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[Introduction to] Disability Rights and the American Social Safety Net

Jennifer L. Erkulwater
jerkulwa@richmond.edu

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Introduction: The Puzzle of Reform

A truism of American politics is that liberal policy reform can be accomplished rarely, only when the stars align and favorable political winds sweep aside previously immovable political obstacles. For this to happen, though, the prerequisites are many. There must be a crisis of such magnitude that the American people abandon their deep-seated mistrust of the federal government and turn for help to a charismatic presidential candidate who promises change. Elected by a landside, the new president must then storm into office, quickly drawing up his reform agenda and forwarding it to Congress. Lawmakers then enact it in short order, in part because many rode into office on the president's coattails and now feel they owe their seats to him and in part because the opposition has been scattered and demoralized by its crushing electoral defeat. Hence, the programs of the American welfare state were established and expanded in two "big bangs." The first of these was Franklin Roosevelt's New Deal in 1933–36, in response to the economic dislocation caused by the Great Depression; the second, Lyndon Johnson's Great Society and War on Poverty in 1964–66, in response to widespread social and racial unrest. But momentum is soon lost, and the gridlock and inaction that typifies American politics return.¹ As a result, outside these two extraordinary periods of liberal activism, there is little policy innovation. Viewed from a historical perspective, this pattern of policymaking explains why, compared to its Western European counterparts, the American welfare state has remained exceptional—exception-

1. Christopher Leman, *The Collapse of Welfare Reform: Political Institutions, Policy, and the Poor in Canada and the United States* (Cambridge: MIT Press, 1980), 23, 26–33.

ally spartan, exceptionally stingy, exceptionally punitive toward the poor.

Yet this truism of American politics is not necessarily true. In fact, this book recounts the expansion of disability benefit programs since 1970, just one occasion in which conventional wisdom is misleading. But how can we account for these successful episodes of liberal reform? How do we explain instances when liberal advocates were able to navigate around political impediments and reach their goals despite the odds? How do we account for the growth of some social welfare programs in a political environment hostile to such innovations? The answers to these questions provide important lessons about how policy innovation occurs in American politics notwithstanding daunting political hurdles.

In some ways, of course, the history of disability benefits in the United States confirms the nation's reputation as a welfare laggard. With the exception of small programs for railroad workers, veterans, and civil servants, until the mid twentieth century, help for sick or injured people was not a national concern. States and local governments retained primary responsibility for running workers' compensation funds, institutions for people with mental illness or developmental disabilities, and the various aid programs for the blind and crippled. It was not until 1956 that Congress extended social insurance coverage to disability, marking the first time that most (but not all) workers were protected against the vagaries of injury and illness. Even then, the new Social Security Disability Insurance program was a strict one, limited to workers over age fifty who had been rendered completely and permanently unable to work with no provision made for temporary sickness or partial disablement.

Disability benefits have come a long way from these modest beginnings. Throughout the 1960s, Congress raised the value of disability payments, dropped the age restriction, covered impairments that were not permanent but lasted longer than one year, reduced the length of time a worker had to be employed before he qualified, and extended public health insurance to some people with disabilities. In 1972, lawmakers expanded cash assistance to disabled adults and children living in poverty. Not surprisingly, in the decades since, spending for entitlements for the disabled has soared, and the programs have grown to encompass larger numbers of younger workers, children, and people with mental disorders—groups that were only a marginal part of early programs. Today benefits for the disabled represent one of the fastest growing segments of the social safety net. As a result, the pendulum has swung from largesse to circumspection. Politicians who once worried about deserving individuals being turned away now fret that too many people who enter the rolls are not really disabled at all.

What is so remarkable about this transformation in social welfare policy is that the years since 1970 hardly seem a time to expect liberal policy change. The era saw the resurgence of a staunchly conservative Republican Party and increasing public doubts about governmental activism. During this time, maturing entitlement programs and slower economic growth enhanced fiscal pressures for spending cuts, and the optimism that launched the War on Poverty in 1964 gave way to dramatic efforts in the late 1970s to scale back the reach of most social welfare programs.² When Democrats in the 1990s adopted a pragmatic approach to antipoverty policy, characterized as a “third way” between the ideological excesses of the Left and the Right, their emphasis on promoting employment and ending long-term dependency on the state seemed to make the expansion of social welfare commitments a dubious enterprise.

In this book, I examine how the expansion in disability benefits occurred in this rather inauspicious political climate. I focus attention on the mobilization of people with disabilities under the banner of a new civil rights movement and on the influence this movement had on social welfare policy. More specifically, I explore three related developments. First, I recount how initially disability benefits policy was closely tied to a medical understanding of disability, a policymaking framework that kept benefit programs limited to a relatively small number of recipients and, in the eyes of disability rights activists, maintained the isolation and inferior social status of people with disabilities. Second, I show how advocates for the disabled challenged the prevailing medical view of disability, advancing in its place a rights-based understanding of disability that eventually encouraged the expansion of benefit programs. Advocates argued that disability—that is, the inability to work and provide for one’s needs because of a medical impairment—was not an inherent feature of a person, but a socially constructed phenomenon that excused discriminatory treatment against anyone who was physically or mentally different from the able-bodied majority. Insisting that the disabled had a right to take part in mainstream society, advocates pressed for the recognition of employment rights, the creation of accessible transportation systems and buildings, and the deinstitutionalization of mental patients. Seizing on the idea of social inclusion, some antipoverty and disability advocates sought to end the “warehousing” of the disabled poor in state residential

2. Thomas Bryne Edsall and Mary D. Edsall, *Chain Reaction: The Impact of Race, Rights, and Taxes on American Politics* (New York: Norton, 1992), and Michael B. Katz, *The Undeserving Poor: From the War on Poverty to the War on Welfare* (New York: Knopf, 1989).

hospitals and group homes and to erect in their place a “new asylum” of income support, health care, and social services. For these advocates, embracing this new rights-based understanding of disability meant that government should not provide income support programs for the disabled because people with disabilities were automatically and utterly incapable of caring for themselves, but because such programs would allow the disabled to live a life of dignity and autonomy within their home communities alongside the able-bodied. Finally, I explain how advocates incorporated their new views into policy, leading to an expansion of disability benefit programs, and why conservatives could not halt program growth but were able to block the establishment of the broad social safety net that advocates for the disabled hoped would make full community integration possible.

