

From Entitlement to Investment:
Rethinking U.S. Disability Policy for the 21st Century

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Rethinking U.S. Disability Policy for the 21st Century

More than a decade after the passage of the Americans with Disabilities Act (ADA) in 1990, disability policy in the United States remains fraught with uncertainty, dashed hopes, and contradictions. While most persons living with disabilities today have an unprecedented quality of life — largely the product of medical and technological advancements that would have seemed more the realm of science fiction than science fact a generation or two ago — they are also experiencing some surprisingly negative trends.

A key concern is employment. A smaller percentage of non-elderly disabled Americans are working today than before ADA's passage, a phenomenon that is not just the result of changes in reporting or survivability, and is present across a range of disability types and severities. Analysts suggest a variety of explanations for this surprising, and depressing, trend, including employer fear of future employee lawsuits under ADA, the costs associated with legally mandated expenditures to assist disabled workers, and increases in spending and eligibility for public assistance programs for the disabled. While welfare reform more generally appears to have dissuaded many able-bodied Americans to forgo long-term dependency in favor of work, we have not engineered a similar change in thinking for the disabled population, and indeed in many ways their dependence on government seems to be growing rather than shrinking.

Another set of problems surround long-term care, as families struggle with ways to take care of disabled relatives without having to put them in costly and impersonal nursing homes. Although disability rates among the elderly have declined in recent years, and some predict a reduced need for long-term care in the future due to improving health and wealth among those nearing retirement age today, increasing rates among younger Americans and the overall aging of the population promise to put these issues at the forefront of public debate during the next two decades.

For the country as a whole, existing disability programs are proving to be expensive, ineffective, and sometimes counterproductive. A conservative estimate of total federal and state spending on services to the non-elderly disabled in the 2002 fiscal year was \$263 billion, a number that far exceeded public assistance for able-bodied recipients. Some of the most controversial issues of the day — from education funding and health care inflation to economic growth and the future solvency of Social Security and Medicare — reflect the costs imposed on all of us by a flawed model for disability policy that focuses on rights and redistribution rather than responsibilities and the creation of wealth. This “Entitlement Model” for serving the nation's disabled has smuggled concepts and principles from the civil rights era into an arena where they are largely inapplicable. It also treats too many disabled Americans as hapless and dependent wards of the state rather than as productive citizens whose value as human capital often remains untapped.

Policy-makers should replace this outmoded and costly “Entitlement Model” with an “Investment Model” for disability policy. Elements of the model include:

- Redefining disability itself to better target services to those who truly need them and separate more clearly the responsibilities of the public and private sectors. The current federal definitions of disability are mutually inconsistent, encourage long-term dependency, and help to disrupt what would otherwise be normal, private responses to individual hardships. As was demonstrated in a brief period of tighter eligibility standards in the early 1980s, defining disability more narrowly, at least for the purposes of doling out government cash or free health care, will help to control cost and allow federal and state authorities to focus their dollars more effectively on the severely disabled Americans who truly cannot find work or secure living conditions on their own.

- Reforming entitlement programs such as Social Security, Medicare and Medicaid to build real financial and human capital and to promote self-sufficiency. The disabled, no less than other Americans, would benefit from a system that allows them to redirect at least a portion of the payroll and income taxes they now pay into private savings accounts. In most such proposed systems, they would also be required to purchase private insurance for disability and long-term care. The accounts — invested in stocks, bonds, and other private assets — would grow over time to such a degree that they would likely provide far greater benefits to those who develop disabilities later in life, as has already been demonstrated in jurisdictions with account-based systems.

- Reshaping the delivery of disability services to include real incentives to place the disabled in competitive employment and shorten their stays on public assistance while spending taxpayers’ dollars where they are likely to generate the greater return. The success of integrated case-management practices in the private disability insurance market suggest that privatization, accomplished as part of Social Security reform and in other ways, would benefit both taxpayers and the disabled. As studies by the General Accounting Office have demonstrated, state-run vocational rehabilitation and disability-determination agencies have a poor record of getting injured or ill workers back on the job. If workers were able to purchase private insurance with their payroll taxes, rather than being compelled to support the public system, they would benefit from innovations already prevalent in the private sector, such as prevention, early intervention, and self-employment options.

- Renewing American federalism to give states and localities more control over disabled programs and more room for creativity and innovation. Unlike other programs serving disabled workers, workers’ compensation insurance is typically not provided by the government, although employers are usually required to purchase it. A competitive market offers employers a variety of providers and delivery mechanisms. Restoring federalism to the rest of disability policy would provide similar advantages. States should have more latitude to experiment with their Medicaid programs, including such ideas as vouchers, competitive contracting, and medical savings accounts. Even in programs traditionally monopolized by the federal government, such as Medicare, a less centralized approach could well result in better services to the truly disabled and lower costs to taxpayers.

I. History of American Disability Policy

From the earliest days of the English colonies in North America, the public sector has played a key but not exclusive role in providing sustenance, treatment, and opportunity for people with physical or mental infirmities. In a pattern we can see replicated today, most colonial Americans accepted the need for some tax-funded (but purely local) services for the disabled while viewing the provision of government aid to the able-bodied poor with far less approval — and often scorn. In setting up their programs, colonial and local governments emulated the system most had left behind in Great Britain. As the Cato Institute's Michael Tanner explains, England's Poor Law, passed in 1601, established four basic principles for government-run charity: 1) care for the poor was a public responsibility, 2) care for the poor was a local matter, 3) public relief was denied to individuals who could be cared for by their families, and 4) children of the poor could be removed from their parents' daily care and apprenticed to others to learn useful skills.¹

Public assistance was often justified by many contemporary politicians and thinkers as the logical extension of the government's duty to maintain order. If destitution led to homelessness, citizens would lose the unhampered use of city streets and public spaces. Importantly, the public had different expectations for the able-bodied who might be temporarily down on their luck and those deemed too sick or infirm to work. For the former, government officials were expected to make rules to discourage chronic dependency. For the latter, the public wanted a benign but efficient system of housing and support for the physically or mentally ill who didn't have families to support them.

The social consensus behind this distinction was broad and deep. Consider the fact that the philosopher John Locke complained as early as 1697 that England's public relief programs, then less than a century old, had strayed from their roots, encouraging vagrancy and dependency among the able-bodied poor by treating them as if they were infirm. "The multiplying of the poor, and the increase of the tax for their maintenance, is so general an observation and complaint that it cannot be doubted," Locke wrote in a draft "welfare reform" plan for the London Board of Trade. He pointed out that relief rolls were rising even during times of plenty, so it wasn't a lack of jobs causing the problem. "The growth of the poor must therefore have some other cause," he wrote, "and it can be nothing else but the relaxation of discipline, and corruption of manners, virtue, and industry being as constant companions on the one side as vice and idleness on the other." Locke advocated requiring work for relief and placing children in environments where they could learn job skills and sound moral values. He argued that the "true and proper relief of the poor... consists in finding work for them, and taking care they do not live like drones upon the labor of others" or live as "beggars swarming in the streets."²

In both England and early America, local officials established two main forms of public assistance. So-called "outdoor relief" provided the non-working poor with small sums of cash, food, or fuel. Although most recipients were widows, children, or the disabled, shiftless

men who lined up for outdoor relief gave it a bad name. As a result, many American towns came up with creative approaches. One was called “home relief.” In lieu of paying taxes to the town to provide outdoor relief, families would accept widows, orphans, or disabled persons for some period of weeks or months. Other towns paid the modern-day equivalent of foster families to care for these individuals year-round. Historian Walter Trattner reports that it was not unusual on a Saturday evening in some locales to “auction off” needy persons in the town square to bidders willing to house them, an intriguing if somewhat disquieting version of competitive contracting.³

Increasingly, however, governments looked for more formal arrangements. Before the Revolution, there were only a handful of institutions providing ongoing assistance. In 1756, the Pennsylvania Hospital opened a separate ward for the treatment of the mentally ill. Virginia created a state mental hospital in 1773. A few other colonial towns had established small freestanding homes to house those with severe physical or mentally illnesses.⁴ But at the beginning of the 19th century, many local governments began to create “poorhouses” where those living on the street were required to go for food and shelter. The able-bodied worked for their room and board, often in desperate conditions. To some extent, officials made poorhouses intentionally harsh to serve as a deterrent against going on the dole. After states began to require cities and counties to set up poorhouses in the 1830s, they became the dominant form of public assistance for much of the next century.⁵

