINTON’S HEALTH SECURITY EFFORT AND THE TURN AGAINST GOVERNMENT IN U.S. POLITICS* (1996).

321. See DeJong & Basnett, *supra* note 102, at 615-16.

322. Watson, *supra* note 318, at 63.

323. See Weber, *Disability and the Law of Welfare*, *supra* note 6, at 953-54.

324. The health policy area thus presents fertile ground for disability rights activists to pursue the strategy Professor Skocpol has labeled “targeting within universalism,” in which universal

To be sure, universal health insurance is at best a long-run goal given today's climate of domestic-policy retrenchment. But disability rights activists can engage in (relatively) universalist social welfare advocacy even today. One of the greatest current threats to people with disabilities is the persistent proposal to transform Medicaid into a block-grant program. As I discussed in Part II, that proposal would likely place people with disabilities—who represent a disproportionate percentage of Medicaid costs—at the greatest risk of having their benefits cut. Yet in defending the program's current entitlement structure, activists need not rely on the unique harm block grants pose to people with disabilities. Rather, they can focus on the need for health care more generally.

To some extent, of course, disability rights advocates will necessarily be called upon to defend disability-specific interventions. Even in the context of universal health insurance, activists will want to assure that the benefits formula provides adequate coverage for those services that are particularly important to people with disabilities. And even when they defend the Medicaid entitlement generally, disability activists will, by their very participation, trigger the feelings of charity and pity many nondisabled people have toward people with disabilities. The attitudes toward disability that remain prevalent in society are too strong to enable activists to fully escape them by urging universal interventions. But by casting demands for social welfare provision in universal terms as frequently as possible, the disability rights movement can help to erode the notion that people with disabilities are fundamentally separate from the community of citizens.

2. *Consumer Control*

A second issue disability rights advocates must confront as they embrace social welfare programs is the issue of consumer control. To date, disability rights advocates have focused their newfound social welfare advocacy on the implementation and expansion of public health insurance programs. As I described in Section A, those activists have sought to compel states to provide the services mandated by the Medicaid Act, and they have sought to expand the eligibility criteria for and the services provided under both Medicare and Medicaid.³²⁵ That medical focus should hardly be a surprise. Many of the services people with disabilities need to enhance opportunities to live and participate in the community are typically

policies are crafted in a way that provides especial benefit to particularly disadvantaged persons and groups. See SKOCPOL, *supra* note 304, at 259-72.

325. See *supra* Section III.A.

regarded as medical services that should appropriately be provided through the health care and health insurance systems.³²⁶

But the medical focus of this new social welfare advocacy carries risks as well. When participants in the disability rights movement urged a move away from a social welfare approach in the 1970s and 1980s, they argued that social welfare programs gave members of the “helping professions” too much power to control the lives of people with disabilities.³²⁷ The medical profession was probably the most frequent target of that critique. Activists contended that medical professionals view disability as a sickness—one for which the individual with a disability must submit to the treatment dictated by a doctor or nurse. The result of this “medical model” is to deny independent agency to people with disabilities and to reinforce the notion that disability is an individual rather than a societal problem.³²⁸ In pursuing medicalized social welfare strategies to achieve the goals of the disability rights movement, activists risk further entrenching the salience of the medical model of disability.

And the risk is not merely the abstract and ineffable one that the law will send the wrong message. The risk is far more concrete. Social welfare interventions financed by the health insurance system tend to be delivered through the infrastructure of the health insurance system. That infrastructure is controlled by medical professionals and is arranged in a way that can itself deny agency and autonomy to people with disabilities.³²⁹ For that reason, disability rights activists in the 1970s and 1980s urged that there is nothing inherently medical in such services as personal assistance or assistive technology and that those services should be provided through a demedicalized process in which individuals with disabilities, rather than medical professionals, have control.³³⁰ Yet by seeking those services through health insurance programs like Medicare and Medicaid, today’s disability activists may be undermining their own goals.

