

Disability in America

By
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Executive Summary

Twenty-eight years ago, appalled by the many barriers throughout America - in architecture, in transportation, in communication, and in other areas - I opened a book by writing:

"America handicaps disabled people. And because that is true, we are handicapping American itself." (Bowe, 1978, p. viii)

In 2006, most of those barriers have come tumbling down. The Americans with Disabilities Act and other laws, notably Section 504, have made a tremendous difference for the nation's 3rd largest minority.

Tragically, however, many Americans with disabilities still live in abject poverty. To illustrate, if we assigned a value of 1 to where adults with no disabilities stand today, here is where those with disabilities are:

Income	.31 (3X as many with disabilities live in poverty)
Employment	.25 (one-quarter as many have full-time jobs)
College	.50 (19% of youth with disabilities go to college)
Health Insurance	.55 (fewer than half of adults with disabilities have private health insurance)

Why this is so is our subject here. I believe that misguided policies - which we can and must change - keep millions from participating in the American Dream.

We can - and must - do better. Step One is to align national, and state, data better with civil-rights and education/training laws so we can track how our policies play out in the real world. Step Two is to integrate the many scattered education and job training programs that today are poorly coordinated. Step Three is to rationalize health insurance. Those are big steps. This publication is a small effort to point the way.

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Background

More than 32 million Americans have severe disabilities, according to the latest **report** from the U.S. Bureau of the Census. That is about one in every 9 Americans (11%). Including those with lesser disabilities, or impairments, the number exceeds 51 million, or 18% of all Americans. Released in May 2006, *Americans with Disabilities: 2002* is based upon data collected between July and September 2002. It is available on the Bureau Web site, <http://www.census.gov>.

The new Census report examines employment, income, public assistance, and education of individuals with disabilities. It breaks down data according to three general categories. Most useful are those about adults (persons aged 21-64, on employment and earnings, or those aged 25-64, on education and other characteristics). The material on persons over age 65, and on those under age 21, is revealing as well. Other reports shedding light on the lives of Americans with severe disabilities have come out recently. One, also released in May 2006, is the Social Security Advisory Board's *Disability Decision Making: Data and Materials*. It is available at <http://www.ssab.gov>. This one focuses upon two major entitlement programs for Americans with disabilities: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

In addition, several longitudinal studies sponsored by the U.S. Department of Education have begun releasing reports. Prominent among them is the National Longitudinal Transition Survey-2, which reports on transition between high school and college or work. The data, at <http://www.nlts2.org>, compare patterns among school leavers in 2003 to those from the initial NLTS (1986-1987). Other information about PreK-12 students with disabilities is posted at <http://www.ideadata.org>. Further, there are reports focusing upon very young children, including infants and toddlers, from the National Early Intervention Longitudinal Study, available at <http://www.sri.com/neils>, upon preschool- and kindergarten-age children, from the PreElementary Educational Longitudinal Study, at <http://www.peels.org>, and upon elementary students, from the Special Education Elementary Longitudinal Study, at <http://www.sri.com/seels>.

There are reams of statistics in these reports, and in many others, as well. The "big picture" that emerges is one that can be told with a handful of charts. Particularly helpful, when possible, is comparison between the current set of figures and those from earlier years. A good reference point is 1986/1987. This is so for several reasons. First, by 1986, the landmark Individuals with Disabilities Education Act (IDEA), then known as the Education for All Handicapped Children Act, had been in effect for 10 years. Second, implementation of section 504, of the 1973 Rehabilitation Act, was also 10 years along in 1987. Third, these years predate the Americans with Disabilities Act (ADA) of 1990, so we can compare figures from before and after implementation of the ADA.

However, not all of these studies are about the same population. As discussed in "Technical Notes" later in this report, different laws and programs use different definitions. Notably, the IDEA defines "child with a disability" as a child or youth who needs special education and related services and has one or more of a list of qualifying conditions. Section 504 and the ADA use three-prong definitions for "individual with disabilities," and extend protection to "qualified" persons. One would hope that demographers could track protected and qualified persons with disabilities according to these laws, so as to help policy makers monitor implementation and enforcement. Sadly, we lack such data (Gould, 2006; Silverstein, Julnes, & Nolan, 2005).