Origins of Private Assistance

Parallel to the poorhouses, and often greater in extent and impact during the 19th century, were private relief societies run primarily by religious organizations. Scholars such as Gertrude Himmelfarb and Marvin Olasky have chronicled the successes of Victorian-era private relief, which was based on reciprocity, temperance, and moral teaching. Like their modern-day counterparts, these programs were often more effective than government programs in assisting those whose poverty was behavioral — arising not from being widowed or disabled but from personal behaviors such as drinking or sexual promiscuity. Why does private relief work better for the behaviorally poor? Because it isn’t an entitlement. Charities set the rules, and can enforce them. The term welfare wasn’t in use and wouldn’t have been accurate. “Unless the person were totally incapacitated,” writes historian Clarence Carson, “more attention was given to reforming the poor, getting them to become productive and self-supporting, than helping them to fare well.”⁶

During the same period, private institutions began to spring up to protect or insure able-bodied Americans in the event they were injured or developed a serious disability. In the for-profit sector, large railroad and mining companies were the first to experiment with “company doctors,” group health plans for employees, and contractual relationships with hospitals and physicians in the late 19th and early 20th centuries. These industries had high accident rates, so it paid for companies to invest in prevention and to keep providers on contract to assure injured workers of timely care. Railroad and mining firms also had many workers deployed in remote locations, further increasing the need for the employer to make sure health care was available.⁷ At the same time, these companies were among the first to develop pen-

sions, both for retirees and the disabled, although eligibility and participation rates remained low until after World War II.⁸ Finally, these companies began to develop informal systems for compensating workers injured on the job, with the primary goal of limiting cost and getting the injured employee back to work as quickly as possible.⁹

Another source of early innovation in health and disability insurance came from the non-profit sector in the form of “fraternal orders” and “benefits societies” that arose in the late 19th century to provide life insurance, disability aid, and other benefits to their members. Based around churches, lodges, or ethnic communities, these organizations began the practice of employing doctors to examine prospective members so that accurate prices could be charged for life insurance. Later, fraternal orders engaged their services to treat existing members on contract.¹⁰ Doctors would often compete aggressively on price to secure these large contracts, thus driving down the cost.

For the disabled, the 19th century was also a time of medical and technological progress. As signified by the publication of Dr. Benjamin Rush’s *Medical Inquiries and Observations* in 1805, physicians began to study mental problems as diseases rather than as stemming from character flaws or supernatural causes. American Thomas Gallaudet and Frenchman Louis Braille revolutionized the education and vocational training of the deaf and blind, the latter inventing a version of the raised-dot alphabet that would invite the visually impaired into the mainstream of letters and literature. Philanthropists and states created numerous schools for the blind and deaf. Dorothea Dix traveled extensively throughout the United States, prodig communities to set up or improve state institutions for the mentally and physically disabled. Although Dix’s efforts focused largely on taxpayer-funded hospitals, the reformist impulse spread throughout the sector. With the advent of antiseptics and aseptic practices in the latter 19th century, hospitals transformed themselves from asylums and hospices for the disabled or terminally ill, respectively, into places of healing. “Americans began to view hospitals not as places to die,” writes economist and medical historian Terree Wasley, “but as facilities for meeting the health needs of the public.”¹¹

The Progressives and World War I

As the Progressive movement began to take the reins of government power in the early 20th centuries, it fashioned a different model for providing relief to the poor and disabled. The American economy was undergoing rapid transformation. Corporations merged to form trusts and holding companies and technological innovation introduced higher and higher levels of “churning” in the workforce. During the depression of the 1890s, an unprecedented number of Americans lost their jobs, joining the ranks of the unemployed that already included displaced farmers and immigrants. Surely, Progressives argued, poverty was no longer a condition for which individuals could be held responsible. It was, rather, the natural consequence of uncontrolled economic and social forces. In effect, the Progressives began to treat all poor persons as their predecessors once treated only the most severely disabled.

Workers compensation was the first arena in which Progressive-era government began to push aside private arrangements for helping the sick and disabled. The sudden creation of

state workers' comp programs in the 1910s was one of the most rapid adoptions of a policy idea in American history, and helped to make the reputations of a number of Progressive politicians — including then-New Jersey Governor Woodrow Wilson. Furthermore, workers' comp represented the first foothold in American politics of the idea that government should take steps to “insure” private-sector workers against some kind of calamity. Once planted, this seed would sprout into unemployment insurance, old age and disability pensions, and widow pensions in the 1930s.

The issue of compensating injured workers had previously been hammered out in the courts. By the turn of the century, the trend was towards employer liability for injuries. But courts had established three common-law defenses: 1) that the injured employee had knowingly assumed the risks associated with his particular job, 2) that a coworker had played a major role in the accident, or 3) that the employee himself had helped to cause the accident. It might appear that this liability-based system was stacked against injured and disabled workers, and to some extent it was. Many were forced to wait for five years or longer for compensation. Others couldn't pierce those common-law defenses at all. But many employers weren't happy with the system, either. For one thing, it brought high administrative costs, even for a successful defense against an accident claim. Some business executives thought they would be better off providing immediate, predictable benefits to workers, regardless of fault, through some kind of company-based insurance system.¹²

With both employers and employees facing incentives to fashion a private workers' comp system, why didn't it come about? The answer is simple. Any private, voluntary workers' comp system (like the government-controlled systems that states subsequently created) would have to be based on a “liability-for-compensation swap.” Workers would sign a contract waiving their right to sue under the old liability standards in exchange for receiving benefits soon after an accident without delay or hassle. Unfortunately, state courts influenced by Progressivism sent a very clear signal that they would not respect such contracts. Judges ruled that workers could not sign away their right to sue, *even if workers did so freely with the expectation that they would gain through immediate, non-fault compensation*.¹³ These decisions made a private-sector solution impossible.

By the early 1910s both legislation and common-law standards concerning workplace accidents had changed so radically that employers, facing high insurance premiums and greater liability, became strong advocates of a government-imposed solution. So did labor unions disenchanted with a liability-based system that seemed to benefit trial attorneys more than injured workers.¹⁴ In most states, lawmakers created a system that retained a private, competitive market for workers' comp insurance but required most non-farm employers to participate and set compensation rates and procedures. In a few unlucky states, lawmakers set up a government-run insurance system with lackluster results. In general, however, the workers' comp movement, while made necessary only because of government's refusal to recognize voluntary contracts, nevertheless retained a component of market competition and pricing that serves as a useful counterpoint to later government “social insurance” programs. Basically, states required employers to purchase workers' comp insurance, under rules set by law, but did not usually provide it.

Federal Programs Begin. While states were creating government-controlled systems for assisting injured private-sector workers, the federal government focused on the public sector. President Teddy Roosevelt created a small workers' comp program for federal workers in 1908. In 1916, Wilson expanded Roosevelt's program to provide federal payments to federal civil service workers who became disabled. It was the first real federal "safety net" program for non-veterans.¹⁵

Historically, disability policy has tracked closely with policies related to veterans, for obvious reasons. Washington's only significant transfer payments during the 19th and early 20th centuries were veteran pensions, although they remained a small share of federal spending.¹⁶ During World War I, Wilson created a new system to provide pensions and other services to veterans, partially as a recruitment tool. The federal government promised to provide disability compensation, insurance, and vocational rehabilitation to assist injured servicemen in returning to work after the war.

