

13. Why I Burned My Book

One afternoon in 1992, I sat in a large wood-paneled seminar room in Stanford University's History Corner. One of the doctoral students gave an interesting talk on mid-twentieth-century U.S. welfare policies, following which the group of faculty and graduate students discussed the history of American welfare. As I listened, it struck me that no one seemed to have much sense of what it was really like to "be on welfare." I wondered if I were the only person there who had actually had that experience. It has often occurred to me that the same lack of direct experience has hobbled the study of disability in general and disability policy in particular, though few scholars in these fields seem aware of that limitation.

My own interest in disability policy and its history grew partly out of the impact of public policies on me personally. The ways in which policy construed "disability" severely constricted my life and work. That direct encounter with the implementation of disability policies not only spurred me to investigate their origins and historical development; it provided me with a perspective other scholars commonly lack.

At the same time, I found that in order to have any hope of building a career as a professional historian and college teacher, indeed, in order to do any kind of work at all, I was inexorably drawn into disability rights advocacy regarding those same policies. Personal inclination made me a historian. Personal encounter with public policies made me an activist.

Based on a keynote address at "On the Move '89," Sixth Annual] Conference for People with Disabilities, YWCA, Riverside, California, May 20, 1989.

In October 1988, I organized a demonstration in Los Angeles to protest so-called work disincentives in federal disability-related welfare policies. The account that follows expands on a speech I made a few months later in which I recounted both that protest and the experience that led up to it.

This essay draws together the themes woven throughout this collection: the discrepancy between "insider" and "outsider" perspectives; the disparities of power between people with and without disabilities; the conflict of agendas between disability rights activists and nondisabled policy makers and professionals; the interplay between disability rights advocacy and disability studies analysis; the continuing struggle of disabled people to gain a voice and to shape our destinies. This story seems a fitting way to conclude this book.

I want to tell you why I burned my book. A deed as shocking as burning a book demands an explanation. It seems particularly mystifying and, therefore, all the more disturbing when the perpetrator has avowedly devoted his life to books. In order to account for that act, I will have to tell you a good deal about myself. I must say, though, that I feel uncomfortable having to disclose so much about my personal life. I would prefer to keep it private. I would rather write biography than autobiography. But it seems to me that some of us are going to have to talk frankly about what it is really like for us as disabled people if we ever hope to break down the barriers of prejudice and discrimination that "cripple" our lives.

I-and most disabled Americans-have been exhorted that if we work hard and "overcome" our disabilities, we can achieve our dreams. We have heard that pledge repeatedly from counselors and educators and "experts," and from our government too. We have seen it incarnated by disabled heroes on television, those plucky "overcomers" who supposedly inspire us with their refusal to let their disabilities limit them. We are instructed that if we too adopt an indomitable spirit and a cheerful attitude, we can transcend our disabilities and fulfill our dreams.

It is a lie. The truth is that the major obstacles we must overcome are pervasive social prejudice, systematic segregation, and institutionalized discrimination. Government social-service policies, in particular, have forced millions of us to the margins of society. Those policies have made the American Dream inaccessible to many disabled citizens.

In saying these things, I risk getting myself labeled as a maladjusted disabled person, a succumber to self-pity, a whining bitter cripple who blames nondisabled people for his own failure to cope with his condition. That charge-or the fear that we might provoke it-has intimidated many of us into silence. As I said, some of us are going to have to risk telling the truth.

The truth is I am a model "rehabilitant." I am, from one perspective, a disabled overachiever, a "supercrip." That shouldn't surprise anyone. I had polio. The rehabilitation system drilled people who had polio in overcoming and then held us up as legendary exemplars of healthy adjustment to disability. American culture has lionized us for our alleged refusal to accept limitations.

So what did I do? I earned my B.A., M.A., and Ph.D. in American history, intending to become a college teacher. And when I published my first book, one reviewer remarked that it drew on "a truly astounding amount of research." Of course it did. Would a postpolio supercrip do anything less? How characteristically disabled of me to undertake so grandiose a project.

Still, I don't want to reduce my work to "overcoming." At the core of my efforts, I pursued a rather simple personal dream: I wanted to write about American history and to teach it to college students.

A succession of dedicated teachers helped me move toward those goals by demonstrating their belief in my talents: Tim O'Keefe at the University of Santa Clara; Norman Cohen, Cliff Kroeber, and Bob Vinter at Occidental College; and especially Robert Dawidoff, my dissertation adviser at the Claremont Graduate School. Leonard Levy of Claremont and Bob Middlekauff of the Huntington Library later helped me get my first publications. Martin Ridge of the Huntington sought to support my research. The endorsement of my scholarship and teaching by these mentors, their confidence that I could have a professional future, were especially important because their support buoyed me up against waves of bias from other quarters. Even while they urged me on, other teachers sapped some of my energy with wounding words of prejudice and occasional overt acts of discrimination.

One undergraduate professor told me that because of my disability no college would ever hire me as a teacher. I guess he thought he was helping me face the hard facts. His opinion that I should pursue a more realistic objective reminded me of something I read around that time in *The Autobiography of Malcolm X*. Early in the book, Malcolm reports the

impact on him of a conversation with one of his teachers. The teacher told the talented and eager teenager that his dream of attending college and law school was unrealistic. Like Malcolm, I felt that my teacher was not only discounting my abilities, but counseling me to give in to discrimination.

A couple of years later as I was completing my master's degree, the chair of the history department told me he thought I would do well in doctoral studies, because, he said, "You're not bitter like most cripples." But he also informed me matter-of-factly that because of my disability no college would ever hire me as a teacher.

I went ahead and applied to several Ph.D. programs in history anyway. One school rejected me because of my disability. Fortunately, in 1971 the Claremont Graduate School accepted me. At the end of my first year there, I applied for a fellowship, but the departmental committee turned me down. I asked for a meeting with them. I wanted them to tell me to my face why they had refused my fellowship application. They explained that because of my disability no college would ever hire me as a teacher. In other words, they didn't want to squander the department's money on me. They suggested I consider archival work. I pointed out that archival work is more physical than teaching. Besides, I said, I want to teach, and I'm going to teach whether you help me or not. They said they felt sure I would succeed, because "we really admire your courage."

The committee's decision to deny me a fellowship because of my disability was an act of discrimination, but it was not an illegal act. In 1972, there was no Americans with Disabilities Act. There was no Section 504. No law prohibited disability-based discrimination. Had it not been for Robert Dawidoff's personal commitment to me and my work, bias might well have defeated my efforts to get my Ph.D. and become a college teacher. At some point, I likely would have given up.

A personal benefactor had paid my first year's tuition. For the second year and for several years thereafter, I had no funding to pay for my doctoral studies. I was living on Supplemental Security Income, a federal income maintenance program for poor people with disabilities. SSI at first provided me with \$ 135 a month. Over five years, the allotment was raised to \$185 a month. Somehow-looking back, I cannot imagine how-I scrimped and scraped together enough to pay the tuition for a single course each year. Because I could not afford the cost of attending classes full-time, I had to petition the Claremont Graduate School to waive its residency requirement, the academic regulation requiring

doctoral students to complete course work within a specified time. I snailed along, enrolling in just one course a year for several years.