The new Census Bureau report uses the term "disability" but means by it not quite the same thing. By "severe disabilities" the Census surveys mean something closer to what the Social Security Administration considers to be disabilities that qualify people for entitlement benefits. From their creation -- 1956 for SSDI and 1972 for SSI -- cash-benefit programs have used a **definition of disability**, and a set of rules, that the **Social Security Advisory Board** itself, as well as the **National Council on Disability**, now recognize are problematic for the many Americans with disabilities who are able and willing to work. We explore some of those problems in this report.

Important, too, in this report is what has happened in medical care in America. To be without health insurance in 21st Century America is a truly frightening prospect, especially for persons with disabilities. Costs of **prescription drugs** alone shot up more in early 2006 than at any time in the past six years. Meanwhile, employer-sponsored health care is generally made available to well-educated workers. Many Americans with disabilities lack the education and training to be eligible for such jobs. Accordingly, they rely upon Medicaid and Medicare for essential health coverage. In effect, they are forced to choose between employment and health insurance. The devastating results play out on the following pages.

There are some bright spots here. Although employment of adults with disabilities overall tends to lag that of working-age persons with no disabilities, Title I of the ADA and Section 504 have helped large numbers of individuals with disabilities (the author among them). Similarly, Title III of the ADA has led to small, but important, accessibility improvements in more than one million retail stores across the country. The **2002 Economic Fact Sheets** from the Census Bureau notes that there are some 200,000 restaurants, 46,000 hotels and motels, about 5,000 motion picture theatres, and many other "places of public accommodation" throughout the nation. Virtually all now are accessible to people using wheelchairs, offer accommodations to customers who are deaf or blind, and make information available in useable form. Then, too, section 504 and title II of the ADA have made many thousands of libraries, local agencies, and public colleges accessible, as well as hundreds of airports, train stations and bus terminals. We also see, over the past 20 years, real improvement in the number

of young people with disabilities who completed high school and went on to college.

Those positive changes notwithstanding, the central fact of "*Disability in America 2006*" is that "one size fits all" government policies (notably SSDI and SSI; see, for example, Social Security Advisory Board, 2006a), health insurance practices (particularly the rapid escalation of costs and the narrowing of employer coverage to some, but fewer than in years past), and other factors continue to conspire to keep the American Dream out of reach for many Americans with disabilities.

Narrative

Americans with disabilities constitute the nation's 3rd-largest minority group. In fact, if people with impairments are added, the total exceeds 51 million and the population is the largest minority group in the U.S. today.