326. See *supra* text accompanying note 102.

327. See *supra* notes 38-45 and accompanying text.

328. See, e.g., SIMI LINTON, CLAIMING DISABILITY: KNOWLEDGE AND IDENTITY 11 (1998); OLIVER, *supra* note 69, at 36-37; see also Carol J. Gill, *Health Professionals, Disability, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia*, 6 PSYCHOL. PUB. POL’Y & L. 526, 530-32 (2000) (arguing that physicians hold negative attitudes about the quality of life of people with disabilities).

329. See, e.g., DeJong & Wenker, *supra* note 98, at 161-62; Mary Johnson, *The Choice That Nobody’s Heard Of*, RAGGED EDGE, Jan./Feb. 1998, at 22, available at <http://www.ragged-edge-mag.com/jan98/choice.htm>.

330. See, e.g., BERKOWITZ, *supra* note 24, at 201-04; Batavia et al., *supra* note 98, at 529-30; DeJong, *supra* note 60, at 14-20; see also PAMELA J. DAUTEL & LEX FRIEDEN, CONSUMER CHOICE AND CONTROL: PERSONAL ATTENDANT SERVICES AND SUPPORTS IN AMERICA (1999) (urging change in Medicaid personal-assistance rules to recognize nonmedical nature of that assistance in recommendation number five of blue-ribbon panel on personal-attendant services).

The proposed MiCASSA statute provides an excellent example. The bill would require states to provide “community-based attendant services and supports” as a mandatory Medicaid benefit.³³¹ Mandated services would include an array of personal-assistance services that would enhance the opportunities for people with disabilities to participate in community life.³³² And the bill takes a number of significant steps in the direction of assuring disabled individuals control of the services provided to them. It would require that individuals with disabilities have the power to “select[], manage[], and dismiss[]” their own assistants.³³³ It would also guarantee individuals with disabilities “maximum control of the community-based attendant services and supports, regardless of who acts as the employer of record.”³³⁴ These requirements would significantly advance the goals of independence and integration for people with disabilities.

But MiCASSA would leave intact a significant expression of the medical model of personal-assistance services—the requirement, in many states’ Nurse Practice Acts, that “virtually any hands-on services provided for pay to a disabled or elderly person” be treated “as the practice of nursing, requiring licensure.”³³⁵ (MiCASSA would not alter the general rule that the states retain the power to regulate the proper practice of medicine.)³³⁶ This requirement often “makes effective in-home services unavailable,” particularly for “those who live in a rural area beyond the reach of a nursing agency, or need an attendant for short shifts throughout

331. S. 971, 108th Cong. § 101 (2003).

332. *See, e.g., id.*

333. *Id.* (amending, if enacted, 42 U.S.C. § 1935(g)(1)(A)(iv) (2000)).

334. *Id.* (amending, if enacted, 42 U.S.C. § 1935(g)(2)(B) (2000)).

335. Johnson & Bowers, *supra* note 294, at 458. Toby Olson, then the head of the Washington State Governor’s Committee on Disability Issues and Employment, gave a powerful example of the restrictions Nurse Practice Acts place on the services unlicensed attendants can perform:

Under Washington state’s current nurse practice law, “it’s illegal to use your own judgment and rent a pair of hands,” as Olson put it.

“If you can tell someone, ‘pick up that blue pill—not that light blue one, but the long blue capsule—and put it in my mouth’—if you’re competent to do that, but you can’t put the pill in your mouth by yourself, then you’re not allowed to have just anyone working for you do it.” It has to be a nurse.

Mary Johnson, *In Thrall to the Medical Model*, RAGGED EDGE, Jan./Feb. 1999, at 12, available at <http://www.ragged-edge-mag.com/0199/a199ft1.htm>. For a relatively recent, comprehensive overview of the restrictions that the states’ Nurse Practice Acts might place on consumer-directed personal assistance, and the move in a number of states to loosen those restrictions, see SUSAN C. REINHARD, DEP’T OF HEALTH & HUMAN SERVS., CONSUMER DIRECTED CARE AND NURSE PRACTICE ACTS (2001), available at <http://aspe.hhs.gov/daltcp/reports/nursprac.htm>.