If individual acts of discrimination on the part of some of my teachers hurt or hindered me, over the long run the discrimination institutionalized in government policies and programs was far more debilitating. At the time of my acceptance to graduate school, I applied to the California Department of Rehabilitation for financial aid. A rehabilitation counselor in the Pasadena office told me that DR did not fund doctoral study. But, he said, they could train me to become a computer programmer. I told him no, thanks. Now, there's nothing wrong with computer programming. It's honorable work. It's just not what I wanted to do. I wanted to teach college.

For several years through the mid-1970s, I hunted for money to pay for my graduate education. I applied for student fellowships. I got none. I asked about financial aid and disability-related charities like the Easter Seal Society. They said they didn't provide that kind of help. I even managed, after a considerable campaign, to become a contestant on the TV game show *Tic litc Dough*. I lost.

Finally one day, not knowing where else to turn for advice or assistance, I happened to call the Rehabilitation Counseling Department at Cal State University, Los Angeles. A secretary put me through to one of the professors. I explained my situation. He told me I had been—how shall I put it?—*misinformed* by the counselor at the state Department of Rehabilitation. Nothing in the law or public policy or DR's own regulations, explained the professor, prevented it from financially supporting my Ph.D. studies in history. DR could help me in whatever way I needed. I just had to persist *with* them tenaciously, he said. I had to refuse to take no for an answer.

Armed with this information and advice, I went back to the Department of Rehabilitation. This time the people in the Pasadena office agreed to enroll me as a client. DR would begin funding my graduate education. But—here was the catch—it would pay no more than the cost of tuition at one of California's public universities. At the Claremont Graduate School, a private institution, tuition stood at three times the rate of tuition at the state's public institutions, such as UCLA. In practical terms, DR's cap on tuition payments meant that I could now take two courses a year, instead of just one.

Perhaps I could have gotten DR to pay more if I had asserted myself with the agency as the Cal State professor had warned me I would have

to do. But at that point, I was still rather naive about the system, still intimidated by it. I hadn't yet realized just how tenacious and aggressive one had to be to make the bureaucracy move.

After several more years during which I labored along in my doctoral studies, the Department of Rehabilitation notified me that it intended to close my case. I had taken too long to complete my degree, explained my rehab counselor. I've taken so long, I replied, because you people won't pay the full tuition. You could have gone to a public university that charges lower tuition, she said. I'm a student in a highly regarded graduate program in history, I told her. Don't I have a right to go to the best school I can get into? You could have stopped with a master's degree, she said; that's enough for an entry-level position. It's not enough to teach college, I answered. I need a Ph.D. to become a college teacher. At last, the counselor confessed that her superiors put pressure on her and other counselors to close out cases in order to improve the agency's overall statistics.

I already knew about DR's practice of terminating cases to make itself look more effective in rehabilitating clients to successful employment. Everyone knew about it. It's one of the ways the voc rehab bureaucracy keeps itself in business. Still, the rehab counselor shouldn't have openly admitted the practice to a client, at least not to this particular client. I quoted her words in a letter to my state assembly member.

My assembly member intervened with top-level administrators in Sacramento. DR reversed itself. They would continue me as a client. They also switched me to a new counselor, a man who himself had a disability. He offered me support DR had never before provided, most important, money to pay for transcription of my dictated research notes. At last I had the means to make significant progress on my dissertation and doctorate.

A few months after the new counselor started working with me, I got a call from his supervisor. He wanted to know if I was satisfied with the counselor. I said I most definitely was. The supervisor said he was glad to hear that, because he had recommended promotion of the counselor to senior rank against the opinion of his (the supervisor's) superiors. I asked why the superiors had opposed promoting my counselor. Because of his disability, said the supervisor. They didn't think he could do the job.

If the struggle to find ways to pay for my graduate studies slowed my progress, an even greater financial dilemma threatened to stop me alto-

gether. My disability incurs enormous expenses. I have no use of my arms, limited use of my right hand, and, because of a severe spinal curvature I use a ventilator a great deal of the time. *As* a result, I employ aides in my home to do the housekeeping and to assist me with tasks like showering, shaving, dressing, and eating. As of October 1988, at the time I burned my book, the wages paid to my personal assistants, plus the rental of my ventilators, exceeded \$20,000 a year. (By the turn of the century, those costs topped \$45,000 a year.) Disability-related living and work expenses have posed the fundamental problem of my adult life. The plain fact is, I am unlikely ever to earn enough in an academic career to cover such costs.

My situation is not unusual. Enormous numbers of Americans with major disabilities grapple with high disability-related expenses. They too could work, at least part-time, but could never earn enough to pay for the services and devices they need.

Necessity has forced many of us to maintain eligibility for federal Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) or both. Both programs provide monthly cash benefits. But that is not what makes them vital to us. Indeed, virtually any of us could earn the \$350 to \$700 monthly allotments we typically receive.

Far more important, SSI and SSDI eligibility make us eligible for other, more essential assistance. For instance, throughout my adult life I have paid my personal assistants through California's In-Home Support Services program. Medi-Cal (the California version of Medicaid) has paid for my ventilators. Without this financial aid, I would have had to spend my adult life in some sort of nursing home. At far greater cost to taxpayers, I might add. In most states, people with disabilities like mine have found themselves in a far more horrendous situation: they get little or no aid for independent living. They are shackled to their families or imprisoned in nursing homes. They are denied access to life and to work. Independent living has enabled me to work productively.

The catch is that for most of my adult life, in order to maintain eligibility for this government aid, I had to refrain from work. Using a combination of medical and economic criteria, federal disability policy defined-and still defines-"disability" as the total inability to engage in "substantial gainful activity." In the 1970s and 1980s, policy makers reckoned as "substantial gainful activity" gross earnings exceeding \$300 a month. (Eventually they raised the SGA level to over \$700 for non-

blind disabled persons.) Anyone who earned above that meager amount was, to their way of thinking, no longer disabled, despite any ongoing medical condition or functional limitations they might have. If you worked and earned more than that, the government would cut off all financial aid to you.

All through the 1970s and much of the 1980s, the all-or-nothing \$300-a-month earnings threshold blocked me from getting teaching experience. If I had taken even part-time work as a college instructor which is the way doctoral students usually seek to make themselves more competitive in the higher-education job market-I would have jeopardized the financial aid that paid for my in-home assistance and my ventilator, the aid that enabled me to live independently and, in fact, to work. As a result, my resume remained almost blank. What college, I wondered, would hire someone with what amounted to zero formal teaching experience and virtually no record of any kind of work at all? And if I did somehow manage to land a faculty position, how would I, on a college teacher's salary, replace the \$20,000 a year in assistance that had made it possible for me to get to that point?

Year after year in graduate school, I fretted about how I could make myself marketable as a college teacher and how I would get by financially if I ever did get a job. Semester after semester, I considered quitting the Ph.D. program. Why beat my head against a stone wall? What was the point? In virtually every semester of graduate school, there came a moment when I had to sit down and decide once again that I would hang in there for one more term.