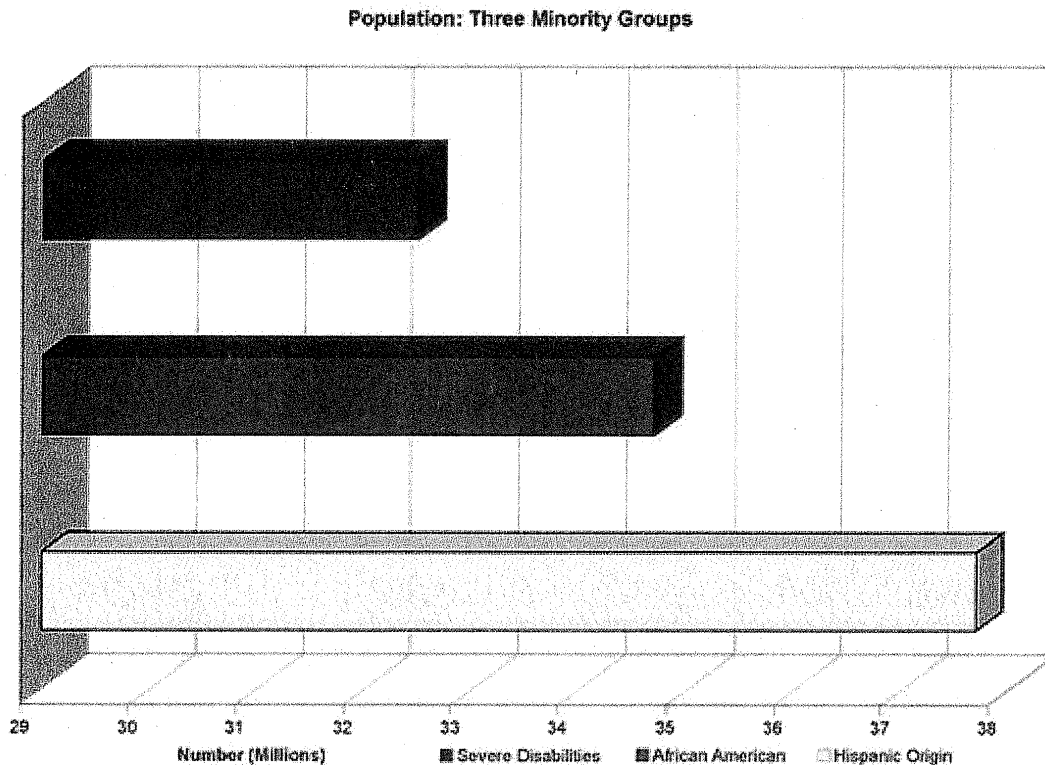


Figure 1. The graphic shows that Americans of Hispanic origin numbered 37.7 million in 2002. They were 13.3% of all persons in the country. African Americans totaled 34.7 million, or 12.5%. Individuals with severe disabilities were third, at 32.5 million, or 11.5%, of the nation's 282,831,000 residents.

Source: U.S. Bureau of the Census (2006), based on the Survey of Income and Program Participation (SIPP).

A striking fact about disability in America in 2006 is how many American adults with disabilities live in poverty. One in every four (26%) subsist on below-poverty incomes.

Fig 2a.

Lived In Poverty, Adults with Severe Disabilities

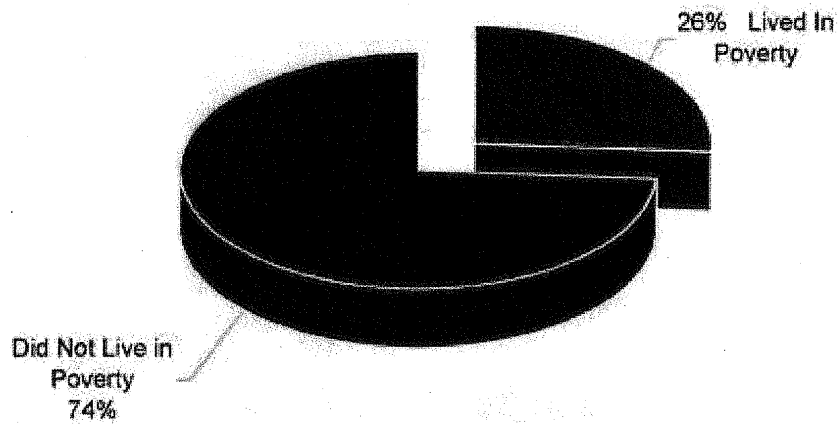


Fig 2b.

Lived In Poverty, No Disabilities

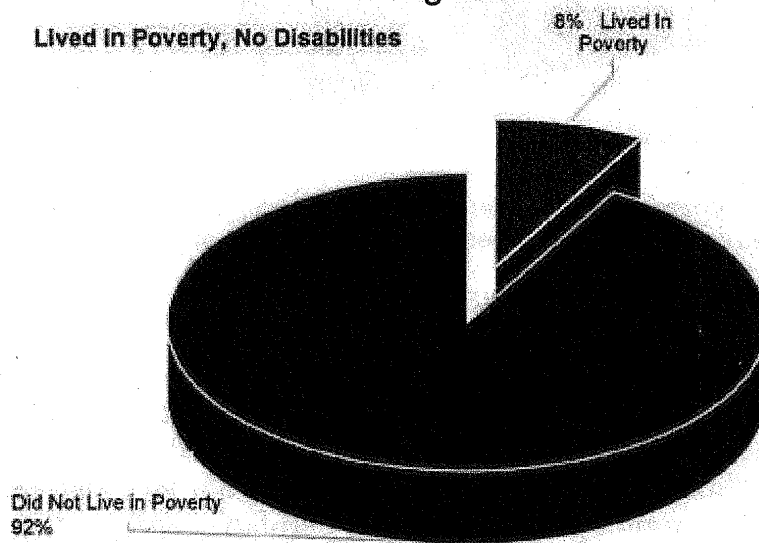


Figure 2 (a, b). These charts compare poverty data between Americans with disabilities and those with no disabilities. In both groups, adults are between 25 and 64 years of age. While 8% of adults with no disabilities live in poverty, more than three times as many (26%) of those who have severe disabilities reside in poverty.