336. Medicaid once required that home services be provided or supervised by nurses; although that requirement has been eliminated from federal law, states still retain the power to impose similar requirements on Medicaid services through their Nurse Practice Acts. *See* GARY SMITH ET AL., DEP’T OF HEALTH & HUMAN SERVS., UNDERSTANDING MEDICAID HOME AND COMMUNITY SERVICES: A PRIMER 12, 41, 56, 60-62 (2000), available at <http://aspe.hhs.gov/daltcp/reports/primer.htm>.

the day.”³³⁷ And when nursing agencies are available to provide personal assistance, they often impose severe restrictions on the use of their services. Some of these restrictions may result from home health agencies’ bureaucratic imperatives of coordinating services to a large number of dispersed individuals.³³⁸ Others may reflect an effort to limit attendant services to those that are “truly medical”—even if more custodial services would be most effective in promoting independence.³³⁹ Disability rights activists in a number of states are currently urging relaxation of the restrictions in their Nurse Practice Acts—and they have won some important victories.³⁴⁰ But until those efforts fully succeed, a statute like MiCASSA will have only limited power to enhance the opportunity for people with disabilities to participate in community life.

To be sure, the crafting of consumer-controlled structures for implementing personal-assistance services raises complex political and policy questions. For the reasons I have discussed, relying on home health agencies to deliver personal-assistance services limits the agency and autonomy of people with disabilities. It may therefore seem attractive from a policy perspective to establish a voucher scheme in which individuals with disabilities serve as employers of their own attendants and receive a fixed amount of money to pay their attendants’ wages. Medicaid’s recent “cash and counseling” demonstration employed a model like this in three states, and it is set to expand.³⁴¹ Other countries have begun to move toward voucherized consumer-controlled personal-assistance services as well.³⁴²

337. Johnson & Bowers, *supra* note 294, at 458.

338. See Johnson, *supra* note 329 (“‘My attendant was not allowed to make lunch or breakfast for my 3-year-old son, only me,’ says Vini Portlitzine of Pennsylvania, who became disabled when her child was still a toddler and found herself on the receiving end of an aide from a ‘home health agency.’”); *id.* (reporting a response to a survey of those who receive attendant services that “[h]ome health agencies refused to send aides before 8 a.m. or after 6 p.m. (aides put clients in bed at 6 p.m.—the end of their shift)”).

339. See *id.* (reporting survey responses, which revealed that “[a]gency rules forbade aides helping a client outside their home, forbade them to put away groceries, forbade them to feed pets”); see also Batavia et al., *supra* note 98, at 535 (“In determining the appropriate *scope* of personal assistance services, there is an ever-present tendency in this country to segregate the medical from the nonmedical domains of home care and to segregate in-home forms of assistance from out-of-home forms. Many disabled persons find these distinctions to be artificial and a source of frustration in their daily lives.”).

340. See, e.g., Valerie J. Bogart, *Consumer Directed Assistance Program Offers Greater Autonomy to Recipients of Home Care*, N.Y. ST. BAR ASS’N J., Jan. 2003, at 8, 8-9 (describing amendments to New York’s statute); Johnson & Bowers, *supra* note 294, at 458 n.25 (describing recent amendment to South Carolina’s statute). See generally Johnson, *supra* note 335 (discussing efforts to reform Nurse Practice Acts).

341. See *Consumer Directed Services: Improving Medicaid Beneficiaries’ Access to Quality Care: Hearing Before the Subcomm. on Health of the House Comm. on Energy and Commerce*, 108th Cong. 1-30 (2003) (discussing experience under the cash-and-counseling demonstration); ‘Consumer Direction’ Goes Off in a Completely New Direction, 27 REP. ON DISABILITY PROGRAMS (Bus. Publishers, Inc., Silver Spring, Md.), Feb. 19, 2004, at 25, 25-26 (discussing plans for expansion of cash and counseling demonstration); Leslie Foster et al., *Improving the*

In addition to the policy benefits of a consumer-controlled voucher scheme, such a scheme may seem attractive from a political perspective: Using vouchers to implement a Medicaid-funded personal-assistance benefit would fit in well with the broader conservative agenda to privatize and impose choice principles on social welfare services.³⁴³ It is therefore possible to envision an across-the-aisle compromise in which people with disabilities receive new personal-assistance services (which plays to liberals' interest in expanding social welfare programs) but must use vouchers to do so (which plays to conservatives' interest in privatized, choice-based social services).³⁴⁴ The disability rights movement's rhetoric of independence and consumer control might in this context lend a liberal patina to the generally conservative policy tool of vouchers.