By 1920, America found itself with an unprecedented number of veterans with disabling injuries. Congress passed the first Vocational Rehabilitation Act that year, which created grant programs for states to set up VR programs encompassing both veterans and non-veterans. In 1930, President Herbert Hoover signed legislation to combine the various federal veterans agencies into the U.S. Veterans Administration, later made a Cabinet-level Department of Veterans Affairs in 1989.¹⁷

One result of the fact that early disability programs evolved out of services to veterans is that recipients began to see themselves as entitled to help. In the 19th century, even states with significant investments in institutions and other programs for the disabled didn't view them as entitlements. These state programs were ways of caring for people who couldn't care for themselves and had few or no family resources to fall back on. They were last resorts for the desperate, not first resorts for the entitled. But disabled veterans had "earned" their payments or health services by their military service. As programs expanded to assist workers from the civil service and private sector, they retained some aspects of the military model, creating a sense of entitlement among an increasing number of disabled Americans (and, perhaps more importantly, their families).¹⁸

The New Deal and World War II

By 1933, government disability programs had already proliferated to include state-run vocational rehabilitation and job-placement programs, state-regulated or provided workers' compensation insurance, federal pensions for disabled veterans and civil servants, and state pensions and institutions for other severely disabled individuals. Although a reflection of creeping government growth, these programs were relatively limited in scope and expense. The New Deal began to change all of that. The 1935 Social Security Act created not only retiree benefits (thus alleviating the financial burden on states and families for caring for many older Americans with disabilities) but also Aid to Dependent Children, which federalized and largely replaced previous state programs offering pensions to widows and children who were either orphaned or severely disabled.

More important than the immediate impact on disability programs were the long-term implications. The Social Security Act represented only the first step towards its advocates' real goal: a comprehensive "cradle to grave" welfare state organized at the federal level. In 1934, when Roosevelt appointed his Committee on Economic Security to fashion social welfare legislation, advocates saw an opportunity to add health benefits to the mix. But Social Security proved more difficult to enact than initially expected. The administration saw national health insurance as too controversial to include in the 1935 act, so the idea was tabled. Even an early version of the bill, establishing a "Social Insurance Board" and authorizing it to study proposals for health benefits, mutated into a provision creating a "Social Security Board" and made no mention of health.¹⁹

The absence of statutory authority didn't worry the national health insurance lobby at all. In 1937, the administration formed a "Technical Committee on Medical Care" whose members ultimately issued a report stating that "it would be desirable to formulate a comprehensive National Health Program," including health insurance funded via general revenues or payroll taxes, direct federal support for hospitals, disability insurance, and federal support for public health and medical assistance programs run by states.²⁰ Each of these elements of the Roosevelt administration's "National Health Program" was accomplished, in one form or another, within 30 years.

Beginning in 1943, advocates introduced a series of bills to create compulsory national health insurance for all workers and their dependents. Harry Truman actually flirted with the idea of aggressively pursuing their passage, but recoiled once he realized the extent of political opposition.

By the early 1950s, activists within and outside government made a fateful change in strategy. Direct advocacy of national health insurance had failed. Many of its proponents in Congress had lost reelection in 1950, and the overall Republican trend did not bode well. A gradual approach, granting the legitimacy of a private (but increasingly regulated) insurance market, would have a better chance. They settled on the idea of limiting their national health proposals to the disabled and the aged, on the grounds that the public would view them as more appropriate beneficiaries of government largesse than workers. Once national health care for the disabled and elderly had taken root, activists could push for expansion to broader segments of the population.

Led by future Health, Education, and Welfare Secretary Wilbur Cohen and others, they recrafted their proposals. The first success was in 1956, when Congress and President Eisenhower agreed to add disability benefits for Americans under the age of 65 to the Social Security package. As a Brookings Institution analysis later observed, advocates viewed the new Social Security Disability Insurance (SSDI) program as "a necessary prelude" to the passage of Medicare. "Incremental change... has less potential for generating conflict than change that involves innovation in principle," the report argued. Social Security executives, "even when undertaking an innovation in principle, tried to cut and clothe it in a fashion that made it seem merely incremental."²¹

Veterans Benefits Expand. While these developments unfolded within the realm of social welfare policy, World War II brought yet another unprecedented wave of disabled veterans into the waiting arms of the federal government. One of Roosevelt's last acts as president was to sign the GI Bill of Rights, which among other things, granted more generous disability benefits to veterans — whether their disabilities were war-related or not.²² Again, the nobility of military service began to devolve into the pathology of entitlement and dependency.

The Great Society and Political Activism

The next step was to create comprehensive health insurance for retirees and the disabled. As with pensions and cash assistance, the idea was to introduce gradually the idea of government provision of health care by focusing on the most compelling cases. Pictures of destitute seniors, the blind, and persons in wheelchairs were worth far more than a thousand words about “socialized medicine.” States already had small-scale programs to assist the aged and others suffering from chronic medical conditions. Rep. Wilbur Mills, a Democrat from Arkansas, and his ally in the senate, Oklahoma Democrat Robert Kerr, fashioned a bill to create a new federal program, called Medical Assistance for the Aged, to provide support for state relief efforts. Congress passed the Kerr-Mills bill in 1960.²³

Mills predicted that the bill would head off calls for a larger federal role in health care. But the strategy failed. During the early 1960s, the push for comprehensive old-age health insurance strengthened. What developed were the contours of a debate that continues to this day. On one side were the ideological heirs of Roosevelt's Committee on Economic Security, who had proposed that health benefits be part of the original social insurance system. The other side, recognizing the political appeal of health care for the elderly and disabled, fashioned a bill that compelled individuals to purchase retiree health insurance but allowed a choice of competing private plans.²⁴

It was the election of 1964, 30 years after Roosevelt's aides first pitched the notion, that created a window of opportunity. Barry Goldwater and the Republicans got creamed. Armed with a huge electoral vote and large majorities in Congress, President Lyndon Johnson embarked on his Great Society agenda, of which Medicare and Medicaid were linchpins. Three decades of steady advocacy and Social Security expansion had also paved the way. In Truman's day, the public was overwhelmingly against the federal government entering the health insurance field. But a January 1965 poll by Gallup found that 63 percent of responding Americans favored a “compulsory medical insurance program covering hospital and nursing home care for the elderly... financed out of increased Social Security taxes.”²⁵

Even this reservoir of public sentiment and Johnson's legislative majorities didn't guarantee passage. The opposition coalesced around two legislative alternatives to the King-Anderson bill again introduced, which a reporter had dubbed “Medicare.” One was known as “Better-care.” It set up a voluntary health insurance system for seniors, covering both hospital and physician charges and funded by a combination of premiums and general tax revenues. Another bill focused attention once again on the problem of the elderly poor. This “Elder-care” alternative would strengthen the Kerr-Mills program that helped states with medical

expenses and long-term care for poor retirees.

The House Ways and Means Committee, headed by Mills, was the stage on which the Medicare and Medicaid dramas were to play out. After the 1964 elections, Democratic leaders reorganized the committee to ensure two Democrats for every one Republican, thus weakening support for the Better-care and Elder-care alternatives. The committee fashioned a compromise package of Social Security amendments that created three new federal entitlements: 1) Medicare Part A hospital insurance, compulsory and funded by payroll taxes; 2) Medicare Part B insurance for outpatient physician charges, voluntary and funded by subscriber premiums and general revenues along the lines of Better-care; and 3) Medicaid, a joint federal-state program for the poor and disabled, elderly or not, that built on the previous Kerr-Mills program and the Elder-care proposal. Johnson signed the amendments into law on July 30, 1965.²⁶

From a legislative standpoint, it was a clever compromise. Along the way, however, any aspects of Better-care and Elder-care that might have ensured a strong private-sector role in health insurance for the elderly and disabled, and confined public subsidies to the truly poor, were stripped out. Far from keeping the federal role in health care limited, the 1965 legislation resulted in a revolutionary change in American medicine. As Robert Helms of the American Enterprise Institute points out, “the Medicare legislation locked the government program into a historical straightjacket.”²⁷

Medicare and Medicaid fueled a massive increase in health care infrastructure and services. Hospitals expanded capacity. Equipment manufacturers made expensive new devices to diagnose and treat disease. The training of new physicians itself became dependent on Medicare funding of major teaching hospitals. But the programs grew far more rapidly than its creators intended or that its funding stream could finance. In 1964, the Johnson administration projected that Medicare would cost \$12 billion by 1990 (after adjusting for inflation). The real number was \$110 billion.²⁸ Just four years into the program, a Senate Finance Committee probe found that some physicians were charging Medicare four times what they billed private insurers. But limited cost controls enacted in 1972 failed to control Medicare’s growth. One reason was that the same legislation expanded coverage to include the non-elderly disabled, just as Social Security had earlier been expanded to include disability insurance in 1957.²⁹

With regard to Medicaid, the disabled were part of the caseload from the start. It was also supposed to stay a relatively low-cost program when lawmakers fashioned it out of Kerr-Mills. It was not to be. In its first year, the program cost \$1.3 billion — \$600 million from federal coffers and \$700 million from the states. By 1970, the federal government had begun to pay a majority of the bill, though states continued to administer the program, and the total cost had topped \$5.3 billion.³⁰ Over the next 30 years, Medicaid costs exploded, exceeding \$200 billion by the end of the century.³¹ The non-elderly disabled, although a relatively small share of enrollees, had by the mid-1980s become the costliest group, consuming more than a third of all Medicaid spending.