Source: U.S. Bureau of the Census (2006) (SIPP).

In 21st Century America, above-poverty levels of income typically are associated with year-round full-time (YRFT) employment. A major reason so many Americans with disabilities live in poverty is that so few work YRFT.

Fig. 3

Worked Year Round, Full Time

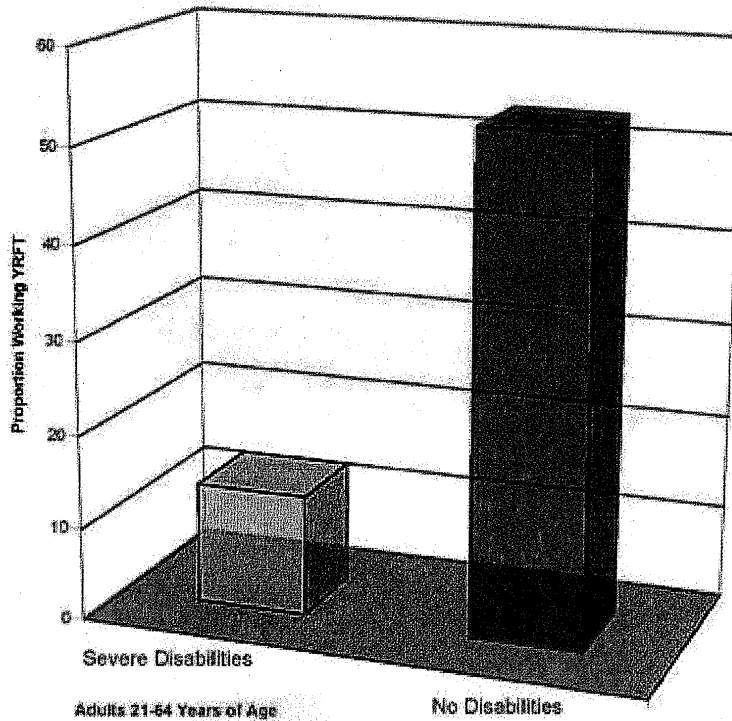


Figure 3. Just 13% of Americans with severe disabilities who are 21-64 years of age work YRFT. That compares to 53% (or four times as many) among adults with no disabilities in the same age range. Source: U.S. Bureau of the Census (2006) (SIPP), Figure 5.

The relationship between employment and earned income is apparent in the Census Bureau's 2006 report. Americans with severe disabilities aged 21 to 64 who had any earned income had a 2002 mean of \$18,363. By comparison, the mean earnings of those with no disabilities were \$32,870. In both cases, earnings were from any employment (including part-time, part-year, etc.). Those with severe disabilities earned just 56% as much. The major reason: far fewer adults with disabilities worked YRFT.

Fig. 4

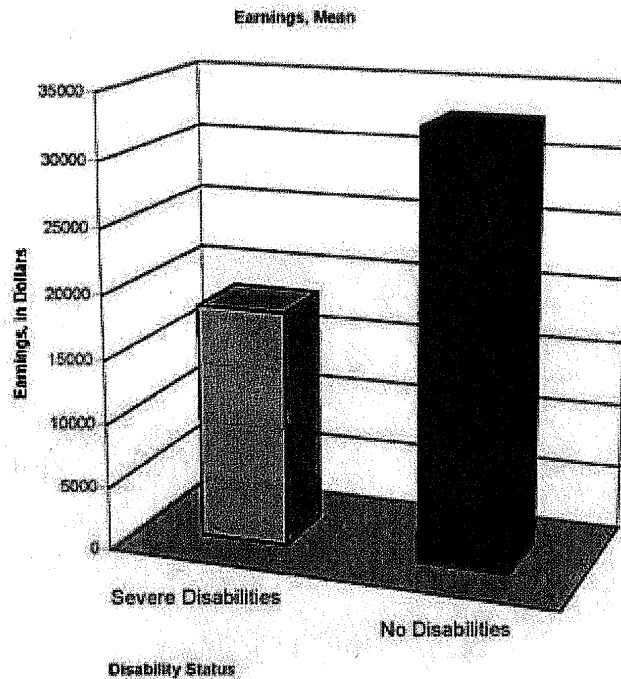


Figure 4. Mean earned incomes in 2002 among American adults aged 21-64 with any earned income differed sharply by disability status. This figure shows that mean earnings of those with disabilities were \$18,363, v. \$32,870 for those with no disabilities. *Source: U.S. Bureau of the Census (2006) (SIPP), p. 9.*