If the policy definition of disability as complete incapacitation for productive work ever made sense, it certainly made none by the late twentieth century. Advances in technology made it possible for even significantly disabled people to work. I completed my doctoral dissertation using a Dictaphone and a word processor.

The historical roots of these public policies that deliberately and systematically deny disabled Americans the right to work require some explanation. In her elegantly persuasive study *The Disabled State*, Deborah Stone, a political scientist, demonstrated that policy makers created the "disability category" in poor relief and social welfare in order to distinguish unambiguously between two economies, one putatively based on "need," the other allegedly grounded in "work." They sought to keep workers in the labor market by restricting admission to the "need-based"

system. Invention of the disability category, Stone argues, attempted to achieve these objectives by defining "disability" as utter incapacity to perform productive labor.

The designers of disability-related early-modern poor relief and modern social-service programs believed that many nondisabled or only partially disabled workers would make false claims in order to win exemption from work. Given that expectation, the policy makers identified prevention of fraud as the central problem in welfare administration. They attempted to detect imposture, Stone shows, by adopting a "clinical concept" of disability. They assumed that this medical model would supply a scientific means of quantifying "disability," thereby objectively measuring and verifying it. Application of medical definitions would supposedly catch fraud, thereby ensuring that only those with legitimate claims to societal aid would get it.

The trouble was-and is-that disability-related poor relief and social welfare have always operated on a foundation of false postulates about the nature of disability. The policies rest on the assumption that physical or mental impairments by themselves produce "disabilities," limitations in social and vocational functioning. These premises undoubtedly have had great appeal because they offer certain advantages for public-policy making and program administration. They give assurance that determination of eligibility for aid can be a fairly clear-cut process. Doctors and other professionals can reduce both impairment and disability to a set of numbers, numbers that will show who objectively qualifies to receive benefits. This assumedly will not only prevent fraud; it will also make program administration more efficient, while helping to keep a lid on public spending.

In reality, this ideological framework for disability welfare policies seriously misconstrues the causes and character of disability. Disability is not an entity that a clinical examination can correlate with the numbers on a schedule of impairments. It is not located in pathological individual bodies. It is not simply caused by impairments or by physiological features that depart from the typical. Instead, disability is produced through the dynamic interplay of a complicated constellation of factors that includes, not only stigmatized physical and mental limitations and physiological differences, but also physical and architectural environments, social arrangements and cultural values, and the impact of public policies themselves. In addition, all of the factors that make "disability" and shape the human experience of disability have, like all historical

phenomena, changed over time. Disability, then, is not a fixed *thing*. It is an elastic and dynamic social category. It is not an objective condition. It is a set of socially produced, highly mutable, historically evolving social identities and roles. Throughout the modern history of disability welfare and rehabilitation programs, some policy makers, program administrators, and medical and rehabilitation professionals have acknowledged these realities about the true complex nature of disability. Nonetheless, policies and programs have continued to operate on the traditional simplistic definitions of disability, its causes and character.

Both politicians and disability policy bureaucrats continue to operate from these premises. And they still see fraud as the major concern. For example, in 1981 the newly installed Reagan administration asserted that more than one out of four Social Security Disability Insurance recipients failed to match the program's eligibility requirements. That is, they did not fit the SSDI definition of disability; they were not really disabled. This view was not unique to conservative Republicans. The preceding, liberal Democratic Carter administration had expressed the same opinion. The difference was that the Reaganites launched a massive effort to "purify" the SSDI rolls of the alleged horde of illegitimate claimants. Tens of thousands of disabled people found themselves kicked off SSDI, thereby losing medical insurance and other essential assistance. As it turned out, the vast majority did meet the program's definition of disability. Most eventually had their benefits restored. But, it is disturbing to note, a significant number who would have won reinstatement did not appeal. Many disabled citizens who are eligible for assistance struggle by on whatever meager resources they can muster rather than traversing the energy-sapping, dehumanizing bureaucratic labyrinth. Even more disturbing, at least a dozen purged SSDI recipients died before they received notification that the bureaucracy had booted them off the program erroneously. The allegation of widespread fraud was never proved. It was a phony issue!

Most scandalous of all, the Social Security Administration resisted federal court rulings regarding its eligibility reviews. SSA did yield when the courts overturned its decisions in individual cases, but it dug in its heels when federal judges enjoined it to make basic changes in how it conducted those reviews. The courts directed the agency to ensure recipients' due process rights and to employ less mechanistic definitions of disability. For several years, SSA refused to obey these rulings. It euphemistically called its defiance of the courts "nonacquiescence." If you

or I refused to "acquiesce" to the decision of a federal court, we would find ourselves looking out through the bars of a cell. Top-level federal bureaucrats are different than you and me. To disability rights activists, SSA's stance evidenced that the problems in the federal social-insurance/social-welfare system stem not only from a policy ideology that distorts the realities of disability, but also from the tenacious exertions of an entrenched bureaucratic institution to safeguard its prerogatives and powers, no matter what the cost in the lives of ordinary people with disabilities.⁴

In addition to designing mechanisms for detecting fraud, policy makers historically have sought to forestall fakery by making both the process of determining eligibility and the experience of receiving benefits-so to speak-arduous. They fashioned what amounted to ceremonies of social degradation for persons seeking or getting assistance. Disabled people who have suffered through this gauntlet know what I am talking about. The politicians and bureaucrats who designed these deliberate indignities figured that only the most destitute, only the "truly needy," would put up with such ignominious treatment.

This institutionalized system of social humiliation has a long history. An integral feature of the English Poor Law system, it went under the euphemistic name of the principle of "less" or "least eligibility" (in modern parlance, desirability or preferability). Though the archaic descriptor is no longer used, the demeaning practice has been continued. The great blind scholars Jacobus ten Broek and Floyd Matson described it in their classic mid-twentieth-century studies of **US** welfare and disabled people. They depicted an institution that from start to finish deliberately robs disabled people of their dignity. "Through an interminable succession of investigations beginning with the application interview and culminating, but not ending in the issuance or withholding of the cash grant," they wrote, "the disabled client finds himself confronted with a presumption not of innocence and eligibility but of guilt and probable fraud Nor is this surveillance a one-time only procedure briefly annoying but soon over and done with; it is continuous and recurrent, ceasing only with the client's death or his transfiguration into a state of self-sufficiency. For the disabled recipient of aid, Big Brother is always watching." To ten Broek and Matson, the hoary principle of "less eligibility" today no longer signifies the pauper's badge, workhouse gruel, bodily punishment, and loss of franchise in general, but it does involve certain major deprivations: the loss of the right to privacy with

continuing review of resources, expenditures, and living circumstances; the pressure on relatives to contribute and the resulting strain on family life; and a lower material standard of living than others enjoy."⁵ In my own experience and the experience of many disabled people I have talked with, little has changed since the 1950s and early 1960s when ten Broek and Matson wrote their brilliant and scathing analyses. Their gendered language is now outdated; their critique still applies.