It might seem odd that disabled Americans are simultaneously eligible for two different government health programs, Medicare and Medicaid. Although sometimes the anomaly is explained by suggesting that the two are complementary — Medicare covering acute-care services and Medicaid the long-term care side of the equation — the reality is far more messy. Medicare does pay for some limited long-term care costs, while Medicaid pays for hospital stays and physician services just as Medicare does, although Medicaid reimbursement rates are typically much lower. Rather than working together as a comprehensive set of health benefits for the disabled, Medicare and Medicaid follow different eligibility guidelines. Only 43 percent of disabled persons enrolled in Medicare are also eligible for Medicaid, which is means-tested. The dual-eligible disabled actually rely on Medicare for the bulk of their hospital and doctor bills, while tapping Medicaid for long-term care and prescription drugs.³²

The Disability Rights Movement

In disability policy, the 1960s and early 1970s were about more than just health policy. As was true with so many other groups of Americans, the disabled during this period began to discover political activism. A pivotal leader of the so-called “disability rights” movement was Ed Roberts, who had been paralyzed from the neck down in a childhood bout with polio. In 1962, he gained admission to the University of California at Berkeley. He soon joined with other disabled students to form a group called the “Rolling Quads” that eventually secured a federal grant to start the Physically Disabled Students Program. From this beginning, the movement spread across the country. Roberts and others began to champion “independent living” programs that allowed disabled persons on public assistance more control over the services they were using. The first independent-living center opened in Berkeley in 1971.³³ Other disabled activists began to demand great accommodation in public facilities such as schools, universities, libraries, parks, and government offices. Later, they turned their attention to private businesses.

In addition to independent living programs, which now exist across the country with federal and some state funding, other legacies of the early disability-rights movement include the reauthorization of federal vocational rehabilitation aid in 1973 and the creation of federally funded special education in 1975. In the former case, Congress modified an existing Rehabilitation Act to increase funding for state-run job training, sheltered employment, and independent living programs for the disabled and established more federal oversight over how these programs were to be run. Perhaps the most significant part of the 1973 legislation, however, was Section 504 — a single paragraph that prohibited discrimination on the basis of disability by any public or private institution receiving federal funds, including schools, universities, social service agencies, and hospitals.³⁴ Armed with this brief but pivotal legal language as well as the resources of new federally funded advocacy councils in a number of states, the disability-rights movement staged demonstrations, conducted media campaigns, and in 1977 took over the San Francisco offices of the then-Department of Health, Education, and Welfare to demand what they termed “equal rights.”³⁵ The movement was consciously emulating the tactics of the civil rights movement of the previous decade, thus adding another element to the entitlement ethos that had already been created by previous political campaigns on behalf of disabled veterans.

The 1975 legislation, originally called the Education for All Handicapped Children Act, followed the example of the 1973 rehabilitation bill by combining federal funding for state-based programs with new civil-rights protections. Given the more politically correct name of the Individuals with Disabilities Education Act (IDEA) in 1990, the legislation approved significant federal funding of local public schools for the first time, in the form of grants for special education services. It also created “early intervention” programs for disabled preschoolers and training programs for educators and parents. Furthermore, it contained a provision that guaranteed disabled children the right to a free and appropriate public education, again mirroring the language of the movement against racial segregation of the public schools during the 1950s and 1960s.³⁶

The 1990s: ADA and Ticke to Work

The politicized disability-rights movement reached the pinnacle of its influence in 1990 with the passage of the Americans with Disabilities Act. Reflecting the shift in emphasis from service delivery to civil-rights enforcement that had been evident in disability policy for decades, the legislation went well beyond the 1973 Rehabilitation Act. It made discrimination against the disabled illegal by virtually all employers and businesses open to the public, and for the first time gave individuals the right to sue over alleged violations.

As Brian Doherty described in a 1995 cover story in *Reason*, the legislation was not the result of thoughtful debate about the constitutionality of such a sweeping directive, a careful calibration of the potential costs and benefits, or even sheer power politics. Its passage was, instead, driven by the testimonials of individual members of Congress with disabilities or disabled relatives and the lobbying efforts of a relative handful of disability-rights activists. “You’d look out in the hall, and see 50 people in wheelchairs and people climbing out of wheelchairs trying to crawl up the Capitol steps, and logic and rationality go out the window,” one congressional staffer told Doherty. “The ADA is filled with lack of definition, everything’s open-ended, but the attitude was, this is a feel-good thing, let the courts decide.”³⁷

That’s precisely what happened. The ambiguity in the law led to an explosion of legal actions and lawsuits. During the first four years of the ADA, the Equal Employment Opportunity Commission (EEOC) fielded some 40,000 complaints. Nearly half of the complaints involved individuals citing back pain and mental or neurological impairments, not the traditional picture of the disabled that many Americans had in their minds. As far as lawsuits went, employers ultimately won the vast majority of them, but the costs of litigation were nonetheless significant for many businesses. “The main result of the ADA is to provide disgruntled or former workers with another arrow in their quiver to challenge an employer’s decision,” observed Washington, D.C. attorney David Copus in an *Investor’s Business Daily* story. “By and large, these arrows don’t hit the target, but they are costly [for employers].”³⁸

By the mid-1990s, there appeared to be increasing evidence that the ADA, which many had expected to improve the lot of Americans with disabilities, had accomplished little. Much of the legal wrangling involved plaintiffs with relatively mild impairments, if any, while em-

ployment rates among the disabled did not appreciably increase, and by some measurements actually declined. Thomas DeLeire, a professor of public policy at the University of Chicago, studied federal data for working-aged disabled men from 1990 to 1995 and discovered an 8 percent drop in employment. The culprit, as is so often the case with intrusive regulation, was an unintended consequence. "It's likely that the ADA led to people with disabilities being perceived as more expensive for employers, both because of the potential litigation and the costs of accommodations," DeLeire said. Another study by researchers at the Massachusetts Institute of Technology found a similar trend, with an average drop of two to three weeks in time worked each year by disabled men.³⁹ As Russell Redenbaugh, a blind investment manager who serves on the U.S. Civil Rights Commission, put it in a 1999 interview, many policy-makers began to fear that "the ADA implementing regulations [had] a chilling effect on the hiring of the disabled."⁴⁰

Both the Republican Congress and the Clinton administration, recognizing the trend of stagnant or declining employment among the disabled, began to reexamine the civil-rights emphasis of recent disability policy. Rather than attributing the low employment rates simply to discrimination, lawmakers turned their attention back to the amalgam of programs already created to serve disabled individuals. They found that many of these programs were largely ineffective. For example, a 1997 General Accounting Office study found that the Social Security Administration had done a poor job of helping SSDI and SSI recipients find and keep jobs. Other studies questioned the effectiveness of state-run vocational rehabilitation programs, even for the relatively small number of disabled beneficiaries who took advantage of their services. Moreover, many analysts observed, eligibility standards for SSDI, SSI, and health coverage under Medicare and Medicaid often deterred disabled beneficiaries from seeking employment, since they risked losing valuable benefits, at least during the transition from dependency to work.⁴¹

In 1999, Congress amended the Social Security Act with the Ticket to Work and Work Incentives Improvement Act. As the title suggests, the legislation focused on two key issues. First, it created the "Ticket to Work" program, which essentially offers a voucher for job-training and other services to disabled Americans that previously could obtain the services only from state-run vocational rehabilitation agencies. Although the program is still being rolled out, it may offer some competition and innovation in the rehabilitation field, where these would certainly be welcome. The other main thrust of the 1999 act was to liberalize eligibility for Medicare and Medicaid in an attempt to reduce the disincentive for disabled beneficiaries to pursue employment. Disabled workers can now retain Medicare hospital insurance for nearly eight years before having to purchase private coverage, compared to the previous 39 months. And states now have greater latitude to offer Medicaid to disabled workers who would otherwise earn too much to qualify.⁴²

II. Current Issues in Disability Policy

America's diverse set of programs and policies serving the disabled has grown by fits and starts over the past century. It now includes health insurance for acute and chronic conditions from Medicare and Medicaid; income support from SSDI, SSI, and state Special Assistance supplements; compensation, pensions, and health care for disabled veterans; separate federal programs for vocational rehabilitation and the mentally ill, and federal funding for special education. Of course, disabled Americans also benefit from other programs for which disability is not itself the path of eligibility. For example, a 1996 federal survey found that disabled Americans received 23 percent of all Food Stamp benefits and 33 percent of Aid to Families with Dependent Children (AFDC), now called Temporary Assistance for Needy Families.⁴³ Both are means-tested programs.