This perspective on policy change is fundamentally political. It emphasizes the central importance of conflicting ideas about disability, the strategies and tactics of advocates, and the political hurdles that the advocates had to overcome. This political interpretation is a different approach than that taken by much of the literature on disability benefits policy. There, scholars assume that there is no political conflict because everyone agrees that the disabled deserve social assistance, or they give politics only a brief mention, focusing instead on the economic or demographic reasons for program change. While these approaches have merit, they cannot account fully for the scale of innovation that has taken place in income support programs for the disabled. It is not simply the case that the program expansion was “natural,” the expected outcome of increases in the size of a program’s target population or inflation. Instead, the expansion was “real” in the sense that it resulted from purposeful policy actions designed to “enlarge the scope or function of a program in relation to its social or economic base.”³ Program expansion of this sort is not merely a change in degree. Instead, it represents an effort “to redefine the relationship” between government and the private sector and “an aspiration for change in the institutions and processes as well as the substance and direction” of policy.⁴ Because I seek to explain program change that cannot be accounted for by quantifiable trends, understanding this sort of real growth requires an approach that is, at bottom, historical and qualitative. I focus on the mobilization of social movements, watershed political events, and departures from the policy norm rather

3. Martha Derthick, *Policymaking for Social Security* (Washington, DC: Brookings Institution Press, 1979), 295.

4. Richard A. Harris and Sidney M. Milkis, *The Politics of Regulatory Change: A Tale of Two Agencies*, 2d ed. (Oxford: Oxford University Press, 1996), 23.

than shifts in the population or labor market. I attend not only to variations in the size of benefit programs but also to transformations in their character and meaning over time.

The Quiet Revolution in Disability Benefits

In this book, I concentrate on developments in America's largest disability benefit program, Social Security. Social Security actually includes two programs for the disabled: Disability Insurance (DI) and Supplemental Security Income (SSI). The two programs share the same definition of disability and rules for certification. The difference is that DI is a social insurance program that provides benefits only to workers who have paid into the program's trust fund and to the dependents of those workers. SSI, on the other hand, is a source of cash support for individuals who live in poverty. In addition, how much a worker and his family receive from DI depends on the amount the worker contributed in payroll taxes, while SSI benefits, meager by comparison, are designed only to bring the recipient's income close to the poverty line. By any measure used, DI has expanded significantly since 1956 when Congress agreed to insure workers against the economic risks of disablement. SSI, added in 1972, has also grown by leaps and bounds. As illustrated by figure I.1, the number of persons awarded DI and SSI was especially pronounced in the years 1972–75 and 1984–95. A commensurate increase in program costs matched this expansion in program participation. Total federal and state spending for SSI increased from \$3.8 billion in 1974 to \$35 billion in 2003, with particularly rapid growth taking place during the 1990s. Meanwhile, total spending for DI benefits tripled from \$3.2 billion in 1970 to \$10.4 billion in 1976. By 1986, costs had nearly doubled to \$20.5 billion; they then more than doubled again to \$42.0 billion in 1996. In 2003, spending on benefits for disabled workers and their families reached \$66 billion.⁵

More important than sheer enrollment numbers and expenditure levels, however, were three trends that accompanied growth. First was the fact that this expansion in spending and enrollment did not occur evenly

5. U.S. Social Security Administration, *Annual Statistical Supplement*, 2001, table 4.A2, 152 (hereafter SSA, 2001 Supplement); Program Highlights from U.S. Social Security Administration, *SSI Annual Statistical Report*, 2003, http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2003/index.html#highlights; and Program Highlights from U.S. Social Security Administration, *Annual Statistical Report on the Social Security Disability Insurance Program*, 2003, http://www.ssa.gov/policy/docs/statcomps/di_asr/2003/index.html#highlights.

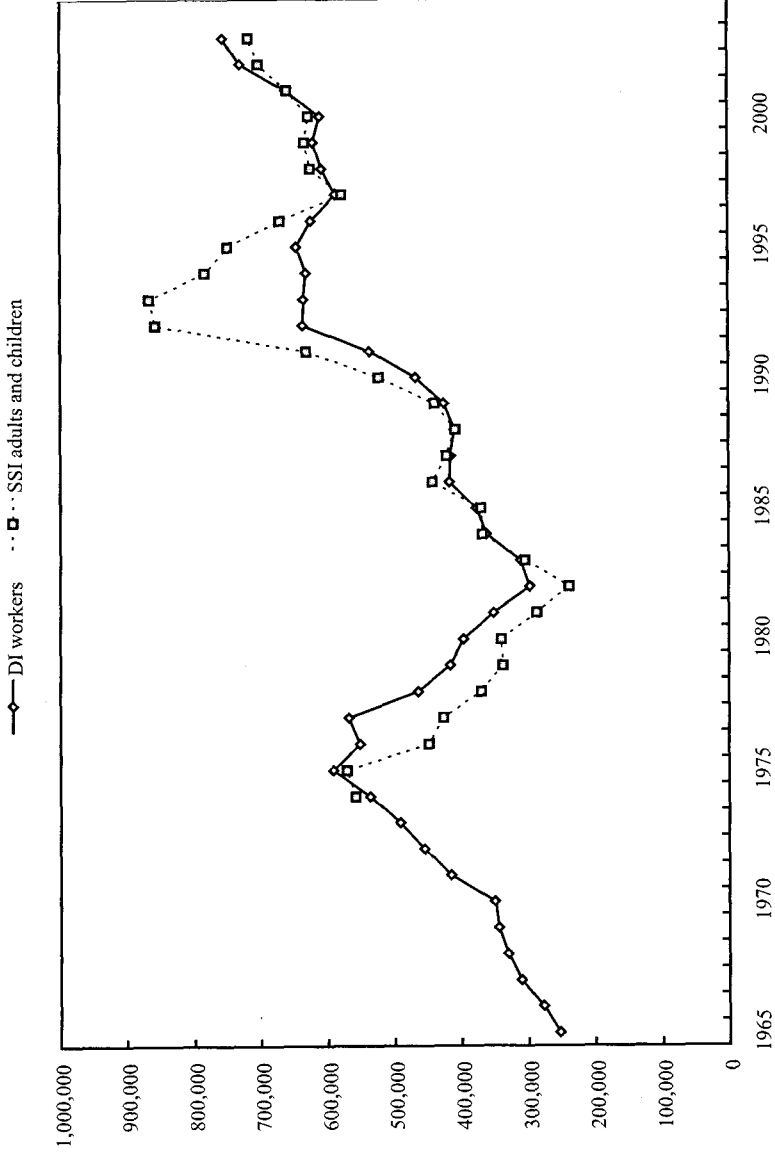


Figure 1.1 Number of Disabled Workers Awarded DI Benefits and Number of Disabled Persons Awarded SSI Benefits by Year, 1965-2003. (Source: For DI, see U.S. Social Security Administration, *Annual Statistical Report on the Social Security Disability Insurance Program*, 2003, table 31, 89; for SSI, U.S. Social Security Administration, *SSI Annual Statistical Report*, 2003, table 47, 105, taking the total awards for all ages and removing those for persons age 65 and older.)