In ten Broek and Matson's view, the modern welfare system not only demeans people with disabilities; it thoroughly disempowers them. "Whatever modest degree of self-control and responsibility, the disabled person may have possessed before entering this web of bureaucracy and paternalism," they noted, "is soon wrested from him by the process of means-test aid. It is the agency of welfare, not the recipient, who decides what life goals are to be allowed, 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 If the recipient does not comply and conform, he may be removed from the roles and have his budget reduced. The alternatives are obedience or starvation."⁶

Seeking the origins and causes of this system of suspicious scrutinizing, ten Broek and Matson traced the underlying ideology back through "Victorian pieties" about "the moral depravity and moral inferiority of the poor." They found its earliest roots in Elizabethan Poor Law images of poor people and disabled people as "victims of their own vices." Some of their observations still resonate decades later in an era when politicians across the spectrum boast that they have "ended welfare as we know it." For example, the two disabled scholars pointed out that the "concept of the characterological causation of poverty and dependency has not only a venerable history but a contemporary reality. In the eyes of that law there are not broad social problems of poverty or injustice to be solved but only individual wrongs to be righted, personal sins of commission to be expiated and corrected. And the proper corrective, in most cases, is some form of punishment."⁷

Many policy scholars have noted that the badge of moral depravity historically was affixed on the able-bodied poor. Only a few have recognized with ten Broek and Matson that poor-relief and welfare policies have always inflicted a parallel moral stigma on people with disabilities. In fact, many policy scholars regard induction into the disability

welfare category as a "privileged" status that "exempts" people with disabilities from work rather than excluding them from productive contribution to society. This was not ten Broek and Matson's view. It is not the view of disability rights advocates. In their opinion, while public policies have ostensibly separated the "unworthy" from the "worthy" poor, those policies have also effectively erased that distinction by marking people in both categories as unworthy. All are morally flawed, all socially discredited. All are punished.

If the punitive element in welfare administration stems from ancient notions of moral defectiveness, ten Broek and Matson traced the sources of the system's paternalistic component to an ideology of poverty and disability that drew its rationale from modern medicine, psychology, and social work. All "welfare clients," they noted, "including the blind and the disabled, have been categorically judged incompetent to manage their lives and affairs." A fundamental though unspoken assumption of welfare administration regards the client as "irrational, irresponsible, abnormal, and incompetent."

It should come as no surprise that this supposition of client abnormality and incompetency shapes the operation of welfare programs, for it appears implicitly, if not explicitly, in many explanations of the causes of poverty, just as it pervades disability, rehabilitation, and special education research and training. Ten Broek and Matson focused on the consequences of this attitude for people with disabilities under the welfare system. In fact, that notion has stood as a core formative principle of most modern disability programs, whether in custodial institutions or community-based support services, medical and vocational rehabilitation or special education, public assistance or private charity. Virtually all late-twentieth-century disability programs of whatever type established mechanisms for clients to appeal adverse decisions, while many programs ostensibly guaranteed them a voice in the drafting of individualized education or rehabilitation plans. But in actual practice, programs have usually operated on the assumption that people with every sort of disability are incapable and irresponsible regarding management of their own lives. In tandem, this presumed personal and social incompetency, along with the putative moral defectiveness of disabled people, make necessary, make inevitable, their placement under professional supervision. Indeed, so pervasive are the deficiencies of disabled people, so omni-incompetent are we, that an array of professionals with many kinds of expertise must superintend our lives. These arrangements force many

people with disabilities to remain as permanent clients of not just one, but many programs and agencies. Professionals and bureaucrats continue to wield the greater power.

As ten Broek and Matson concluded, the "chief effect" of these features that historically have characterized disability-related social-service policies and programs has been "to perpetuate dependency and discourage initiative." "Continuous surveillance, loss of independence, and inadequate allowances all combine to produce conditions which run sharply counter to the principles of personal rehabilitation." These tendencies make the recipient "a ward under agency guardianship, in flat contradiction of the declared goal of helping individuals meet their essential needs and recover and maintain their personal capacities for self direction." Noting that rehabilitation involves, not just physical, but social and psychological, elements, ten Broek and Matson declared, "Integrity of personality cannot be built upon a foundation of humiliation." "A system of aid ... which continually impresses upon the recipient a sense of his helplessness and dependency, which withdraws from him the daily experience of management of his own affairs, and which enfolds him in an atmosphere of custodialism and guardianship weakens the fiber of self-reliance, deters self-improvement, and threatens the very independence that is indispensable to salvation." Their observations about recipients of Aid to the Blind capture the experience of all disabled recipients: "The blind aid recipient is soon made aware, and continually kept conscious, of the inferior position into which he has been thrust. He comes to feel that he is the victim of unique discrimination; that other groups in society-organized labor, farmers, industrialists-make no such sacrifice in personal liberty when they receive a helping hand from the government. And with this deepening realization, his resentment is compounded, his frustration and insecurity are intensified, his alienation from self and society is completed. He feels himself robbed of self-respect and the right to resume a useful role in society." The recipient is schooled in "passive adjustment ... to an immutable social reality." Which is to say, the welfare system compels people with disabilities to acquiesce in their own inferiority and marginalization.

Not only do the deprivation of dignity and independence defeat the goal of rehabilitation, in ten Brock and Matson's view the financial provisions of the aid programs stymie that objective in material ways. First of all, "the smallness of the grant continually hinders and prevents rehabilitation." The amount of financial assistance provided to disabled re-

cipients barely staves off destitution, if it does so at all. And "destitution," they declared, "is a poor foundation from which to accomplish the difficult task of self-reconstruction-economic, social, and psychological. Yet destitution is made a condition of eligibility for public assistance." Here they put their finger on one of the Catch-22's that have always been central to disability welfare policies. to

But the enforcement of poverty on disabled recipients does not end with these provisions. "Rehabilitation is struck still another blow by the means-test requirement that a recipient utilize all his property and income to meet his current needs." Policy planners would later call this rule "the resource limit." In the 1980s, an SSI recipient who was single could accumulate no more than \$1800 in "resources." A couple, both receiving SSI, could accrue just \$2000. Recipients who somehow had resources in excess of those limits had to "spend down" in any given month to get their resources below the threshold before the month ended. In other words, policy prohibited-and continues to prohibit-any savings, any planning for the future, any effort toward development or accomplishment. As ten Broek and Matson argued: "Reasonable accumulations of personal property, if not required to be applied to the meeting of immediate needs, might be used as stepping stones to independence of the relief rolls. Retention of reasonable amounts of income, *especially earned income*, also performs a vital function in the rehabilitative process, both for its incentive value, and as a means of moving from public aid to self-support." 11

Disability rights activists a generation after ten Brock and Matson have argued that even if savings do not ultimately lead to "independence of the relief rolls," disabled recipients should be allowed to save what they can. The combination of earnings and savings surely would encourage, perhaps not economic independence, but at least economic productivity-and with it payment of some taxes. It certainly would enhance their quality of life, while putting a stop to the ludicrous requirement that they "spend down," which often means spend wastefully.