Using the FY 2002 federal budget and a variety of federal data and projections, I prepared a conservative estimate of how much federal and state governments spent on services to the disabled in that fiscal year. I excluded planned spending on elderly Americans who are also disabled, because they are not the focus of this paper. My projection of disability-services spending for those under age 65 was \$263 billion in FY 2002, of which approximately 82 percent was federal spending and 18 percent state and local spending (primarily Medicaid). From FY 1995 to 2002, disability-services spending grew about twice as fast (58 percent) as the total budget (29 percent). By far the largest category of disability services is health care, which totaled at least \$139 billion in FY 2002. By my calculation, health care spending for the disabled — by Medicaid, Medicare, and the Department of Veterans Affairs — will have grown by a whopping 85 percent since FY 1995.⁴⁴

This brings up another critical question: how many Americans are disabled? Depending on the survey instrument and definitions used, one can come up with widely differing answers. For the purposes of this report, I will zero in on the percentage of working-aged Americans who report a mild or severe disability. Two federal surveys — the Survey of Income and Program Participation (SIPP), conducted by the U.S. Census Bureau, and the Current Population Survey, which is a joint project of Census and the Bureau of Labor statistics — provide upper- and lower-bound estimates of the disability population.

The SIPP definition is relatively loose, reflecting the approach also used in the Americans with Disabilities Act. It asks survey respondents to report any disabilities, even those that do not limit the respondent's ability to work or perform other tasks. The most recent survey, conducted in 1997, found that 19.7 percent of the total sample was disabled. However, I will exclude both children under 15 and the elderly from my analysis, given that both groups typically are not in the work force and that the risk of developing a physical or mental infirmity rises steadily after the normal retirement age of 65. According to the 1997 SIPP, about 17.3 percent of working-aged Americans were disabled, with 10.6 percent having a "severe" disability.⁴⁵ Updating the numbers to comport with the above spending projections for 2002 yields an estimate of 32.2 million Americans between the ages of 15 and 64 with some kind of self-reported disability and 19.7 million with a severe one.

The Current Population Survey uses a more precise definition. It defines respondents as having a “work disability” if 1) they did not work in the week they were surveyed due to a chronic physical or mental illness, 2) they did not work at all during the previous year because of illness or disability, or 3) they were under 65 and on either Medicare or SSI, thus meeting the disability test required for program eligibility. In 2000, the CPI estimated that 9.7 percent of working-aged Americans had a work disability and only 6.4 percent had a severe disability.⁴⁶ Updating the numbers using the 2002 estimates show 18 million disabled and 11.9 million severely disabled.

Disability and Cost to Taxpayers

If we accept the lower estimate from the SIPP and the upper estimate from the CPS as our high and low bounds, states and the federal government in FY 2002 spent an average of between \$13,350 and \$14,600 for each disabled person of working age. Naturally, this is only a rough approximation for the purposes of discussion. It is also an average; most people with mild or moderate disabilities do not consume many government services, while some severely disabled individuals on cash assistance, Medicare, and Medicaid cost many times the average expenditure. Nonetheless, the magnitude of the overall expenditure helps to explain why such programs as Medicare at the federal level and Medicaid at the state level present such significant fiscal challenges in the future. Trustees for the Medicare program project that expenditures for Medicare Part A will exceed its revenues by 2016. After that date, either the payroll tax earmarked for Medicare will have to rise, benefits will have to be reduced, or the program will have to receive additional support from the general federal budget, financed either through program reductions or general tax increases. The program’s long-term finances were worsened in 2003 with the passage of a new prescription-drug program that will likely exceed its projected cost of \$400 billion over 10 years. The bill also contains a demonstration project for private-sector competition in Medicare, but the project is well off in the future and strictly limited in scope and duration.⁴⁷

With regard to Medicaid, both Washington and the states experienced rapid, often double-digit annual growth in expenditures in the late 1980s and 1990s, due primarily to eligibility expansions, higher prices, and increased utilization. After a brief respite in the mid-1990s, the Medicaid program is once again growing far faster than overall government spending, forcing some states to cut reimbursements, raise taxes, or shift funds from education and other programs. According to federal projections, Medicaid will likely grow at an average annual rate of 8 percent through 2008, with expenditures for the disabled caseload alone growing at a still-higher 9 percent rate. Already, Medicaid spends an average of \$9,000 per disabled recipient, compared to less than \$2,000 per poor child or adult. This average expenditure for the disabled has more than doubled in the past 20 years, and the ranks of disabled recipients is expected to grow at a 2 percent annual rate, compared to a 1 percent rate for the rest of the Medicaid population.⁴⁸

Some analysts suggest that Medicare and Medicaid may turn out to be more affordable than these dire predictions would suggest. They point out that growth in nursing home expenditures, primarily covered by Medicaid, has leveled off in recent years, and that rates of

disability among the elderly are falling due to better nutrition, health care, and living standards. A recent study from the National Academy of Sciences found that disability rates for those over 65 years of age took a precipitous drop in the late 1990s, reflecting a variety of lifestyle and medical factors. It also found that the number of elderly persons in nursing homes has actually fallen by 200,000 over the past decade, thus alleviating some of the pressure on Medicaid.⁴⁹ Another Academy study, published in 1997, concluded that observed declines in disability among the elderly, if continued, would have significant implications “for the fiscal stability of Medicare.”⁵⁰

Unfortunately, this good news may neither eliminate nor greatly reduce the forecasted growth in Medicare and Medicaid costs. One reason is that, even with lower rates of disability, the Baby Boom generation is so large that its aging will still put tremendous pressure on the health programs. In addition, some of the reduced illness and disability predicted by the optimists is due to valuable but expensive treatments, including prescription drugs and surgical techniques, that will still consume significant Medicare and Medicaid dollars. Imagine how wonderful for longevity and quality of life, but how costly for government health programs, would be the development of effective treatments for Alzheimer’s disease and other illnesses and disabilities now largely untreatable. Overall, according to a study by Harvard University’s David Cutler and the Federal Reserve Board’s Louise Sheiner, even an optimistic estimate of disability rates and medical price inflation suggests that the share of GDP devoted to Medicare alone will increase by nearly 50 percent over the next 50 years. If medical costs grow at a rate closer to what they have in recent history, then a continued decline in disability among the elderly won’t keep Medicaid spending from increasing more than five-fold to 10.4 percent of GDP.⁵¹

As far as nursing home care is concerned, some analysts have predicted far lower expenditures than baseline forecasts would suggest, in part because increasing longevity means more opportunities for spouses to provide informal care instead of institutional care. But the number of persons entering old age who have never been married or who are divorced will also increase, thus offsetting the potential cost savings from longevity. Finally, even if the nursing home population continues to shrink, rising costs per patient will still push overall expenditures well above their current share of GDP.⁵²

Perhaps most important, however, is the tendency of many defenders of the current Medicare and Medicaid structure to consider only trends among the elderly population in their optimistic forecasts. The reality is that the under-65 population is experiencing growing, not shrinking, rates of disability and the taxpayer costs associated with this development are surging.⁵³ As already noted, Medicaid costs per recipient rose more quickly during the 1980s and 1990s for the disabled than for any other beneficiary group, and their share of total Medicaid enrollees will increase dramatically over the next decade.⁵⁴ In a National Bureau of Economic Research paper published earlier this year, three researchers from the RAND Corporation concluded that the disabled population under the age of 65 grew by 35 percent to 40 percent from 1990 to 1996, offsetting a corresponding decline in the elderly disabled. Much of the deterioration in health among the young, they argued, might be attributed to increases in asthma and Type 2 diabetes, the latter usually the consequence of obesity. They also observed

that increased incentives to claim disability benefits, including SSDI, could well explain some of the observed increase.⁵⁵ For the purposes of evaluating how these trends will impact government expenditures, however, it doesn't matter whether the increasing disability is due to worsening health or greater use of government benefits. Both suggest the possibility of continued growth in Medicare, Medicaid, and other programs serving the disabled even if spending growth tapers off for the disabled elderly.