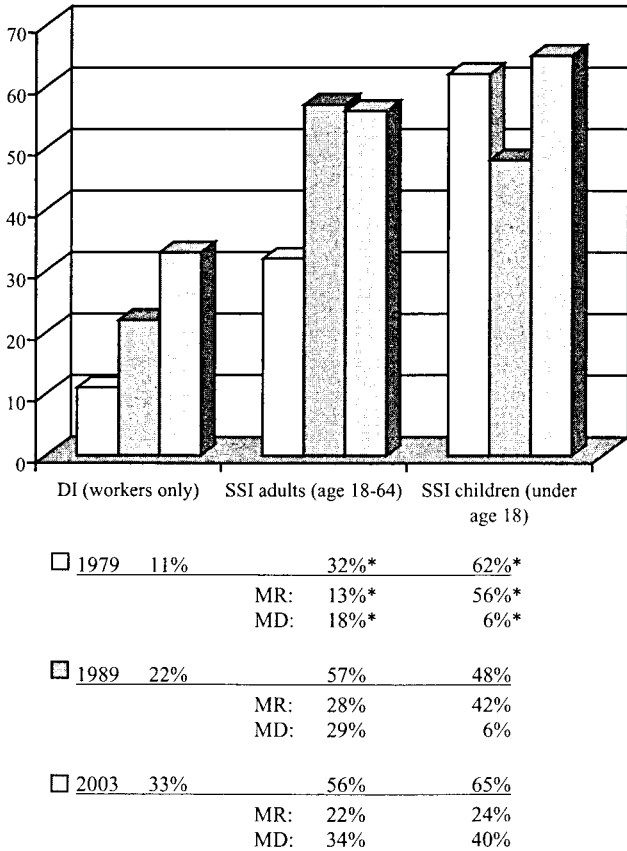


Figure I.2 Proportion of Persons with Mental Retardation (MR) and Other Mental Disorders (MD) on the Social Security Disability Rolls, Selected Years. (Source: For DI, see U.S. House of Representatives, Committee on Ways and Means, *Background Material and Data on Programs within the Jurisdiction of the Committee on Ways and Means (2001 Green Book)*, table I-43, 81, and U.S. Social Security Administration, *Annual Statistical Report on the Social Security Disability Insurance Program 2003*, table 6, 37. For SSI, see U.S. Social Security Administration, *Annual Statistical Supplement*, 1980, table 131, 229; *Annual Statistical Supplement*, 1989, table 9.F1, 336; and *SSI Annual Statistical Report, 2003*, table 25, 57. Figures on the percentage of SSI recipients currently receiving payments by diagnostic category are not available for 1979. Instead, figures presented are for the percentage of awards made that year by diagnostic category.)

among groups of the disabled. Instead, it was concentrated among impairments that are difficult to measure and verify—impairments such as chronic pain, backaches, fatigue, muscle weakness, and anxiety. Mental disorders are the most common of these “soft” impairments. Figure I.2 shows the growth in the proportion of the mentally disabled in the DI and SSI programs over time. Presently, one in three disabled workers and nearly

two out of three SSI recipients suffer from a mental disorder; respectively, these are double and triple the proportions since the 1970s. The prevalence of mental disabilities is even more striking among children enrolled in SSI. Between 1989 and 2001, the proportion of children with a mental impairment grew more than fivefold, increasing from only 6 percent of all children receiving SSI to 32 percent. Today, children and adults with mental disorders outnumber beneficiaries in all other diagnostic categories.⁶

The rising numbers of beneficiaries with mental disorders contributed to a second trend that accompanied the expansion of DI and SSI—that is, the growing presence of younger people on the disability rolls. Because some of the most severe mental illnesses occur in young adulthood and can disrupt education plans and budding careers in a way that will have a lasting impact on future employment prospects, beneficiaries with mental impairments are, on the whole, younger than beneficiaries with other conditions.⁷ Thus, as mental disorders became more prominent on the disability rolls, the age of the typical person receiving disability payments dropped precipitously. Between 1960 and 1993, the average age of workers enrolled in DI fell from 54.5 years to an all-time low of 47.7 years. (It has since rebounded to 51.3 years).⁸ Because SSI pays benefits to children, its recipients, on average, tend to be even younger than DI beneficiaries. Currently, one-third of SSI recipients are under the age of 40 compared to only 14 percent of disabled workers. But even when children are excluded from the calculations, almost twice as many adult SSI recipients as disabled workers are under the age of 40, largely because

6. U.S. Social Security Administration, *SSI Annual Statistical Report*, 2001, tables 45 and 46, 98, 99.

7. Ronald C. Kessler, C. L. Foster, W. B. Saunders, and P. E. Stang, “Social Consequences of Psychiatric Disorders I: Educational Attainment,” *American Journal of Psychiatry* 152, 7 (1995): 1026–32; JoAnne E. Turnbull, Linda K. George, Richard Landerman, Marvin S. Swartz, and Dan G. Blazer, “Social Outcomes Related to Age of Onset among Psychiatric Disorders,” *Journal of Consulting and Clinical Psychology* 58, 6 (1990): 832–39; Ann Vander Stoep, Shirley A. Beresford, Noel S. Weiss, Barbara McKnight, Ana Mari Cance, and Patricia Cohen, “Community-Based Study of the Transition to Adulthood for Adolescents with Psychiatric Disorder,” *American Journal of Epidemiology* 152, 4 (2000): 352–62; and Sue E. Estroff, Catherine Zimmer, William S. Lachicotte, Julie Benoit, and Donald L. Patrick, “‘No Other Way to Go’: Pathways to Disability Income Application among Persons with Severe Persistent Mental Illness,” in *Mental Disorder, Work Disability, and the Law*, ed. Richard J. Bonnie and John Monahan (Chicago: University of Chicago Press, 1997), 61.

8. U.S. Social Security Administration, *Annual Statistical Report on the Social Security Disability Insurance Program*, 2000, table 15, 52 (hereafter SSA, 2000 DI Report), and U.S. Social Security Administration, *Annual Statistical Report on the Social Security Disability Insurance Program*, 2003, table 19, 66.

SSI enrolls a larger proportion of people with mental impairments than DI does and because DI claimants must show a history of employment before they qualify while SSI applicants do not.⁹

The larger proportion of mental disorders and the relative youth of current DI and SSI beneficiaries contributed to a third trend associated with program expansion. Given that persons with mental disorders tend to stay on the disability rolls longer than anyone else, as the average age of beneficiaries dropped, the length of time that the typical beneficiary received disability payments increased.¹⁰ According to Kalman Rupp and Charles Scott, a disabled worker entering Disability Insurance today is expected to collect benefits for an average of 10.9 years, up from an expected duration of 9.5 years in 1975.¹¹ SSI recipients are expected to stay on the rolls even longer. Rupp and Scott estimate that the adults and children presently enrolled in SSI will, on average, spend the next 17.8 years receiving payments.¹²

Taken together, these three trends—the growing prevalence of mental disorders and other soft impairments, the increasing youth of beneficiaries, and longer spells on the disability rolls—add up to administrative and political trouble. In recent decades, the Social Security Administration (SSA) has struggled to find a reliable way of evaluating mental disorders, one that will adequately separate true medical conditions from mere personality flaws. Critics, meanwhile, remain dissatisfied, arguing that people who are found disabled today simply do not meet the strict standard of disability that Congress intended when it created DI in the 1950s. At the same time, given the relative youth of DI and SSI beneficiaries,

9. Author's calculations based on SSA, 2001 Supplement, table 7.E3, 290 (includes aged recipients), and author's calculations based on SSA, 2000 DI Report, table 8, 39.