There has been one way recipients in recent decades might permissibly gather some savings. The Social Security Administration calls it a Plan to Achieve Self-Support (PASS). The plans are time-limited schemes for accumulating specified amounts toward purchase of particular items SSA has approved as appropriate means toward vocational rehabilitation. Here again the bureaucracy determines what disabled individuals really need and what activities they may legitimately undertake.

In addition, those who have applied for a PASS have often found it hard to get local SSA offices to approve their requests. Given the institution's ideology of poverty, disability, and welfare, the whole idea of recipients saving any money at all rather than spending every penny on current needs violates the bedrock principle that only the utterly destitute, totally incapacitated, and therefore truly worthy should receive aid. In practice, SSA has operated the PASS as a minor concession to rehabilitation.

Given the system's premises, given its ideology of both poverty and disability, the conflict between welfare and rehabilitation criticized by ten Broek and Matson was inevitable. Policy makers set out to discourage all but the "truly needy" from applying for aid in order to maintain a sharp separation between the "work-based" and "need-based" economies. As a result, they made it not only hard and humiliating to go from work to welfare, but also virtually impossible to move in the other direction, from welfare to work. In order to limit access *into* the so-called need-based economy, they deliberately limited exit *out of* that system as well. Thus, the effort to restrict able-bodied workers' access to social service benefits simultaneously constituted people with disabilities as a stigmatized category, a segregated caste relegated to a permanent state of clientage. That disabled caste was deployed to define the boundaries of legitimate need. In the end, it came also to define the features of social normality by incarnating their inversion.

The mechanisms used to restrict disabled people's access to the labor market and society came in the late twentieth-century to be called, in one of the system's modern euphemisms, "work disincentives." Those so-called disincentives are, in fact, penalties, punishments designed to keep disabled people out of work, out of society, and out of life. Likewise, if we try to marry or raise a family, the government penalizes many of us through—here's yet another euphemism—"marriage disincentives." Throughout the recent decades, politicians have talked incessantly about "family values." Yet the policies they perpetuate have relentlessly undermined the families of disabled Americans. Marriage and work penalties hit disabled women even harder than disabled men. Marriage sometimes mitigates women's poverty, but the disability policy disincentives exacerbate the impoverishment and isolation of women with disabilities by helping to keep their employment and poverty rates high and their marriage rates low. Meanwhile, disabled students who get government welfare benefits and accept scholarships face education disin-

22.



centives. So, whether we seek to learn, to work, or to love, the state punishes millions of us. It cuts off assistance with the high disability-related expenses many of us face, costs we probably could never earn enough to cover. These policies reinforce the degraded social status that has helped make the disability category in social welfare unattractive. Robbing us of our dignity has also helped intensify the stigma and segregation many of us endure.

During much of the twentieth century, these sorts of practices-the arduous and degrading process of obtaining assistance, the stigmatization of those granted it, and the work and marriage restrictions placed on recipients-interacted with intense social prejudice. Just as ten Broek and Matson described, people with many kinds of disabilities found themselves not only defined as incapable of work, but viewed as incompetent to manage their lives-and even sometimes as a threat to society. More and more were placed under the supervision of professionals. Some were permanently incarcerated in institutions. The systematic denial of the chance to work, joined with restrictions on education, marriage, and most forms of social intercourse, has entailed what John Gliedman and William Roth call "perhaps the most radical act of social declassification possible."¹² For a great many people with disabilities, it amounted to social death.

Meanwhile, invention and maintenance of the disabled caste advanced the ideological and economic interests of an array of professional groups in the modern welfare state. "Disability" became a multibillion dollar industry. Many states still keep adults with physical or developmental disabilities imprisoned in nursing homes and other public and private facilities that exploit them for profit. Even those of us at large in society pull in high profits for vendors of a great many services and products. A few years ago, I designed a device for my use in the bathroom. Knowing it would prove handy for people with similar disabilities, I sought ways to make it available. It would cost only a few dollars to manufacture, but a vendor eagerly told me we could sell it for at least fifty dollars a unit. The government would pay for it, he said. Hence comes the overpricing of everything from hearing aids to wheelchairs. This greedy arrangement between the private and public sectors, between vendors and the government, keeps many people with disabilities in a permanent state of clientage. We have to stay clients in order to get the devices and services we require.

The long history of poor-relief and social-service policies that have marginalized and sought to disempower people with disabilities might lead us to believe that they have suffered helplessly and passively as victims of enormously powerful institutions. But the historical evidence uncovered thus far suggests active resistance on the part of at least some disabled people. Two brief examples will illustrate that opposition.

Abram Courtney's pamphlet *Anecdotes of the Blind*, published in 1835, tried to convince the public of the capabilities of blind people and to promote their education. He recounted his adjustment to complete blindness in his teens and twenties and reported his encounters with other blind people, describing their activities and occupations. He made particular mention of two blind men who had married. Desiring to work productively and to support himself, Courtney became an itinerant peddler. He hired a boy to assist him as he traveled through upstate New York, Ohio, and Pennsylvania selling his wares. Customers initially bought his goods because of the novelty of a blind peddler and out of pity. But on his subsequent trips, he frequently encountered the view, often expressed with hostility, that he should go to the almshouse. In other words, he was told he should withdraw from society. Along with his attempt to educate the sighted public, Courtney expressed indignation at the prejudice he met with on his travels in Jacksonian America. Paraphrasing Shakespeare's Shylock, he wrote: "If you prick a blind man, does he not bleed? If you tickle him, does he not laugh? If you treat him with contumely, does he not feel mortification and bitterness of heart? Shall he not also have an honest pride?"

Exactly a century later in the Depression-era America of 1935, a group of disabled young adults banded together as the League of the Physically Handicapped. They demonstrated against job discrimination in federal work relief programs. They sent a delegation from New York City down to Washington, D.C., to the Works Progress Administration headquarters to protest job bias in WPA projects. They were not only taking political action to compel changes in institutional practices. They were redefining "disability" as a social, economic, and even political condition, rather than simply a medical or physical phenomenon. And like Abram Courtney, they were attempting to fashion a new social identity.

As with other minorities, we tend to see disabled people as passive victims of fate or history. Abram Courtney and the League of the Physically Handicapped indicate that in important ways, individually and col-



lectively, people with disabilities have been actors in our own history. As with other minorities, we have sought to carve out maneuvering room for ourselves within the constraints of social ideologies and arrangements. We have attempted to modify social belief" in order to expand our social power. In particular, we have sought ways to use our talents and to contribute to society through productive work.

I have spent much of my life seeking ways to elude social stigma and outwit discrimination. I have wanted to escape the roles of dependent cripple or inspirational overcomer. I, like the members of the League of the Physically Handicapped, have tried to work productively and to fashion for myself an alternative social identity. Like Abram Courtney, I have claimed as my right "an honest pride." Yet for my entire adult life, many government policies have been deliberately designed to prevent me, not just from pursuing my profession, but from attaining the socially respected place in society that goes with honest work. Millions of other Americans with disabilities find their attempts at productivity and pride blocked by these same segregationist work penalties and the social prejudice those policies express.