But there are substantial drawbacks to the cash-and-counseling model of personal-assistance services. For one thing, only a fraction of individuals with disabilities have the time, inclination, and skills to search for, hire, and train their own personal assistants.³⁴⁵ In this respect, people with disabilities are no different from anyone else. Many people, disabled and nondisabled, who want to hire household assistance—babysitting, housecleaning, or personal assistance—find that the burdens of becoming an employer are great; they seek help from specialized employment agencies that screen, train, and refer candidates for these jobs. If it is to serve the needs of people

Quality of Medicaid Personal Assistance Through Consumer Direction, HEALTH AFF., Mar. 26, 2003, at W3-162, W3-163 to W3-164, <http://content.healthaffairs.org/cgi/reprint/hlthaff.w3.162v1.pdf> (discussing results of cash-and-counseling demonstration in Arkansas); see also KAISER COMM'N ON MEDICAID & THE UNINSURED, AN OVERVIEW OF THE INDEPENDENCE PLUS INITIATIVE TO PROMOTE CONSUMER-DIRECTION OF SERVICES IN MEDICAID (2003) (discussing the Bush Administration's Independence Plus Initiative, which will allow states to adopt a cash-and-counseling approach to, inter alia, personal-assistance services through a Medicaid waiver).

342. See Sharon M. Keigher, *Austria's New Attendance Allowance: A Consumer-Choice Model of Care for the Frail and Disabled*, 27 INT'L J. HEALTH SERVICES 753, 755-57 (1997) (describing an Austrian program, established in 1992, that provides fixed cash payments to individuals with disabilities to enable them to purchase attendant services); Joshua M. Wiener et al., *Consumer-Directed Home Care in the Netherlands, England, and Germany* (Oct. 2003) (unpublished manuscript), available at http://research.aarp.org/health/2003_12_eu_cd.pdf (discussing voucher- and cash-grant programs in the Netherlands, England, and Germany).

343. On the rise of privatization and choice, see, for example, MARTHA MINOW, *PARTNERS, NOT RIVALS: PRIVATIZATION AND THE PUBLIC GOOD* 22-28 (2002); Matthew Diller, *Form and Substance in the Privatization of Poverty Programs*, 49 UCLA L. REV. 1739 (2002); Jody Freeman, *Extending Public Law Norms Through Privatization*, 116 HARV. L. REV. 1285, 1291-95 (2003); and Gillian E. Metzger, *Privatization as Delegation*, 103 COLUM. L. REV. 1367, 1376-94 (2003).

344. See Keigher, *supra* note 342, at 761-62 (describing how such a political compromise resulted in passage of Austria's attendance allowance).

345. See Bob Kafka, *Empowering Service Delivery*, RAGGED EDGE, Sept./Oct. 1998, at 28, available at <http://www.ragged-edge-mag.com/0998/b998ft6.htm> ("This traditional independent-living movement approach to how personal attendant services should be delivered may work for some individuals who have the desire and skills to run things on their own. But for the vast numbers of people who have disabilities, it's just not working.").

with disabilities, a comprehensive personal-assistance policy must leave room for such agencies.

Moreover, disability rights activists should regard the conservative agenda behind the cash-and-counseling program as a threatening one. Such a program would likely reduce the wages paid to personal assistants, as they would move from working for (frequently unionized) home health agencies to working for hard-to-unionize individual household employers.³⁴⁶ Although one result would be the lowering of costs for personal-assistance services,³⁴⁷ the lower costs can be double edged. If voucher amounts are pegged to lower wage projections, they may be insufficient to attract a stable, qualified workforce of personal assistants.³⁴⁸ As the Kaiser Commission on Medicaid and the Uninsured recently reported, low wages have already led to a “shortage of direct care workers who are trained and willing to provide community-based personal assistance and other long-term services.”³⁴⁹ There is thus reason to fear that a cash-and-counseling approach to attendant services would serve as yet another means of using deinstitutionalization to cut costs rather than serve the interests of people with disabilities.³⁵⁰