Individuals may have unearned income, as well - from investments, from savings, etc. In this area, too, we see that Americans with severe disabilities are far behind. Among adults 25-64 years of age, an astonishing 76% of those with severe disabilities had individual incomes in 2002 of less than \$20,000. To place that figure into context, consider that the poverty threshold in 2002 for an under-65 individual living alone was \$9,359.

Fig. 5a

Individual Income: Adults with Severe Disabilities

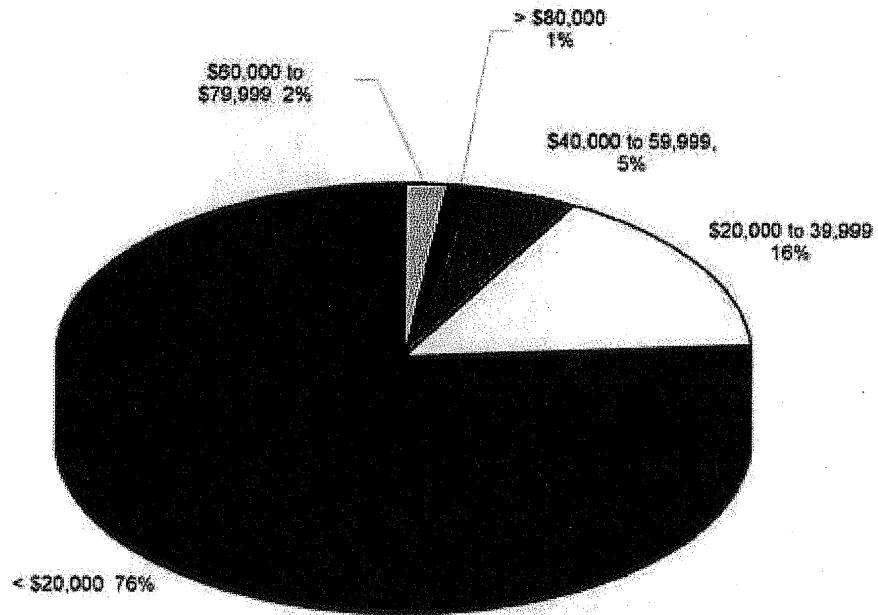


Fig. 5b

Individual Income: Adults with No Disabilities

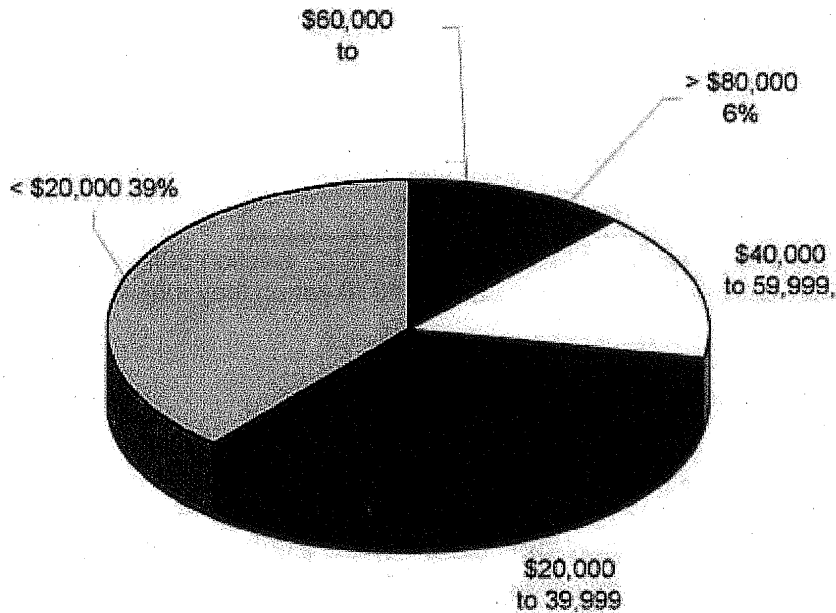


Figure 5 (a,b). These figures show that among adults with severe disabilities who were in the 25-64 age range, incomes from all sources tended to be very low. Three out of every four (76%) had \$20,000 or less in individual income in 2002. At the other end of the spectrum, just 1% had individual incomes that year of \$80,000 or more. Adults with no disabilities fared far better.