10. Scott Kochlar and Charles G. Scott, "Disability Patterns among SSI Recipients," *Social Security Bulletin* 58, 1 (1995): 3–14, and Kalman Rupp and Charles G. Scott, "Trends in the Characteristics of DI and SSI Disability Awards and Duration of Program Participation," *Social Security Bulletin* 59, 1 (1996): 3–21.

11. Kalman Rupp and Charles G. Scott, "Determinants of Duration on the Disability Rolls and Program Trends," in *Growth in Disability Benefits: Explanations and Policy Implications*, ed. Kalman Rupp and David C. Stapleton (Kalamazoo, MI: W. E. Upjohn, 1998), table 4.2, 150.

12. Because SSI is a means-tested program, the figures for SSI are arrived at after correcting for exits resulting from income changes rather than recovery, death, or retirement. When exits due to income changes are not taken into account, the average length of stay on SSI is substantially lower, reflecting the volatility in family income of SSI recipients. When the analysis is limited to adult SSI recipients, the average length of stay drops to 11.3 years, still higher than the average duration on the DI rolls but now more closely in line with it. Rupp and Scott, "Determinants of Duration," table 4.5, 159.

some lawmakers have urged the SSA to intensify its rehabilitation and employment support efforts rather than simply send out disability checks. Indeed, some elected officials now worry that the long stretches that DI beneficiaries and especially SSI recipients spend collecting payments will not only encourage long-term “welfare” dependency among the disabled, a term once reserved for single mothers, but also push program costs higher far into the future.

Trying to Explain the Growth of Disability Programs

How did this extraordinary change in Social Security disability benefits take place? Typically, sociologists and economists attribute the growth in benefit programs to increased public demand. This demand, in turn, is the result of either demographic changes or the state of the economy. The two most consequential demographic shifts are the growth of the U.S. population and the “graying” of the Baby Boom generation, both of which are expected to lead naturally to higher incidences of chronic illnesses, limited mobility, and senility. Yet, while population shifts are certainly a factor, the enrollment increases in DI and SSI that occurred during the 1980s and 1990s were far out of proportion with demographic changes. Although the U.S. population increased by 11 percent between 1984 and 1993, the number of DI and SSI recipients grew by 60 percent over the same time period.¹³ In addition, since the 1970s, the most dramatic growth in the Social Security disability programs has taken place, not among beneficiaries nearing retirement, as anticipated, but among younger workers.¹⁴

Economic explanations are, likewise, incomplete. All studies clearly show that when the economy slides into recession, applications for disability payments increase. Though the impact of unemployment varies widely from study to study, none have found the opposite effect.¹⁵ Much

13. U.S. Congressional Research Service (CRS), prepared by David Koitz, Geoffrey Kollman, and Jennifer Neisner, *Status of the Disability Programs of the Social Security Administration*, 1992, 51.

14. Between 1980 and 1990, the median age of the population rose from 30.0 to 32.9 years old, an increase attributable in large part to longevity among the oldest cohort. These individuals, however, tend to receive Social Security retirement pensions rather than disability payments. In the age brackets where dependence on disability pensions is expected to be the most pronounced, age 50–64 years, the population actually fell, reflecting the low birth rates of the 1930s. *Ibid.*, 3 n. 5.

15. A review of studies that have investigated the effect of the unemployment rate on the Social Security disability programs can be found in Kalman Rupp and David C. Stapleton, Introduction to *Growth in Disability Benefits*, ed. Rupp and Stapleton, 15–16.

more muddled, however, is the relationship between unemployment and the number of applications actually approved for benefits. Historically, economic changes track imperfectly the trends in awards. For example, enrollment in the Social Security disability programs was far below what economists would have predicted during the recessions of 1980 and 1981–82. On the other hand, increases in DI and SSI enrollment continued well after the 1990–91 recession ended.¹⁶ Noting that unemployment had receded by 1993 while enrollment in SSI and DI still stood at an “all-time high,” congressional researchers argued that “it would be misleading to conclude that the dominant factor behind recent growth . . . was a poor economic picture.”¹⁷ Moreover, studies found that during the economic boom of the mid to late 1990s, the employment rate for persons with disabilities declined significantly even though employment increased for the general population. This decline occurred despite the fact that the enactment of the Americans with Disabilities Act (ADA) in 1990 was supposed to have opened the workplace to the disabled and ended their need to depend on welfare.¹⁸ In short, employment of the disabled, enrollment in disability benefit programs, and the state of the economy remain rather loosely related.

Concentrating primarily on explaining the growth that took place between 1980 and 1994, a study conducted by David C. Stapleton and his colleagues placed these social and economic conditions in context. Accounting for the effect of population growth, the aging of the population, unemployment, economic restructuring, cuts in state general assistance programs, the HIV/AIDS epidemic, and rates of immigration and poverty, the researchers concluded that the three major reasons for the growth of the programs after 1989 were the 1990–91 recession, efforts by state and local governments to shift the costs of welfare spending onto federal programs, and changes in the “supply” of benefits. With their model, Stapleton and his colleagues could explain almost half the annual increases in applications filed for DI and SSI, but they found it much more difficult to account for the increasing share of applications approved for payment. Altogether their variables accounted for one-

16. David Stapleton, Kevin Coleman, Kimberly Dietrich, and Gina Livermore, “Empirical Analysis of DI and SSI Application and Award Growth,” in *Growth in Disability Benefits*, ed. Rupp and Stapleton, 56–58.

17. CRS, *Status of the Disability Programs*, 51.

18. Richard V. Burkhauser, Andrew J. Houtenville, and David C. Wittenburg, “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*, ed. David C. Stapleton and Richard V. Burkhauser (Kalamazoo, MI: W. E. Upjohn Institute, 2003), 72–73.

quarter of the annual growth in awards for DI but just 7 percent of the annual growth in SSI awards. The model also was unable to explain a large proportion of the growth in applications from workers under the age of fifty, persons with mental disorders or musculoskeletal impairments, and individuals claiming SSI. Yet these were the very groups of the disabled that most interested policymakers, because they represented the most rapidly increasing parts of the Social Security disability programs.¹⁹ Stapleton and his colleagues attributed the growth that they could not explain to changes in policy, changes that encouraged individuals to apply for benefits and administrators to grant awards. Though these factors were exceedingly difficult to measure with the same precision as economic factors were, the researchers concluded that they undoubtedly mattered.²⁰

While theories that focus on population shifts and labor market transformations explain an important piece of the puzzle, these approaches are incomplete. Because politics is outside the purview of these researchers and because policy changes are difficult to measure in a quantitative manner, one is left with the impression that the programs serve only as conduits through which larger changes in the population or business cycle are translated into policy outcomes. How these social conditions are mediated by governing institutions, political actors, and even the programs themselves remains obscured. Disability programs, however, are far from static, black boxes, automatically converting external inputs into policy outputs. On the contrary, they are politically dynamic and highly responsive to legislative, judicial, and administrative actions. As congressional researchers have noted, “the programs’ volatility probably results from . . . what many view as subtle rule and process changes.”²¹ Though seemingly small and inconsequential, these “subtle rule and process changes” have had a profound and far-reaching impact on disability programs.