In the late 1970s, in the tradition of ten Broek and Matson, and, without knowing it, as successors to Courtney and the League, disability rights activists started calling for removal of work disincentives from Supplemental Security Income and Social Security Disability Insurance. In 1980, Congress authorized the Social Security Administration to create a national demonstration program called Section 1619 that would allow SSI recipients to go to work and retain medical insurance and other assistance. Year after year, SSA failed to publicize this program. The Reagan administration took no stand on the issue. Instead, it allowed SSA's top officials to obstruct reform. In 1983, the General Accounting Office recommended that Congress require SSA to conduct such experiments. In 1986, disability rights advocates once again lobbied for permanent reform, and once again the Social Security Administration fiddled with its statistics to predict that enabling us to work and pay taxes would cost taxpayers billions. A Social Security spokesperson even had the audacity to tell the *Los Angeles Times* that government policy contained no work disincentives.

The Social Security Administration of course claimed that allowing us to work while we received assistance with our disability-related living and medical expenses would cost the government billions of dollars. A national pilot project launched in 1980 proved just the opposite. The

government and society got millions back from disabled people who had at last become workers and taxpayers. Despite this, for seven years the Reagan administration ignored the issue, while the Social Security Administration blocked permanent institutionalization of the SSI reforms. Finally in 1986, Congress overrode SSA's resistance. It ordered permanent elimination of most work disincentives from SSI. The new rules in Section 1619 would permit recipients to earn up to a threshold amount equivalent to the cash value of all the assistance they received plus the amount of their "impairment-related work expenses."

For twenty years, I had wondered and worried how I would ever fulfill my dream of teaching and writing American history. I had finally finished my Ph.D. in 1984 but still could not take even a part-time teaching position without jeopardizing the financial aid that paid for my ventilators and income assistance. With the arrival of Section 1619, the work penalties that had blocked me were at long last gone. Or so I thought.

In March of 1988, I learned that although Section 1619 would permit me to earn a living as a college teacher, the reformed rules would not allow research fellowships or publishing royalties. The Social Security Administration would continue to regard such income as "unearned," like royalties from oil well stocks.

The Huntington Library, a world-renowned research institution in San Marino, California, fifteen minutes from where I lived, had just offered me a fellowship to continue my work on George Washington's role in post-evolutionary America. I would have to turn that fellowship down. More problematic, in October the University of California Press would publish my book, *The Invention of George Washington*. I needed that first book to make myself attractive in the college-teaching job market. UC Press expected the book to sell pretty well. That was the problem. Even if it yielded only modest royalties, that money would not fit the Section 1619 definition of "earned" income. So I could lose some or all of the assistance I depended on to work and live and, literally, to breathe.

Don't ask me how the policy makers decided that earnings from a book it took me ten years to write would be "unearned." They live in an Alice-through-the-Looking-Glass realm, where significantly disabled people who work are not really disabled after all.

I wrote President Reagan and other top federal officials to describe my situation. Scholarly careers, I explained, are rarely lucrative. I could earn a full-time salary as a college teacher, obtain grants occasionally,

publish scholarly books, and still not have enough income to pay for my disability-related living and work expenses. If I cannot apply for and accept research fellowships or publish books, I said, I cannot advance in my profession. If I lose the government aid that pays for my in-home assistance and ventilators, I cannot live independently *or* work.

President Reagan vigorously advocated getting the government off Americans' backs. He could have initiated changes in SSI policy, as I requested him to do. He did not. Instead, he forwarded my letters to the commissioner of Social Security, Dorcas Hardy.

At first, Commissioner Hardy referred me to the Glendale, California, Social Security office. This was simply, as the members of the League of the Physically Handicapped would have put it, "the runaround." She knew that the claims representatives in the local office could only inform me of the regulations about which I had already complained to the president.

Then in June 1988, Commissioner Hardy offered a suggestion. "If you can establish an employer-employee relationship" with the University of California Press regarding publication of your book or with the Huntington Library regarding research there, she wrote, "your income may be treated as earnings under Section 1619." (Note the noncommittal "may." No guarantees, no venturing out on a limb by the bureaucratically cautious commissioner.) Despite my skepticism about this proposed solution, I checked it out with Dr. Martin Ridge, director of research at the Huntington Library. He told me that the Huntington could not legally pay me fellowship money in the form of a salary. Neither could I establish an employer-employee relationship with my publisher. They had bought a literary property of my creation. They had not hired me.

Commissioner Hardy's advice was not just unworkable. It sidestepped the central issue. The suggestion that a scholar who happens to have a disability should seek to establish an employer-employee relationship with a grantor or publisher struck me as discriminatory. Scholars without disabilities do not seek or obtain such arrangements. Why should I be required to do so just because I'm disabled? Why should I not work under the same arrangements as others in my profession?

Commissioner Hardy had another idea. "If the Internal Revenue Service determines that you are self-employed in a trade or business," she said, "your income may be treated as earnings under Section 1619. Otherwise, your income must be classified as unearned." (That noncom-

mittal "may" again, followed by an emphatic "must." Bureaucrats make sure to protect not just their backsides, but also their administrative prerogatives.) Well, I studied the Internal Revenue Service publications concerning fellowships and royalties. I discovered that the IRS makes no distinction between self-employment and salaried employment. It classifies research fellowships and publishing royalties as taxable *earned* income. I would have to pay income taxes on any book royalties. It seemed to me only fair for the Social Security Administration to acknowledge that I earned such income and to treat it as earnings under Section 1619.

Finally on August 26, 1988, Commissioner Hardy notified me that SSA would regard any income I obtained from research fellowships and book royalties as "unearned" and that this would adversely affect my eligibility for SSI.

When I read the commissioner's peremptory warning that SSA would punish me if I received any royalties from my book, something in me reached a breaking point. Years of finding myself trapped and thwarted by this system, years of feeling demeaned and degraded by it, came to a head. I said to myself, "I've had enough." I decided in that moment that when my book came out in October I would burn it in protest.

I spent the next two months carefully planning the book burning. I mailed a series of flyers to activists in the Southern California disability community to keep them up-to-date on the preparations. I phoned dozens of people urging them to participate in the protest. I contacted television and print news reporters. I spent hours on the phone trying to educate a *Los Angeles Times* writer about the intricacies of government disability policies.

I also figured that if I really were going to burn my book, I had better do it right. First off, I didn't want to set *myself* on fire. At the same time, I wanted to make the burning of the book visually dramatic. So one afternoon I went over to my friend Vince Pinto's house. I brought with me several books I had been planning to throwaway. I picked those particular books because they had glossy paper dust jackets like the jacket my book would have. Vince and I and his aide spent an hour at Vince's backyard barbecue practicing how I would burn my book.