Disability Services and Employment

As the RAND researchers noted in their study, the relationship between government programs and the tendency for individuals to identify themselves as disabled and leave the workforce is a cause for great concern. By creating incentives for those who may have mild or moderate disabilities to become dependent on government assistance, the nation's disability services system is not only a burden to the taxpayer but also a threat to the well-being of many disabled Americans in the long run. Decades of social science research have documented the value of work as a means of adequate support, as a source of satisfaction and self-worth, and even as a means of maintaining good physical and mental health. For many Americans, the workplace is where they face and overcome their greatest challenges, have their greatest social interaction with non-relatives, and often meet potential friends or spouses. Those shut out of the world of work suffer the loss of many such amenities. So when government provides benefits and services in such a way that discourages employment, it can actually reduce the quality of life of the disabled person it is trying to assist.

"Most people see work in a number of ways, besides just as a means to earn income and to purchase the necessities of life and items of interest to them," said a case manager for a private disability insurer. "It's also a social outlet, a place where you become stimulated with new assignments or opportunities for learning. Every day there are new interactions and challenges. Work provides structure to someone's life. When you take that away because of illness or injury, the individual loses a part of their structural foundation."⁵⁶

The evidence is clear that current disability programs fall short of providing adequate work incentives for the disabled, as Washington policy-makers concluded in the debate leading up to the passage of the 1999 Ticket to Work and Work Incentives Improvement Act. To begin with, the evidence of a decline in work participation by the disabled is pretty clear. According to the SIPP data, the percentage of all Americans between the ages of 21 and 64 who were employed increased from 75 percent in 1991-92 to 78 percent in 1997. But employment rates for the disabled fell from 52 percent to 49 percent during the same period. The trend was particularly pronounced for those with learning disabilities and mental or neurological disorders, while employment rates for the blind and those restricted to wheelchairs — two groups more traditionally associated with severe disability — actually saw employment gains. However, these latter groups make up a relatively small share of the total disabled population (about 5 percent, according to the SIPP definition).⁵⁷

Although long-term data are not available, there does seem to be a match between these employment-rate declines and the availability of government benefits. A recent paper by David

Autor of MIT and Mark Duggan of the University of Chicago noted that the share of non-elderly adults receiving SSDI and SSI benefits rose from 3.1 percent in 1984 to 5.3 percent in 2000.⁵⁸ A key reason for this exploding caseload (the actual number of beneficiaries more than doubled) was that SSDI and SSI eligibility was liberalized in the mid-1980s after a period of relatively tight eligibility guidelines in the late 1970s and early 1980s.

Specifically, rapid growth in caseloads after 1972 — when SSI was created and the non-elderly disabled made eligible for Medicare — led the Social Security Administration to reform its eligibility process and exercise firmer control over state disability-determination agencies. As a result, the percentage of SSDI applicants approved for benefits fell from 45 percent in 1976 to 32 percent in 1980. SSI approval rates fell even more sharply. Congress followed this administrative action by requiring more frequent disability reviews and even tighter eligibility rules for SSDI. As hundreds of thousands of “disabled” individuals left the welfare rolls, the issue became controversial. Several states refused to comply with federal disability-determination guidelines.⁵⁹

By 1984, the political winds had shifted. Congress enacted new rules that had the effect of dramatically loosening eligibility for cash assistance, and thus for Medicare and Medicaid services. Autor and Duggan report that by 1986 SSDI awards were 38 percent higher than in 1982 and SSI awards had more than doubled. Not only did the number of disabled Americans on the dole increase, but their makeup also changed markedly. They became, on average, younger and less severely disabled. The mortality rate for SSDI recipients dropped by a third from 1984 to 1999.⁶⁰

Many other studies confirm the relationship between disability benefits and employment rates.⁶¹ One might go as far as to say that it has now become close to a consensus position across the political spectrum. On the Left, MIT’s Jonathan Gruber has concluded that generous SSDI benefits do reduce labor force participation, particularly for older workers, although he does not view this as a problem since it results in an income “transfer to the relatively poor-off population of disabled.”⁶²

The problem isn’t just that many people, especially those with relatively mild disabilities, are ensnared in a system of public assistance that seems to offer more valuable benefits than a job would offer. Even those SSDI, SSI, Medicare, and Medicaid beneficiaries who express a desire to enter the workforce are hampered from doing so by ineffective state-run vocational rehabilitation and job-placement programs. In 1993, about one-third of SSDI recipients who returned a survey from the Social Security Administration indicated a willingness to return to work. Yet few SSDI recipients are referred by their state to vocational rehabilitation programs, and many are not accepted as clients. In 1995, only about 17 percent of persons served by VR agencies were placed in employment (and these placements included those who became “homemakers” or “unpaid family workers”).⁶³ Furthermore, these VR outcomes aren’t exactly stellar. The General Accounting Office found that most of the gains in employment and earnings of VR clients tended to fade after two years, with earnings for many returning to pre-VR levels after eight years.⁶⁴

III. Disability Services and Civil Society

The negative relationship between massive governmental expenditure and self-sufficiency is not confined to the area of employment. Although our system clearly fails to maximize the work effort of disabled Americans, there will always be many disabled persons, employed or not, who will need significant assistance with their daily needs. The issue of long-term care for the disabled and elderly is a perplexing one; it receives insufficient attention from many policy-makers yet it has a pervasive impact on state and federal budgets.

To start with, it is not always easy to distinguish long-term care from acute care. Someone living with a chronic illness can spend a great deal of time in a hospital setting, receiving acute care, as well as receiving long-term care at home, in a nursing facility, or somewhere in between. Lines must be drawn, of course, particularly for the purposes of fashioning public policy, but it is important to keep in mind how medical care for the disabled can overlap with daily chores such as bathing, feeding, and eating.

Second, the private sector has always played the lead role in providing long-term care to the disabled, and remains the main provider even in today's world of massive Medicare and Medicaid expenditures.

I am not referring to the private market for long-term care insurance, however, which remains minuscule. According to the most recent comprehensive data, private insurance paid for only about 11 percent of formal long-term care expenditures in the United States. About 27 percent was financed with out-of-pocket spending by patients and their families, and another 5 percent was covered by philanthropy. About 57 percent of such spending was covered by Medicaid, Medicare, and other government programs.⁶⁵

So why do I suggest that the private sector continues to bear the primary responsibility for long-term care? Because most such expenditures are informal. They consist of the dollar value of the time spent by spouses, children, and other family members and friends who attend to the daily needs of disabled individuals. One recent study estimated that such informal long-term care expenditures should be valued at nearly \$200 billion — far larger than the \$123 billion in formal expenditures on nursing home and home-based long-term care in 1999.⁶⁶

With the exception of child-rearing, caring for a disabled parent, child, or sibling is perhaps the most basic function of a family. And assisting those in the community with physical or mental disabilities has been a core function of religious institutions and other charities throughout human history. Although modern medical marvels and technological advances have transformed the lives of the disabled, much of what we call “long-term care” consists of such everyday tasks as brushing teeth, feeding, clothing, and changing bed pans. The work hasn't changed much over the years.