346. In Canada, the implementation of a voucher-type scheme known as “individualized funding” led in many provinces to significant erosion in personal attendants’ pay and working conditions. See LEN BUSH, NAT’L UNION OF PUB. & GEN. EMPLOYEES, SELF-MANAGED CARE AND INDIVIDUALIZED FUNDING: NOT THE SAME THING! 12-13 (Nov. 17-20, 2000), available at http://action.web.ca/home/clcdisab/attach/disab_conf_nov2000_bush.pdf; see also Wiener et al., *supra* note 342, at 17 (describing argument by “some stakeholders” that “being an individual worker under Direct Payments [England’s voucher scheme] has disadvantages compared to being employed by a local social service authority with union protection”).

347. See, e.g., Wiener et al., *supra* note 342, at 22 (“[W]hile much of the policy interest in consumer-directed home care derives from a desire to empower people with disabilities and give them more control over their lives, this approach is also attractive to governments because of its lower per person costs.”).

348. See BUSH, *supra* note 346, at 12-13 (describing this problem under the Canadian individualized funding system). Wiener and his colleagues report a shortage of workers available under the Dutch, English, and German voucher policies, though that shortage in part reflects broader trends in the home-care workforce—whether they work in consumer or agency models. See Wiener et al., *supra* note 342, at 16-17.

349. KAISER COMM’N ON MEDICAID & THE UNINSURED, *OLMSTEAD V. L.C.: THE INTERACTION OF THE AMERICANS WITH DISABILITIES ACT AND MEDICAID* 5 (2004).

350. This country certainly has a history of attempting to implement deinstitutionalization “on the cheap,” *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 610 (1999) (Kennedy, J., concurring in the judgment), with devastating results for deinstitutionalized populations. See, e.g., Michael L. Perlin, *Competency, Deinstitutionalization, and Homelessness: A Story of Marginalization*, 28 HOUS. L. REV. 63, 89-90 (1991) (discussing budget-cutting and privatizing motives for deinstitutionalization). More generally, privatization of social welfare programs in this country has recently served an agenda of “reducing the welfare rolls in a manner that spares public officials from the political consequences of appearing harsh and uncaring about the poor.” Diller, *supra* note 343, at 1757. There is nothing inherently conservative about privatization. See, e.g., Freeman, *supra* note 343, at 1314 (arguing that “perhaps privatization can enhance public law norms by extending them to realms where they typically do not play a significant role”); Metzger, *supra* note 343, at 1377 (“[H]istory demonstrates that increased privatization often goes hand in hand with expansion rather than contraction in public responsibilities.”). But privatization

A more promising approach would retain an agency-provider model of service delivery but give people with disabilities a greater voice in the operations of the provider agencies. A handful of independent living centers—self-help organizations run by people with disabilities³⁵¹—have operated attendant-services programs for a number of years.³⁵² Longtime disability rights activist Bob Kafka has proposed that independent living centers across the country take over the personal-assistance business more generally, by setting up home- and community-based support service agencies that would be controlled by people with disabilities and would deliver attendant services according to the “independent living principles” of consumer control and demedicalization.³⁵³ Although much of this new model of “empowering service delivery” remains to be fleshed out—and although community-controlled service provision has a checkered history in American social welfare policy³⁵⁴—disability rights activists might fruitfully focus their energies on elaborating and testing that model.³⁵⁵

C. *The Coherence of the Disability Rights Movement*

In addition to these policy dilemmas, a turn to social welfare strategies potentially raises a deeper problem for disability rights advocates: It might endanger the coherence and viability of the disability rights movement as a movement. Although activists in the 1970s and 1980s were sincere in their belief that existing welfare programs harmed people with disabilities, their opposition to welfare served a separate function. Opposition to welfare, and the concomitant embrace of the broad notion of “independence,” helped to unify previously unaffiliated groups of disparate people with diverse disabilities. People with different disabilities had very different needs, but people with nearly all types of disabilities could sign onto an

in this country has, as Professor Diller describes, often been used as a covert means of reducing public investment in social welfare. See HARVEY FEIGENBAUM ET AL., *SHRINKING THE STATE: THE POLITICAL UNDERPINNINGS OF PRIVATIZATION* 131-39 (1998); Metzger, *supra* note 343, at 1377-78.