In this book I emphasize the central importance of political contests regarding the meaning and scope of disability. Of course, given the com-

19. Stapleton et al., “Empirical Analysis,” 71–74, and Exhibit 2A.4, 92.

20. *Ibid.*, 72, 74–75. Similarly, two researchers trace rising levels of unemployment among people with disabilities to the policy liberalizations made to DI in the 1980s and 1990s. See Nanette Goodman and Timothy Waidmann, “Social Security Disability Insurance and the Recent Decline in the Employment Rate of People with Disabilities,” in *Decline in Employment of People with Disabilities*, ed. Stapleton and Burkhauser, 339–68. See also Richard V. Burkhauser and David C. Stapleton, “A Review of the Evidence and Its Implications for Policy Change,” in *Decline in Employment of People with Disabilities*, ed. Stapleton and Burkhauser, 389–93.

21. CRS, *Status of the Disability Programs*, 53–54.

plexity of a phenomenon like disability, complete explanations are likely to be multifaceted.²² Political interpretations, therefore, are best seen as a complement to, rather than a competitor with, social and economic analyses. My intention is not to displace these theories but to enhance them with an approach that is decidedly political and that accounts for program expansion that cannot be accounted for by the conventional explanations. Only by turning our attention to how program rules and processes are shaped by political conflict can we make sense of the vast changes that have occurred and continue to occur in disability and social welfare policy.

Why Study the Politics of Disability

Ideally, political scientists would balance the attention that economists and demographers place on quantifiable economic and social factors with comparable attention to the political origins of the growth in disability benefits programs. This has not been the case, however. Political scientists rarely examine disability as an important chapter in the development of American social welfare policy. There are two reasons for this neglect. First, disability is an exceedingly complex policy area, which until recently discouraged interest in its politics. Spread over law, economics, sociology, rehabilitation studies, and medicine, issues of disability have spawned a thicket of policy complexities that few have dared to tread. As historian Edward Berkowitz points out, disability policy is a jumble of disconnected programs “born in many different eras,” frequently working at odds with one another and “reflect[ing] many styles of policymaking.” Workers’ compensation, veterans’ pensions, special education, health care, civil rights, income-support, and legal torts all address disability issues. Yet they are seen as separate and discrete policy areas and rarely viewed as a whole.²³ One observer declared in frustration, “From

22. Other reasons suggested for the growth in DI and SSI in the early 1990s are structural changes in the economy that had a particularly adverse impact on the employment opportunities of the disabled, the lack of any other income support available for people with disabilities, and the incentives to enroll provided by the linking of disability benefits to public health care coverage. Edward Yelin, *Disability and the Displaced Worker* (New Brunswick, NJ: Rutgers University Press, 1992); Richard V. Burkhauser, Robert Haveman, and Barbara Wolfe, “How People with Disabilities Fare When Public Policies Change,” *Journal of Policy Analysis and Management* 12, 2 (1993): 251–69; and Aaron Yelowitz, *Why Did the SSI-Disabled Program Grow So Much? Disentangling the Effect of Medicaid* (Cambridge: National Bureau of Economic Research, 1997).

23. Edward D. Berkowitz, *Disabled Policy: America's Programs for the Handicapped* (Cambridge: Cambridge University Press, 1987), 1.

this welter of programs, no policy emerges, only inconsistency and conflict.”²⁴ Trying to make sense of this morass is exceedingly difficult, and the need to master countless medical and legal concepts and the details of the many disparate programs that comprise our nation’s disability policy poses a formidable challenge. Scholars are deterred from tackling the subject, which, more often than not, has been left to specialists whose technical language has obscured broader political trends. As a result, “disability has not received the attention it deserves as a policy problem.”²⁵

The second reason that the politics of disability have not received the scholarly consideration it warrants is because political scientists are generally interested in explaining controversy, and they see very little of it in disability programs. The literature on American social welfare policy draws a sharp distinction between programs for the deserving poor and those for the undeserving poor. The latter receives a great deal of attention, and indeed, much of what we know is based largely on studies of Aid to Families with Dependent Children (AFDC, now called Temporary Assistance for Needy Families or TANF), the cash assistance program that most Americans had in mind when they used the word “welfare” in its most pejorative sense. But as Steven Teles points out, the politics of family assistance is not indicative of the broader patterns of welfare state politics in the United States. “AFDC is different,” he explains. “No other program of the American welfare state is so unpopular.” No other program raises, to the same degree, the acrimonious issues of race, gender roles, and sexual and personal responsibility. Turning his attention to the other programs that comprise America’s social safety net, Teles notes, “Although there are occasional political debates about these parts of the original American welfare state, they are for the most part uncontroversial and politically stable.”²⁶ Yet scholars tend to dismiss these programs, including programs for the disabled, as requiring little critical scrutiny

24. Editorial introduction to “The Right to an Adequate Income and Employment,” in *The Mentally Retarded Citizen and the Law*, ed. Michael Kindred, Julius Cohen, David Penrod, Thomas L. Shaffer, report sponsored by the President’s Committee on Mental Retardation (New York: Free Press, 1976), 271.

25. Berkowitz, *Disabled Policy*, 225–26.

26. Steven Teles, *Whose Welfare? AFDC and Elite Politics* (Lawrence: University Press of Kansas, 1994), 1, 2. Robert Greenstein, in fact, points out that contrary to what many scholars write about means-tested programs, many including the Earning Income Tax Credit, SSI, Food Stamps, and Medicaid have been quite resilient in the face of retrenchment. See Robert Greenstein, “Universal and Targeted Approaches to Relieving Poverty: An Alternative View,” in *The Urban Underclass*, ed. Christopher Jencks and Paul E. Peterson (Washington, DC: Brookings Institution Press, 1991), 437–59.

because they are targeted at a group that everyone agrees merits social assistance. Supposedly, there is no political conflict to explain.²⁷

Scholars connect the privileged moral status of the disabled to American cultural values prizing hard work and self-sufficiency. Government programs use administrative categories like disability or age as mechanisms to enforce social judgments about who should work and who is allowed to receive social aid. Only those individuals who are considered infirm are entitled to assistance; all others must find employment. According to this line of reasoning, because their medical condition renders them functionally incapacitated, the disabled are not expected to work, and since their infirmity is not their fault, providing social assistance to them does not violate social norms.²⁸

Applying this simplistic distinction, scholars find it all too easy to account for policy outcomes. For instance, Daniel Patrick Moynihan noted that in 1972, federal aid to the elderly and disabled poor easily passed Congress while reforms designed to enhance assistance to poor families collapsed. The reason, he wrote, “was not only a matter of equity but of politics”: The elderly and disabled “were the ‘deserving poor,’ and they were voters”; poor mothers and their children were neither.²⁹ Striking a similar refrain, historian Walter Trattner dismissed the enactment of SSI as nothing more than an effort targeted at individuals “who are clearly unemployable,” thus demonstrating “the lasting strength of America’s work ethic.”³⁰ Likewise, Paul Pierson notes that in the United States and Great Britain conservative attempts in the 1980s to cut disability programs faltered because “few groups are more deserving of public support than the sick and disabled.”³¹ But he goes no further in explaining how the deservingness of the disabled is translated into the political clout necessary to withstand retrenchment pressures.