We quickly hit upon a method. We wadded up some newspaper, stuck it under the barbecue grill, and soaked it with lighter fluid. We also saturated the books with lighter fluid and stood each one in turn on top of the grill. Next, Vince's aide handed me a long fireplace match he had al-

ready lit. I turned a half-turn to my right and ignited the newspaper kindling. The flames started up under the books, then consumed them.

We all agreed that I was ready.

My planned protest got enthusiastic support from the Southern California disability community. Leaders of the California Council of the Blind, the Greater Los Angeles Council on Deafness, several independent-living centers, local chapters of the California Association of the Physically Handicapped, Able Advocates of Santa Barbara, and ADAPT of Southern California endorsed the demonstration.

On October 18, some forty people gathered in front of the federal building on Los Angeles Street in downtown L.A. There were adults with disabilities who were trying to work, or wanted to and could work, but were thwarted by work penalties. There were college students with disabilities who wondered if they would be prevented from following the careers they dreamed of pursuing when they graduated. There were parents of disabled children who wanted those youngsters to have a useful and fulfilling future. There were teachers and counselors who labored to help people with disabilities get an education or job training. They were paid with government funds to do this, but government policies baffled their efforts. We all came together to demand an end to work and marriage penalties.

Vince and his aide transported Vince's barbecue in his wheelchairlift-equipped van. We set it up on the sidewalk in front of the main entrance to the federal building. Parker Center, the headquarters of the Los Angeles Police Department, stands right across the street. Several LAPD cops, along with security personnel from the federal building, warily stood watch during the protest and book burning.

I had hired a Deaf commercial-art student from Pasadena City College to make brightly colored placards bearing slogans television viewers would be able to read easily. One placard declared: "We Want to Work! Why Won't the Government Let Us?" Another demand I borrowed from the League of the Physically Handicapped: "Jobs. Not Tin Cups."

A row of placard holders stood to one side, as another group of demonstrators paraded in an elongated circle. Two of them led the protesters in disability rights chants. Wheelchair riders carried placards on their laps.

Meanwhile I stepped up to the wooden lectern I had borrowed and read a statement explaining the reasons for our demonstration. Then I moved over to Vince's barbecue. A friend handed me a lighted match. I

turned and ignited the newspaper wads under the grill. A copy of my book stood on top of the grill. The front cover of the book jacket had a striking design: a photographic reproduction of Antoine Houdon's famous white marble bust of Washington against a red and blue background with the words "*The Invention George Washington*" and "Paul K. Longmore" above and below. The image was bold, noble, majestic. At first the flames licked the bottom of the book. Then they engulfed my name and George Washington's head and the book's title.

I somberly watched the fire consume my book. I had planned the protest. I had rehearsed how to burn the book. I had even thought about what sort of expression I should have on my face. But I could never have prepared for the emotional effect on me of the act itself. I was burning my own book, a book I had spent ten years of my life laboring over, a book that had earned me my Ph.D. in history, a book I felt proud of and, in fact, loved. It was a moment of agony.

Everyone in the crowd looked on quietly, soberly. Several wept. As with my own reaction, their emotional response surprised me. I asked my friend Carol Gill, a disabled psychologist who participated in the protest, why she thought so many people had reacted so strongly. She said she believed that those friends and colleagues were partly expressing their love for me. At the same time, she said, the entire protest and especially the burning of the book gave tangible form to the pain they felt about their own lives. They too felt thwarted by a government that stymies their efforts to work and make a life. They too felt dehumanized by a society that devalues them.

The demonstration ended. The protesters dispersed. An LAPD officer approached the three or four of us who were cleaning up. He asked my name. He wrote it down. I asked if there was a problem. He said he just wanted the information for the record.

That evening, news broadcasts on KNBC-IV (the NBC affiliate in Los Angeles) and KIIJ-IV (an independent station) aired stories about the book burning. The next morning, the front page of the *Los Angeles Times* Metro section ran a long story on the protest. The article included a large photo of me watching my book burn.¹³

Subsequent events gave hope that the book burning might have the political impact we sought. In November, a high-ranking Social Security Administration official privately admitted to a disability rights advocate that the book burning had given the agency "a black eye" and that the work disincentives were "stupid." That same month, the *New York Times* published an opinion piece of mine on the work penalties issue.¹⁴

In December, National Public Radio broadcast a story about a quadriplegic man in Montana who received \$15,000 a year in Medicaid. That financial aid enabled him to live independently. Then he won election to the state legislature. Because of the modest salary he would receive from that part-time job, the Social Security Administration told him it would cut off his assistance even though he would not be earning enough to live on.

In January 1989, the new Congress convened in Washington. It took up the Social Security Work Incentives Act, a bill first introduced in the previous session. The proposed legislation aimed to eliminate the major work penalties in Social Security Disability Insurance. Congressmen Robert Matsui (Democrat, California) and Steve Bartlett (Republican, 'Ihas) carried the bill in the House; Senators Robert Dole (Republican, Kansas) and Donald J. Riegle, Jr. (Democrat, Michigan), brought it before the Senate. When disability rights advocates alerted Congressmen Matsui and Bartlett about the book burning and our demands, they decided to add to their bill an amendment that would address the SSI work penalties we had protested. The new provision would classify publishing royalties, speaking honoraria, and research grants and fellowships as "earned" income for purposes of reckoning the income threshold under Section 1619.

In February 1989, I learned that the Social Security Administration was vigorously opposing the entire bill. Once again SSA twisted statistics to claim that reform would cost \$5 billion over five years. Concerned about the budget deficit, Congress began pulling back. The bill's provisions were seriously weakened. In negotiations with congressional staffers, SSA agreed to recognize publication royalties as "earned" income for SSI recipients, but the bureaucrats dug in their heels about research scholarships, grants, and fellowships. They adamantly insisted on continuing to regard that sort of income as "unearned." The few changes SSA would agree to got folded into the Omnibus Budget Reconciliation Act. That legislation allowed honoraria and publishing royalties. Today, almost a decade and a half later, the rule barring grants and fellowships remains in place. Over the years, a number of disabled undergraduate college and graduate students have had to turn down scholarships or face losing the personal-assistance services and medical coverage they required.

Meanwhile, the struggle to root out work penalties has continued. In

late 1999, Congress passed and President Clinton signed a new Ticket

to Work and Work Incentives Improvement Act. It won support and praise across the political spectrum as the most important disability related federal legislation since the Americans with Disabilities Act of 1990. Politicians, both Left and Right, and some disability rights activists exuberantly forecast that WIIA (later TWJIA) would remove SSI/SSDI work "disincentives" and enable millions of disabled Americans to go to work. In fact, contrary to the hyperbolic claims, TWJIA is only an incremental move toward the removal of work penalties. The act's greatest value lies, not in the specifics of its modest provisions, but in initiating a key ideological shift in disability policy: it permits the first small steps toward delinkage of medical insurance coverage from impoverishment. In other words, in states that choose to participate some disabled people could qualify for Medicaid and other publicly funded support services without having to remain destitute. They could go to work while retaining eligibility for that vital assistance. This represents an important conceptual breakthrough in disability-related social-service policy making. But for the present and for many years to come, perhaps for decades, that conceptual advance will result in only limited practical changes because of the act's circumscribed provisions.