Although the long-term care of the disabled remains largely a private function, government has taken on vastly more responsibility for these basic and intimate needs over the past

four decades. In 1960, before the creation of Medicare and Medicaid, nearly 85 percent of all nursing home expenses, for example, were paid for by patients' families or philanthropists. By 1970, the proportion had fallen to less than 60 percent. In 1999, it was only 40 percent.⁶⁷

In the Medicaid program, it is very much the long-term tail that tends to wag the rest of the dog. Consider that in the 1998 fiscal year, about 19.3 million Medicaid recipients made prescription drug claims and 18.5 million made physician claims. Only 1.6 million spent some time in a nursing home. Yet nursing home expenses were by far the single-largest category of spending, making up a third of all Medicaid expenditures that year. If you add in home-based care, the long-term care proportion climbs to 41 percent.⁶⁸ In the Medicare program, spending on home health care — which serves but is not necessarily limited to those persons self-identified as disabled — grew tenfold between 1987 and 1995. This explosion in costs led to action by the Republican Congress and the Clinton administration in 1997 to rein in Medicare reimbursements to home health agencies and make other changes designed to reduce cost.⁶⁹

It is too early to tell how much these changes will impact taxpayers and the disabled, but this is not the only important question. The existence of Medicare and Medicaid has led to a sharp reduction in private responsibility for the long-term care of the disabled. There is a human cost, as well as a financial one, to this development. Many parents or children who were once considered the solemn responsibility of their families are now being cared for by strangers, with significant taxpayer subsidy. An entire industry of lawyers, accountants, and benefits consultants now exists to counsel families on how to shield their assets and make their disabled members eligible for benefits (some elderly couples are even encouraged to divorce in order to maximize their Medicaid benefits).

The results are tragic. Some families are given incentives to shed their responsibilities. Some lose touch with their disabled relatives. Churches, synagogues, mosques, and other charitable institutions are discouraged from assuming a larger role. Patients lose at least some of their ability to choose what daily services they receive, and from whom. Civil society — that intricate set of voluntary social relationships — is eroded. In the short run, it may be impossible to reverse these trends and begin to increase private responsibility and self-sufficiency. But policy-makers should keep this goal in mind when fashioning alternatives to grapple with the more immediate problem of taxpayer cost.

IV. A New Model for Disability Services

As has been demonstrated, America's costly and sprawling system of disability services was not built according to a coherent long-term plan, although politicians and activists did work patiently over many years to create specific programs such as Medicare. Beginning with the politically powerful constituency of disabled veterans early in the century, and then expanding markedly in the 1960s with the contemporaneous growth of the civil-rights movement, the "Entitlement Model" has come to dominate disability policy. As the ADA example shows, this model has important drawbacks. By treating virtually all disabled Americans as

permanent or semi-permanent wards of the state, rather than as persons with the potential to become more self-sufficient, our current government programs work against the interests of both taxpayers and the disabled themselves.

It is time for a new model for disability services, one chosen consciously by state and federal policy-makers and reflecting the latest innovations in technology, service delivery, and finance. This new “Investment Model” reflects a fundamental shift in public policy away from the disabled-as-entitlement mindset, although it does not contemplate the complete elimination of government programs. Rather, it seeks to transform these programs, as much as possible, from ongoing and broadly used entitlements to short-term and targeted investments, while revitalizing the role of private institutions in providing critical assistance to the disabled. To begin to implement the new model, policy-makers must take action in four key areas:

- Redefining Disability

The process of identifying persons with disabilities and approving their eligibility for services is broken. As evidenced by the widely varying estimates of the disabled population by federal statisticians, there is no coherent definition of what disability is for the purposes of approving government benefits. As already noted, state agencies that handle disability determination are approving many more applicants for benefits than was true 20 years ago. Moreover, the passage of ADA encouraged millions of Americans to consider themselves disabled for the first time.

An expansive public definition of disability has several deleterious consequences. First, to the extent that it allows Americans with only modest levels of impairment to obtain government services, it inflates the cost of disability programs and consumes dollars intended to assist those whose severe disabilities truly prevent employment or self-sufficiency. Moreover, by encouraging dependency, a loose definition of disability encourages those who could work and otherwise make positive contributions to society to remain on the dole, thus harming the broader economy and society.

Redefining disability, at least for the purposes of administering public services, should begin by separating out those physical and mental conditions that can be eliminated or substantially reduced through medical or technological intervention. In this case, a disability should be a physical, mental, or emotional condition, disorder, or pathology that causes a significant impairment or inability to perform a major life activity (such as work in the case of working-aged applicants or education in the case of children). After all, most Americans at one time or another in their lives will experience a substantial inability to see, an inability that prevents them from reading, working, or other functioning “normally.” Of course, the vast majority of them can use corrective lenses that virtually eliminate the problem. They are not disabled in any meaningful sense.

Redefining disability in this way may seem unduly harsh. But remember that the purpose is to determine eligibility for cash assistance and free medical care. It has no other meaning.

Those with various physical and mental infirmities can and should receive assistance from family, friends, and charitable institutions if they need it. But they are not wards of the state in the way that a severely deformed or disabled person might be, and should not be treated as such. An expansive definition of disability is one of the reasons why the public sector's role in disability has grown so rapidly.

Finally, a more narrow definition of disability will be necessary if other reforms of the disability-services system are to succeed. Frankly, there are many possible pitfalls to making programs such as SSDI, SSI, Medicare, and Medicaid more user-friendly and more conducive to future employment. Unless policy-makers are careful, they will offset any potential gains from the reforms by making the programs more attractive to *potential* beneficiaries, thus increasing application, awards, and expenditures. Moving towards a more restrictive system for determining program eligibility, as was attempted in the early 1980s and is worth trying again, is an indispensable component of the new Investment Model for disability services.

- Reforming Federal Programs to Build Real Assets for the Disabled

Although some Americans are born with disabilities, the vast majority of those now identified as disabled have developed their physical or mentally infirmities later in life, either through accident or through a combination of genetic and environmental factors. Since the Social Security Act of 1935, they have essentially been forced to set aside a portion of the incomes of themselves and their families in order to “insure” against the possibility that a disability would render them unable to support themselves. But for reasons made clear in the Cato Institute’s work on the Social Security and Medicare systems, the “insurance” provided by the federal government has turned out to have a paltry payoff. Unlike true insurance systems, in which current revenues are invested in real income-producing assets in order to pay future claims, the Social Security and Medicare systems are allowed to “invest” only in special, non-negotiable Treasury securities. In effect, American workers have loaned their savings to the government, which has proceeded to squander much of the loaned funds on transfer payments and government “investments” of little value.

The disabled, no less than other Americans, would benefit from a system that allows them to redirect at least a portion of the taxes they now pay into Social Security and Medicare into private savings accounts. In most such proposed systems, they would also be required to purchase private insurance for disability and long-term care. The accounts — invested in stocks, bonds, and other private assets — would grow over time to such a degree that they would likely provide far greater benefits to those who develop disabilities later in life.

This is not just a theory. Where private disability benefits are allowed, disabled workers are almost always better off than their peers in federal programs. For example, the city of Galveston, Texas, opted out of Social Security in 1981 and its workers receive retirement and disability benefits through personal accounts. A 1999 GAO study found that a 21-year-old low-income disabled worker would receive \$829 per month from the personal account plan, while a similar worker would receive nothing from Social Security. Among older low-income workers, Galveston’s disability benefits averaged between 50 percent and 100 percent higher

than under Social Security. In Chile, a 1996 study found that the country's privatized system paid disability benefits that averaged 75 percent more than under the prior government-funded system.⁷⁰

- Reshaping the Delivery of Disability Services

One of the biggest potential advantages from Social Security privatization is that it would likely improve work incentives for the disabled. A competitive market for private disability insurance already exists, but a mandate to millions of workers to purchase such coverage in lieu of relying on the government would create additional options. Studies by the General Accounting Office clearly show that private disability insurers in the United States are much more successful than their public-sector counterparts in placing disabled workers back into employment and keeping them there.⁷¹

Private insurers act quickly to find out what a newly disabled person needs and how to deliver it. They confer with medical providers to ensure that therapies, prosthetics, drugs, and other treatments are given with the goal of maximizing future employment. They also tend to offer job placements right off the bat, while the Social Security system has long waiting periods during which recipients become dependent on monthly benefit checks. Little things can often mean a lot. Simply maintaining constant communication helps to reassure the disabled worker that there is a job to return to and that the employer and insurer are concerned about his or her recovery.⁷²