No doubt, to the extent that the American people and politicians make judgments about the moral worth of supplicants for social assistance, no-

27. Arthur W. Blaser, “Taking Disability Rights Seriously,” *New Political Science* 25, 4 (2003): 594.

28. Lance Liebman, “The Definition of Disability in Social Security and Supplemental Security Income: Drawing the Bounds of Social Welfare Estates,” *Harvard Law Review* 89, 5 (1976): 853. See also Deborah A. Stone, *The Disabled State* (Philadelphia: Temple University Press, 1984), 15–28.

29. Daniel Patrick Moynihan, *The Politics of a Guaranteed Income: The Nixon Administration and the Family Assistance Plan* (New York: Vintage, 1973), 198.

30. Walter I. Trattner, *From Poor Law to Welfare State: A History of Social Welfare in America* (New York: Free Press, 1974), 271.

31. Paul Pierson, *Dismantling the Welfare State? Reagan, Thatcher, and the Politics of Retrenchment* (Cambridge: Cambridge University Press, 1994), 139.

tions of deservingness are worth taking into consideration. But a stark dichotomy is too simplistic. To begin with, the emphasis placed on deservingness treats disability as a monolithic category when, in fact, impairments are diverse in nature and their relative deservingness is equally as varied. People in wheelchairs are regarded as the deserving disabled by most Americans, but mental disabilities, childhood behavioral and learning disorders, and chronic pain are poorly understood impairments that elicit as much skepticism as they do empathy. Indeed, the disabled often encompasses individuals whom most of us might judge as decidedly undeserving—drug addicts, alcoholics, troubled children, and persons with personality disorders, for instance. Moreover, far from being fixed, the distinction between the deserving and undeserving varies over time. Old age, disability, and childhood are valid reasons to stay out of the labor market, and the old, disabled, and children are supported by public assistance or private charity. Motherhood once was seen this way, too, but this exception is hotly contested today, particularly in the case of single mothers living in poverty. The boundaries of deserving categories are often uncertain as well. Age is easy to determine, but there is no widely accepted definition of “disability.” The condition can easily be feigned, and because different people have different ideas about what constitutes a disability, even well-intentioned individuals using the same standards find it difficult to reach the same conclusion in specific cases.³² Disability, in short, is inescapably subjective, and attention to these issues soon reveals that who is “clearly employable” and who is deserving of social assistance is not necessarily so clear a demarcation after all.³³

Although boundary questions are resolved for the time being when programs are enacted and legal definitions crafted, the subjective nature of disability opens the door to recurring political contests during the administration and amendment of programs. So while judgments of moral worth no doubt matter, policy outcomes are not simply the straightforward consequence of those judgments. Focusing exclusively on a specific group’s moral worth fails to examine how government policies and political debate shape our understanding of deservingness. The delineation of this crucial distinction—who is deserving and who is not—is a decidedly

32. Stone, *Disabled State*, 23.

33. See, among others, Liebman, “Definition of Disability,” 833–68; Stone, *Disabled State*; Claire H. Liachowitz, *Disability as a Social Construct: Legislative Roots* (Philadelphia: University of Pennsylvania Press, 1988); Matthew Diller, “Entitlement and Exclusion: The Role of Disability in the Social Welfare System,” *UCLA Law Review* 44 (1996): 361–465; and Lars Noah, “Pigeonholing Illness: Medical Diagnosis as a Legal Construct,” *Hastings Law Journal* 50 (1999): 241–307.

political enterprise, one that reveals a great deal about the ideas that animate American antipoverty efforts.

Readers familiar with the literature on disability will immediately recognize my argument as reminiscent of Deborah Stone's seminal work on disability policy, *The Disabled State*.³⁴ Seeking to explain the puzzle of program expansion, Stone argues that the pressure for liberalization is, to a great degree, inherent in the nature of disability benefit programs. While government programs attempt to ground disability on something objective, such as the presence of a medical illness or injury, the condition is intrinsically subjective. Consequently, no matter how tightly policymakers try to define disability, as an administrative category, disability is elastic; it can be stretched or contracted over time. Yet restrictive disability programs require constant vigilance against lax interpretations of disability as well as against those applicants who would feign the condition for pecuniary gain while expansive pressures continually emanate from the political, legal, and social contexts. Thus, in all nations, the trend has been inexorably in the direction of programmatic growth regardless of time or place.

This book serves as a complement to *The Disabled State*. Taking Stone's analysis of the subjectivity of disability as a starting point, this study investigates the specific actions political actors and interest groups undertook in their efforts to mold the interpretation of disability to serve their policy ends. Stone argues that disability as an administrative concept is inherently expansive; this study analyzes how advocates took advantage of this conceptual opening.

Incorporating a deeper understanding of disability into our picture of the American social welfare policy serves a much-needed corrective purpose. Scholars have long compared programs in the United States to the extensive welfare states of Western Europe and found America wanting. The possible reasons for this disparity are many, ranging from theories that point to the weakness of the labor movement in the United States, the lack of a political voice among the poor, the disruptive effects of race on efforts to build coalitions between poor and working class citizens, and institutional obstacles—such as the Senate filibuster, the presidential veto, and the tradition of judicial review—which allow small but well-organized conservative groups to block popular legislative initiatives.³⁵

34. Stone, *Disabled State*.

35. For a review of the various explanations of American welfare state development, see Edwin Amenta and Theda Skocpol, "States and Social Policies," *Annual Review of Sociology* 12 (1986): 131–57; Jill Quadagno, "Theories of the Welfare State," *Annual Review of Sociology* 13 (1987): 109–28; Hugh Hecl, "The Political Foundations of An-

The common thread behind these scholarly works is the premise that the American welfare state is a failure or, at best, an unrealized project. Rather than a universal welfare state that aids all (or most) citizens as a matter of right, the United States is stuck with a residual welfare state, one that does little to redistribute resources equitably among rich and poor and that provides only the bare minimum (if that) to citizens who fall through the cracks of the market-driven economy.