TWJIA does not institute permanent, comprehensive nationwide reform to eliminate work disincentives from 551 and 55DL. Rather, it authorizes, but does not require, individual states to establish time-limited "demonstration" projects, which is to say, experimental programs, to offer Medicaid to specified pilot groups of workers with disabilities. TWJIA also permits states to cap both the total expenditures for these projects and the numbers of participants enrolled in them. In addition, it allows states to liberalize or do away with the income and resource limits in currently existing benefits programs, but it does not direct them to do so.

The effectiveness of these experiments in promoting productive employment will depend on the package of features they offer in their Medicaid buy-in programs. If states fail to provide adequate access to health insurance and support services, many disabled people will continue to find it impossible to go to work. An instance of that sort of dereliction has apparently already occurred in Minnesota. That state has reportedly adopted a flawed Medicaid buy-in, return-to-work policy.

Not only will defectively designed state-option demonstration programs continue to block disabled people from seeking productive work; they will also expose the long-term campaign for reform of disability

policies to a significant political risk. Opponents of change want to keep in place the traditional system that dichotomizes "work" and "need." They will seize on the small numbers of disabled persons who seek employment under faulty TWA pilot projects as evidence of the failure of work incentives. They have already attacked work incentives provisions such as the Plan to Achieve Self Support and Section 16 I 9. Low employment rates due to deficient Medicaid buy-in programs will hand them ammunition to shoot down comprehensive national reforms.

A more immediate political obstacle already confronts disability rights advocates. TWIIA's neo-federalist approach necessitates cumbersome state-by-state lobbying for adoption of demonstration projects. The few states with well-organized and highly politicized disability organizations, such as California, have already mobilized to get their legislatures to adopt appropriately designed programs. But in most states, disability rights advocacy is less experienced, extensive, and effective politically. In those places, one can reasonably predict that the demonstration projects will vary widely in quality and efficacy. And, of course, some states will opt not to try TWIIA experiments at all. In many states, disabled citizens will find that they do not enjoy the equal protection of the laws.

Whatever the merits of particular state experiments, all of the TWIIA demonstration projects will expire within a few years. At that point, it will take an act of Congress to extend them. Some disability rights advocates hope and expect that the projects will generate a database that will persuade Congress to enact comprehensive national reforms. But they admit that the accumulation of that data may take a decade. That is, assuming that the state projects work as effectively as the highly optimistic forecasts predict. One would not be unduly pessimistic to expect the opponents of change to stall full-scale reform for as long as fifteen to twenty years. In other words, the multitude of disabled people who want to work and could work may be forced to languish in the "need-based" SSI/SSDI system for another generation.

As for me, well, my book, *The Invention of George Washington*, never earned the kind of royalties I had both hoped and feared it would draw. So, fortunately or unfortunately, it never put me in danger of losing the assistance I needed. On the other hand, it did help me finally get a tenure-track teaching position. Several schools turned down my applications for full-time openings in Early American history and even for part-time lectureships. A faculty member at one of those schools told me frankly that some of his colleagues doubted if I could do the job, given

my disability. At times I wondered if every search committee would bear out the warnings of my old professors that no school would ever hire me. But at last, the history department at San Francisco State University offered me a position, indeed, welcomed me as a colleague. At long last, in my mid-forties, I began my teaching career. Working sedulously, I tried to make up for lost time. I now hold the rank of full professor.

I do not tell you this to brag about my achievements or to boast about my tenacity and perseverance or to exhort other disabled people to try harder. That is the sort of individualistic claptrap usually fed to us. It keeps us believing that if our lives are limited, it is because of our disabilities or our lack of pluck. I recount my professional progress to make the point that I was liberated from the thrall of crippling public policies by successful disability rights lobbying. No matter how hard I worked, I could never have succeeded without the removal of work penalties. What tore them out of my way was the *political* tenacity and perseverance of our disability community. I got this far because of the achievements of the disability rights movement.

So here I am, having achieved in my profession much of what I had dreamt of as a young man. It took far longer than I expected or wanted. It came much later than it should have. The government denied me years of productive work, years I will never get back. Still, I am here.

But now I face a new worrisome dilemma. Both federal and state disability benefits programs regard retirement pensions as "unearned income." If and when I retire from my job and begin receiving the pension I am currently paying into, I will incur a substantial "share of cost" -that is, payment out of my own pocket-before I can receive any government financial assistance to pay for my ventilators or my personal assistance services. The "share of cost" will likely be so high that I will not qualify for any government aid at all. But my pension will not cover both my ordinary living expenses and the tens of thousands of dollars I will face annually in disability-related expenses.

As in the past, I am not the only disabled person controlling this problem. Thanks to SSI Section 1619, growing numbers of Americans with significant disabilities are seeking and holding jobs and pursuing careers. Some have had to take early retirement because middle age and hard work have exacerbated their functional difficulties. To their shock and dismay, they have discovered that by retiring and beginning to receive pensions, they become ineligible for the government assistance that has enabled them to live independently and work. They don't know



how they're going to survive. They are alerting the rest of us to the danger we too will soon face.

For decades, the government warned us that if we got jobs it would take away the assistance that made it possible for us to live independently and to work. Now the government is warning us that if we retire from our jobs it will take away that assistance. **In** other words, the old premises about people with disabilities remain in place. The old penalties that try to deter disabled people from productive work still threaten us. We still must fight policies that exclude or punish us.

The core of what I said in my statement just before I burned my book in October 1988 unfortunately remains true today:

"We, like other Americans, should have the right to work productively. Work and marriage penalties ... , far more than our disabilities, thwart our efforts and our lives. We demand an end to these discriminatory government policies."

"We are here today, not just for ourselves, but on behalf of millions of Americans with disabilities. My book represents, not just my work, but the work that we all want to do and could do. The burning of a copy of my book symbolizes what the government does to us and our talents and our efforts. It repeatedly turns our dreams to ashes. We find that outrageous, and we will no longer quietly endure that outrage."

"We, like all Americans, have talents to use, work to do, our contributions to make to our communities and country. We want the chance to work and marry without jeopardizing our lives. We want access to opportunity. We want access to work. We want access to the American Dream. "

Notes

Acknowledgments: I am grateful to Doug Martin, a longtime activist on these issues and a longtime friend, for correcting my errors and clarifying my explanations about disability policies and politics in this essay.

1. In the academic year 1971-72, I received financial assistance through a federal program called Aid to the Totally Disabled. Late in 1972, Congress created the Supplemental Security Income program by combining ATD with two other programs, Aid to the Blind and Old Age Assistance.

2. Deborah Stone, *The Disabled State* (Philadelphia, 1986).

3. Edward Berkowitz, *Disabled Policy: America's Progress for the Handicapped* (New York, 1987), 122-44; Kenneth A. Rasmussen, "An Overview of the History of Disability Policy: An Historian's and Insider's Perspective," paper presented at the Society for Disability Studies, Fourth Annual Meeting, Oakland, California, June 26, 1991, 28-31.