So-called disability management is an emerging discipline within the ranks of American DI firms as well as overseas. Just from 1996 to 1999, the number of U.S. firms with integrated case-management as part of their disability insurance policies rose from one-quarter to nearly half. On average, these employers reported a savings of nearly 20 percent, as the reduction in payments to employees offset the management costs of getting them back to work quicker.⁷³ Certainly, the insurers have a strong financial incentive to get recipients back to work. But it is a win-win situation, since disabled workers are also better off in the long run, economically and otherwise, when they are able to reenter the workforce quickly and successfully. And in the long run, employers benefit from the higher productivity levels that return-to-work programs generate.⁷⁴

Part of what makes disability insurance work better in the private sector and in other countries is that these systems assume a high level of responsibility on the part of the disabled themselves, rather than focusing purely on encouraging them to work through cash and benefit incentives. Many private DI contracts explicitly require that workers developing disabilities must cooperate with return-to-work efforts. At Met Life, a leading disability insurer, the process begins shortly after an injury or illness is reported. "We believe that when someone a claim with us either for a short-term or long-term disability one of our first questions is, 'tell us about the job. Tell us how this injury or illness is preventing you from returning to work,'" said Elizabeth Corp, a certified disability-management specialist with the company. "We want people to return to work. We are constantly focusing on that. We don't want the mindset of 'I'm too ill to work.'" ⁷⁵

In Germany and Sweden, laws and policies require that an individual's potential for returning to work be assessed soon after the onset of a disabling condition, rather than after the receipt of many months of benefit checks. The German system is striking in this regard; every applicant for a disability pension is considered for vocational rehabilitation and return to work before being determined eligible for permanent benefits, much like the way TANF recipients in such states as Wisconsin are treated. They are considered work-placement clients first, cash beneficiaries last.⁷⁶

Private insurers also have both the incentive and the customer-client relationship to prevent costly disability claims through early intervention — something rare in the public sector. UnumProvident client Richard Birnbaum, for example, is an audio engineer for network news operations. Early in his career he bought an income protection policy from Provident in case he ever lost his hearing. But a different problem, lugging heavy machinery for field work, led to his first disability claim for a torn and partially detached rotator cuff that prevented him from taking news jobs. The insurance company solved the problem by providing Birnbaum with new, lighter audio equipment. "UnumProvident handled my claim quickly and thoroughly," Birnbaum said in a company newsletter. "Now I'm back in the field and I'm completely satisfied."⁷⁷

This story helps to illustrate a broader point about privatizing disability case-management: it would allow for more coordination across different benefits and services. Some insurers are experimenting with an integrated approach in which long-term disability, short-term disability, workers' comp, and even group health insurance are sold as a single package. One Liberty Mutual customer experienced a cost savings of 28 percent through integration, while other businesses report less worker confusion and more worker satisfaction with their benefits.⁷⁸ If all Americans were allowed to purchase private disability coverage with Social Security dollars, the possibilities for integration with the existing private health insurance and workers comp markets would be obvious — and potentially rewarding.

Still another area where private insurers have shown greater initiative than public-sector bureaucrats have is in promoting entrepreneurship among disabled beneficiaries. Unfortunately, only a small minority of VR clients chose self-employment as an option. In our dynamic market economy, opportunities for entrepreneurial activity still abound, and the disabled, no less than other Americans, should be encouraged to pursue them. Some insurers, for example, allow beneficiaries to use a portion of their prospective cash benefit as start-up capital for a new business.⁷⁹

Making greater use of private disability insurers would have the happy side effect of reducing demands on the Medicare and Medicaid programs. At least some of the re-employed disabled would be eligible for and able to afford private health insurance. And those who continued to receive government health insurance would likely be healthier (unemployment correlates with poor health outcomes), thus reducing medical expenditures.

The concepts of privatization and competitive delivery of disability services may extend beyond Social Security, however. The new Ticket-to-Work legislation already discussed may

offer some guidance as to the practicality of vouchers for the purchase of VR and other services. At least in theory, consumer choice of vendors should improve the quality of services while putting downward pressure on prices. However, there are risks to converting programs such as VR, special education, and services to veterans into voucher programs. Unless policy-makers are willing to tighten program eligibility, the prospect of sizable vouchers for job training, education, or health care might well encourage more individuals to apply for services, thus swamping the system and offsetting any predicted cost savings. As such policy analysts as Bill Eggers and Bob Moffitt have pointed out, attempts to reform disability programs without taking such effects into consideration could have the perverse result of reducing work effort among the disabled and increasing cost to taxpayers.⁸⁰

- Restoring Federalism

Private savings accounts for retirement and retiree health care, private disability insurance, and competitive markets for VR may prove to be invaluable elements of the new Investment Model. But we should be honest enough to admit that many problems facing the current system of disability services do not have an obvious solution. Once the federal government took over responsibility for many of these functions, the natural market process of innovation and change was interrupted. The creation of Medicare and Medicaid froze into place ways of paying for medical services that the private sector was already starting to abandon. The creation of SSDI in 1956 and SSI in 1972 left the federal government with the responsibility of paying monthly benefit checks to millions of Americans, but few incentives to think far outside the box and consider different ways of assisting disabled workers.

Workers' compensation offers an important counterpoint to these programs. Unlike other programs serving disabled workers, workers' comp is typically not provided by the government, although employers are usually required to purchase it. A competitive market offers employers a variety of providers and delivery mechanisms. Moreover, each state sets its own workers' comp policies. Some have used a heavy hand, in a few cases even monopolizing the workers' comp market with substandard government programs. In other states, a more liberal set of regulations has allowed greater innovation and competition. While there remains tough issues to address in workers' comp, it has demonstrated the value of allowing states to experiment with different programs and regulatory approaches.

Restoring federalism to the rest of disability policy would provide similar advantages. States should have more latitude to experiment with their Medicaid programs, including such ideas as vouchers, competitive contracting, and medical savings accounts. Arizona has long operated a unique Medicaid program, particularly in its use of a competitive contracting model for long-term care. Providers bid to receive contracts to deliver long-term care services in each county. There is compelling evidence that the system holds down cost vs. more traditional methods of paying for nursing home care. On the other hand, there are critics who say the system provides inadequate services and imposes eligibility standards that are too restrictive.⁸¹ I tend to think that the Arizona model offers other states some important lessons about how to rein in their burgeoning long-term care costs, but I also think that additional research and experimentation is needed.

More recently, a promising experiment in Medicaid reform called “Cash and Counseling” began in Florida, New Jersey, and Arkansas. Cash and Counseling allows people receiving Medicaid benefits to get money directly for buying personal assistance services instead of services through a care agency. The idea is that patients, if given information and the ability to direct dollars on their own, will be able to purchase more appropriate services more efficiently than if a bureaucrat made the decision on their behalf. Typically, participants in the three Cash and Counseling demonstration projects have chosen to use the money to help underwrite the cost of care from their own family members. While there is some obvious potential for abuse, the program does offer the welcome prospect of re-establishing the traditional notion of family responsibility for the primary care of a disabled parent, spouse, or child. Such a re-establishment could not only save money over time due to lower rates of institutionalization but could also serve to remove government impediments to family formation and stability. The early evidence is intriguing. A U.S. Department of Health and Human Services study found that 82 percent of Arkansas participants said the Cash and Counseling program had improved their lives, with an average cost savings of 18 percent through less use of hospitals and nursing homes. Other studies have confirmed that the program improves the quality of service while not reducing the safety of patients.⁸²

More experimentation along the lines of Cash and Counseling is needed. Indeed, we need experimentation not just in Medicaid but in Medicare. In the future, policy-makers should rethink the relationship between these two programs, which overlap in important ways. One possible approach would be to merge them, convert them into state-run programs with federal financial participation, and then allow significant divergence from the current program design. States could be more or less aggressive in converting the programs from a defined-benefit to a partial or full defined-contribution system, for example, thus possibly breaking the logjam that threatens to prevent a national resolution to the Medicare crisis.

Conclusion

The magnitude and complexity of America’s disability-services policy precludes a comprehensive treatment here of each program’s problems and potential solutions. My purpose was to put the system in a historical context, to provide a general overview of its extent and cost, and to sketch out an alternative model that would treat the disabled not as pitiful wards of the state destined for perpetual dependency but instead as fellow citizens who, with some public or private assistance, are fully capable of contributing to the national economy and society. By transforming our disability policy into one of investing in unrealized human capital, rather than one of entitlement, policy-makers can benefit both taxpayers and the disabled themselves.

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