This book is different. I contend that what is exceptional about the United States is not its failure to conform to a specified trajectory of welfare state advancement but instead the peculiar way in which policy is made. Explanations that focus primarily on political constraints do little to account for those instances when progressive reformers triumphed despite the odds, other than to view them as unusual and infrequent events. I argue, however, that in many ways the United States is particularly open to the demands of organized interests, including liberal public interest groups representing weak and marginalized people, like the disabled. Throughout the book, I examine the struggle of advocates to circumvent institutional barriers and ideological opposition in order to end discrimination against the disabled and further their integration into mainstream society. But I also consider how the American attachment to work and self-sufficiency, the shift of American politics to the right in the late 1970s, and the fragmentation of its governing institutions shaped and ultimately constrained the effectiveness of these advocacy efforts. What emerges from this analysis of disability policy is a richer picture of social welfare politics than admitted by simplistic characterizations of the United States as a welfare laggard.

The Plan of the Book

In order to illustrate the ebbs and flows of social welfare and disability politics, I examine Social Security and disability rights policy from the 1960s to the present. This period begins with the federal government assuming greater responsibility for poverty and economic inequality in the 1960s and early 1970s and ends with policymakers placing increased emphasis on ending dependency and scaling back social welfare spending in

tipoverty Policy,” in *Fighting Poverty: What Works and What Doesn't*, ed. Sheldon H. Danziger and Daniel H. Weinberg (Cambridge: Harvard University Press, 1986), 312–40; and Francis Fox Piven and Richard Cloward, *Regulating the Poor: The Functions of Public Welfare*, 2d ed. (New York: Vintage, 1993).

the late 1990s. I argue that policy decisions made in the 1950s as disability was added to the array of risks covered by social insurance set the limits within which future welfare and disability reform would take place. By defining disability as a medical condition that precluded work, policymakers erected a set of institutions that was not easily adapted to the “human rights” or “social” model of disability championed in the 1970s by advocates seeking to overcome the exclusion and secondary social status of the disabled. Still, even within these constraints, advocates were able to open Social Security to previously excluded groups of the disabled by taking advantage of judicial activism and congressional deadlock. But the reform interpretation of disability, which I call the “functional approach,” made peace with rather than challenged Social Security’s medicalized notion of disability. The key difference between the medical model and functional approach was that the functional approach allowed maladaptive and inappropriate behaviors to qualify as disabilities while the medical model often demanded more rigorous evidence in the form of clinical observations or laboratory tests. Because the functional approach took an expansive view of disability, advocates then sought to apply it to DI and SSI in order to bring more people under the protective umbrella of the welfare state. Their goal was to transform Social Security from a strictly compensatory program for middle-class workers into a safety net for disadvantaged persons with disabilities, many of whom were plagued by mental impairments that were not easily measured according to clinical criteria. Nevertheless, advocates did not entirely displace the medical paradigm. Rather than argue that disability was a social construct—a key underpinning of the rights model—the functional approach accepted that medical impairments were inherently debilitating and limiting, a compromise that, as I explain in later chapters, left policy reform incomplete.

In chapter 1, I begin with a discussion of the political and policy environment that served as the backdrop to efforts to restructure disability and social welfare policy. I highlight the shifts in the ideas that framed how society approached the problem of disability, transformations in American politics that made government accessible to newly mobilized disability groups, and the conditions that set limits on the ability of the advocates to realize their larger policy goals. I focus on the factors that leave American government open to initiatives of reform-minded actors as well as those that continue to frustrate their ambitions.

In chapter 2, I describe the advocates who are the protagonists of this political history. I trace their origins to the disability rights movement of the late 1960s and early 1970s. Or perhaps, I should say “movements,”

for as I make clear, the disability rights movement was actually a banner encompassing smaller movements of people with disabilities, including the patients' rights movement and the independent living movement. Not all activists were of the same mind regarding what policy reforms would best bring an end to the many disadvantages that the disabled confronted. Nevertheless, what activists shared in common was a strong belief that people with disabilities had a right to social inclusion—that is, the right to be full participants in the social life of their communities as equals with able-bodied people. Social inclusion, however, meant the ability to live free of the confines of residential hospitals and other medical institutions, and this required the establishment of a broad social safety net of income support, assistive services, and health care. I illustrate how advocates for mental patients drew from these new ideas about disability to argue for a shift from asylums toward community mental health care. I trace how the interest that patients' rights reformers had in community mental health care inspired their antipoverty activism and ultimately led them to organize around Social Security issues.

In chapter 3, I turn the focus from social movements outside of government to policy entrepreneurs within government. While advocates were formulating their plans for an expanded system of social supports for disabled people, a small circle of executive officials and lawmakers made it happen by pushing the Supplemental Security Income program through Congress in 1972. The irony, however, is that though SSI eventually became a vital part of the social safety net that advocates envisioned, neither they nor their rhetoric of disability rights had anything to do with the program's passage. SSI became law precisely because it was not framed as a rights or a disability issue, thus underscoring the difficulties disability advocates would face in creating a broad safety net based on the principle of inclusion. I explore why elected officials created SSI despite the fact that the disabled did not demand it as well as how the program opened Social Security policymaking to previously excluded groups of the disadvantaged disabled. As I explain, SSI inadvertently pushed Social Security policy toward the expansive understanding of disability that the advocates favored and became a cornerstone of the social safety net they hoped to erect.

In chapter 4, my narrative moves from the liberal confidence that characterized the years of the Great Society and the early years of the disability rights movement to the fiscal austerity and cost consciousness of the Carter and Reagan years, and shows how advocates traversed this adverse setting. I explain why advocates turned their attention from disability rights and patients' rights to Social Security and how they sought to re-

orient the program to serve the needs of the deinstitutionalized and disabled poor. I recount the frustrations advocates faced as President Reagan attempted to retrench social welfare programs across the board and the strategies they used to resist these moves.

In chapters 5, 6, and 7, I examine the strategy of the advocates and their opponents across three political forums: litigation, legislation, and administration. In chapter 5, I look at the role that federal judges played in shielding DI and SSI from budget cuts and pushing the boundaries of the programs beyond the strict medical interpretation of disability that Congress had sanctioned when it first created DI in the 1950s. Covering the years between 1982 and 1991, I explain how the federal courts were politicized by the Reagan administration's retrenchment efforts and why judges were receptive to the advocates' arguments for program expansion.

In chapter 6, I focus on how Congress dealt with social welfare and disability policies in light of the demands made by advocates. I explain why, throughout the mid and late 1980s, conservatives could not halt the judicially driven program expansion nor could liberals muster enough political support to build legislatively on the court decisions. With Congress deadlocked and divided until the mid 1990s, advocates were nonetheless adept at locking in the gains they had made in the courts and sneaking additional expansive measures past skeptical lawmakers. Judicial activism, cost-shifting by state governments, and administrative reforms pursued by sympathetic bureaucrats at the Social Security Administration facilitated program expansion even in the absence of congressional agreement. In addition, I examine why, despite their success with Social Security, advocates failed to build congressional support for a comprehensive system of income support and social services for disabled people living in the community. I trace this failure, in part, to the fight to win the enactment of another prize sought by the disabled community, the Americans with Disabilities Act, a broad bill designed to guarantee equal access rights for people with disabilities.