351. For a discussion of the independent living movement, see Bagenstos, *supra* note 4, at 987-99.

352. See Kafka, *supra* note 345.

353. *Id.*; see also Batavia et al., *supra* note 98, at 536-37 (“Whether the funding for a national personal assistance services program derives from federal, state, or private coffers, we believe that the program ideally should be based on an entirely new legislative authority that does not suffer the drawbacks of health care or social service funding. Such statutory authority should be entirely consistent with the precepts of the independent living model.”).

354. See, e.g., DANIEL P. MOYNIHAN, *MAXIMUM FEASIBLE MISUNDERSTANDING: COMMUNITY ACTION IN THE WAR ON POVERTY* (1969).

355. Some of the types of institutional and programmatic structures developed by the emerging community-development movement might well provide a model here. See, e.g., WILLIAM H. SIMON, *THE COMMUNITY ECONOMIC DEVELOPMENT MOVEMENT: LAW, BUSINESS, AND THE NEW SOCIAL POLICY* (2001).

“independence” agenda.³⁵⁶ And, in unity, the disability rights movement found strength. The ability of disability rights leaders to hold the movement together contributed significantly to the passage of the ADA.³⁵⁷

A renewed embrace of social welfare law might threaten to disunify the disability rights movement in at least two ways. First, individuals with disabilities who do not need social welfare interventions to get and keep jobs—those for whom antidiscrimination law is sufficient—may perceive no interest in advocating for those interventions. Second, the design and funding of social welfare programs may pit people with different impairments against one another in internecine struggles for limited domestic-policy resources.³⁵⁸

These are significant concerns, and they deserve more discussion than I can give them here. The stress that social welfare strategies will place on the unity of the disability rights movement probably cannot be avoided entirely. But there are at least some tools for managing the tension. In this regard, universalism in the design of social welfare programs has particular appeal. Not only does universalism help to avoid the stigmatizing nature of programs that identify people with disabilities as uniquely incapable of performing the usual functions of citizenship, it also helps to avoid fights between people with different disabilities for a scarce pool of resources devoted to people with disabilities in general.

As I acknowledged above, a general presumption in favor of universalism does not eliminate zero-sum questions of distribution. Even a universal benefit will necessarily be crafted according to rules that help some people more than others. And resources are and will remain limited. But disability rights advocates should make no mistake: The failure to embrace social welfare interventions has distributive consequences as well. As a number of commentators have noted, the rights-focused, welfare-opposing approach of those who advocated the ADA disproportionately benefits a relatively advantaged class of people with disabilities—precisely the sort of people who crafted that approach in the first place.³⁵⁹ Disability rights advocates will do best to bring these distributive choices out in the open and to recognize the limitations of the ADA for many classes of people with disabilities.

356. For further support for the argument in this paragraph, see Bagenstos, *supra* note 4, at 1008-13.

357. See SHAPIRO, *supra* note 33, at 126-27.

358. There is a long history of such internecine battles among impairment-specific disability organizations. See Bagenstos, *supra* note 4, at 1009.

359. See, e.g., *id.* at 1013-14 & n.383.

CONCLUSION

Disability rights activists will face a number of political and policy dilemmas as they rely increasingly on social welfare law. I do not pretend even to have begun to resolve those dilemmas. But it is important that activists recognize the important choices that lie ahead. The antidiscrimination approach exemplified by the ADA has not come close to achieving full employment and community integration for people with disabilities, and there is no reason to expect that it ever will. Although the ADA remains exceptionally important, social welfare interventions will also be necessary to achieve those goals. The important tasks for the disability rights movement in the twenty-first century will be, first, to confront honestly the promise and limitations of an antidiscrimination approach and, second, to craft social welfare laws and policies that address the movement's own critique of social welfare responses to disability. These will not be easy tasks, but they will be exceptionally important for the lives of tens of millions of people with disabilities.