In chapter 7, I consider developments within the Social Security Administration that helped the advocates further open DI and SSI to deinstitutionalized adults and children. I chronicle how between 1985 and 1991 the SSA translated judicial and congressional decrees into administrative rules and practices that ultimately pushed program expansion even further than the courts or Congress anticipated. I also examine why these reforms to DI and SSI led to administrative breakdown and controversy by the early 1990s.

By 1993, with the Social Security disability programs growing rapidly

and clearly in disarray, lawmakers tried to assert order and arrest the rising tide of disability claims. In chapter 8, I examine conservative efforts to roll back the liberalizations of the 1980s and early 1990s. Although retrenchment proponents were able to make significant headway, they were unable to realize their more far-reaching ambitions. In fact, many of the liberalizations that advocates had achieved remained embedded in administrative rules and practices, sheltered from the reach of opponents. The chapter explains why retrenchment proponents were able to scale back some aspects of DI and SSI while leaving others untouched.

Finally, in the conclusion, I balance the ledger by turning attention from the advocates' triumphs to their disappointments. While advocates were able to expand the DI and SSI programs, their larger hopes of an extensive array of community clinics, health care benefits, income support, sheltered work programs, and social services was not to be. This chapter explains why advocates were unable to bring about more expansive reforms to American social welfare policy. I argue that the most significant limitation advocates confronted emerged out the interaction between their strategic choices and the political climate in which they operated. Because no institution wholeheartedly supported their quest for social inclusion, advocates framed the establishment of employment and equal access rights as an alternative to spending for entitlements. Thus, policymakers, even some activists themselves, came to see disability rights and social welfare assistance as mutually exclusive policy approaches, a development that undercut the logic for a comprehensive social safety net. As a result, many individuals with disabilities still remain vulnerable to joblessness, poverty, and social isolation. This chapter shows what advocates lost in their drive for disability rights, as institutional constraints compromised their efforts, and by turning attention to the more comprehensive policies of Western Europe, it attempts to shed light on the possibilities for American disability policy.

A Word on Studying Social Security and Disability

Although there are more than seventy federal programs targeted at people with disabilities, I focus on Social Security's Disability Insurance and SSI programs. I chose these two programs because their size and scope make them important in their own right. Unlike the many smaller income support programs targeted at specific occupational groups, DI and SSI are open to the public, thus making them the largest of the disability benefit programs. Excluding outlays for health care, DI and SSI together

account for almost three-quarters of the federal government's annual spending for disability programs. No other program comes close to rivaling their size regardless of whether the measure is total persons enrolled or annual expenditures.³⁶ Also, because eligibility for disability benefits is tied to eligibility for public health care programs, growth in these two programs drives up spending for Medicare and Medicaid as well. What happens in Social Security disability policy, therefore, has considerable fiscal consequences for the other parts of our nation's welfare state.

In addition, the fact that DI and SSI are individual entitlements brings to the fore the importance of categorical boundary drawing. Unlike discretionary programs, entitlements are "legal obligations that require the payment of benefits to any person . . . that meets the eligibility requirements established by law."³⁷ Thus, each person who satisfies Social Security's eligibility requirements is entitled to benefits regardless of cost. How much the federal government spends in a given year is determined by how many persons qualify and how the benefit payments are calculated rather than by annual congressional appropriations. Consequently, lawmakers cannot hold the line on program growth by simply capping spending, as they might for community mental health programs and other social services block grants. If Congress wants to limit the number of persons on the Social Security disability rolls, it must tighten the standards used or change the formula for computing benefit levels. As a result, the categorical boundary of disability—that is, how disability is defined statutorily and administratively—emerges as vitally important in regulating the scope of the DI and SSI programs. This book explores how this boundary is drawn and redrawn over time.

Furthermore, although the range and types of impairments is vast, this study concentrates on programmatic growth in the following three areas: (1) adults with mental disorders, (2) children with disabilities, and (3) adults disabled by alcoholism or drug addiction. There are two reasons for this approach. First, by looking specifically at these groups, I can evaluate how notions of moral worth are disputed and refined through politics. Although the disabled are widely regarded as deserving of social assistance, the mentally disabled, substance abusers, and disabled children—at least those children with emotional, learning, and behavioral problems—put this assertion to the test. Moreover, these groups are

36. U.S. General Accounting Office, *Adults with Severe Disabilities: Federal and State Approaches for Personal Care and Other Services*, HEHS-99-101, 1999, 2.

37. Aaron Wildavsky, "The Politics of the Entitlement Process," in *The New Politics of Public Policy*, ed. Marc K. Landy and Martin A. Levin (Baltimore: Johns Hopkins University Press, 1995), 143.

what make disability benefits controversial. Of all the diagnostic groups eligible for Disability Insurance and SSI, mental disorders, childhood disabilities, and substance addiction grew the fastest during the 1980s and 1990s. This development defies conventional wisdom since program expansion has taken place precisely among those groups of the disabled whose status as “deserving” is most vigorously contested. Singling out these three groups, therefore, takes us into those aspects of policy that have been at the forefront of political conflict.

Of course, there are other areas of disability that are not explored in this book. For example, the number of claims filed for musculoskeletal impairments, like chronic back pain, and infectious diseases, in particular HIV/AIDS, has grown rapidly in recent years. But I do not examine advocacy on behalf of individuals with these impairments. Thus, it is possible that by focusing on mental disability, addiction, and childhood disability, I present a picture of policy reform that is exaggerated in its coherence. Indeed, deinstitutionalization and the patients’ rights movement may have given advocates for children and the mentally disabled an integrity and consistent rationale that representatives for other impairments lacked. Other areas of disability may not be as well organized as they were, and groups in those areas perhaps did not draw on the same ideas or use the same tactics as the advocates in this study do.

With these caveats in mind, I still believe that the advantages of focusing on these three groups outweigh the shortcomings. I am explaining the increase in disability awards and expenditures that cannot be accounted for by the standard statistical studies. Thus, rather than examine a large sample of individual cases covering all impairment groups, I have chosen to concentrate on those that will allow me to explore more fully and intensely the connections between advocacy movements, political institutions, and ideas. In addition, I do not necessarily try to present a picture representative of all disability groups so much as I strive to cover the central issues at the crossroads of disability and social welfare politics. To the extent that mental disorders, addictions, and childhood disabilities represent the largest, the fastest growing, and the most controversial aspects of the Social Security disability programs, these areas are most indicative of the political debate surrounding disability and welfare issues. Where appropriate, however, I draw connections between Social Security and additional disability and social welfare programs. The purpose of this two-track approach is to give the reader the rich detail necessary to comprehend how policy reforms occurred while at the same time arrive at an appreciation of the larger political forces driving social policy making.