Source: U.S. Bureau of the Census (2006) (SIPP), Table 4

The portrait so far of Americans with disabilities in 2006 is not what one would hope to see 16 years after passage of the Americans with Disabilities Act (ADA) of 1990. To understand why so many Americans with disabilities are not participating in the American dream, we need to delve more deeply. A good place to begin, now that we've brought up the ADA, is a timeline that helps us to trace recent history.

Federal laws that continue to influence the lives of Americans with disabilities date back 50 years. The first was Social Security Disability Insurance (SSDI), in 1956. SSDI offers Medicare coverage, plus monthly checks, to individuals who are below normal retirement age and have disabilities that limit or prevent work. It was followed, in 1972, by Supplemental Security Income (SSI). SSI provides monthly checks designed to bring people's incomes up to the poverty threshold, plus Medicaid coverage. (There are a few exceptions, as in California, where health insurance is offered, instead, through MediCal.) Note that the first two

national disability programs were entitlements. Civil rights and rights in education followed in the 1970s and in 1990.

Fig. 6

1956	SSDI
1972	SSI
1977-78	504, IDEA
1990	ADA
2006	NOW

Figure 6. This timeline shows SSDI in 1956, SSI in 1972, Section 504 and what is now the Individuals with Disabilities Education Act in 1977-1978 (when they took effect) and the ADA in 1990.

Brief descriptions of the laws appear below.

SSDI is Social Security Disability Insurance. It began August 1, 1956 as a program for persons who were “permanently and totally disabled” prior to retirement. Initially, only persons age 50-64 were eligible. They received a check monthly and were enrolled on Medicare. At age 65, they were automatically transferred to Old Age and Survivors Insurance (OASI). Today, there is no minimum age requirement and the transfer to OASI occurs at full retirement age, which may be 66 or 67.

SSI is Supplemental Security Income. It was authorized by the Social Security Amendments of 1972 (Public Law 92-603), on October 30, 1972.

IDEA is the Individuals with Disabilities Education Act. It began as PL 94-142, the Education for All Handicapped Children Act of 1975. What is now IDEA was implemented effective the 1977-1978 school year.

504 is Section 504. It was the final sentence in the Rehabilitation Act of 1973. Section 504 was implemented in 1977, when regulations carrying it out were issued by the U.S. Department of Health, Education and Welfare. In 1978, rules applying to federal agencies themselves were added.

ADA is the Americans with Disabilities Act of 1990. Provisions on employment took effect July 1992 (employers having 25+ workers) and July 1994 (those with 15-24 employees).

Employment

In 2006, we have data on some 14 years' experience with the ADA's employment protections (mid-1992 to mid-2006). These data are limited - they include persons with disabilities as defined by the Census Bureau (see McNeil, 2000 and Stern, 2006). They do **not** report on the specific population of "qualified individuals with disabilities". We do not have such data. Bearing in mind this very large qualification, let us look at what the Census reports tell us.

Title I of the 1990 ADA requires employers with 15 or more workers, as of mid-1994, to practice non-discrimination in employment of "otherwise qualified" persons with disabilities. (Employers with 25+ workers were covered as of mid-1992.) Specifically, job requirements must be related to the job (and not include job-irrelevant abilities); reasonable accommodations must be offered during interviews, on the job, and in training; promotion and advancement in the business must follow these rules as well; benefits, including health insurance, must be the same for workers with and without disabilities; and termination, if made, must be based on job-related factors.

Each March, the Census Bureau conducts a supplement to its Current Population Survey (CPS) that asks disability-related questions. Table 2 of the annual reports on these surveys provides employment-related data, from which the following charts were drawn. Note that in these numbers, "disability" refers to persons with disabilities and includes those with severe disabilities. Note, too, the difference in age ranges: The CPS tracks persons from age 16, while the SIPP, which we discussed earlier, starts at age 21; because so many 16-21 year olds do not work, proportions employed are lower in the CPS than in the SIPP. There are other methodological differences between CPS and SIPP that help account for the divergences in percentages.

Fig. 7

Employment, by Year

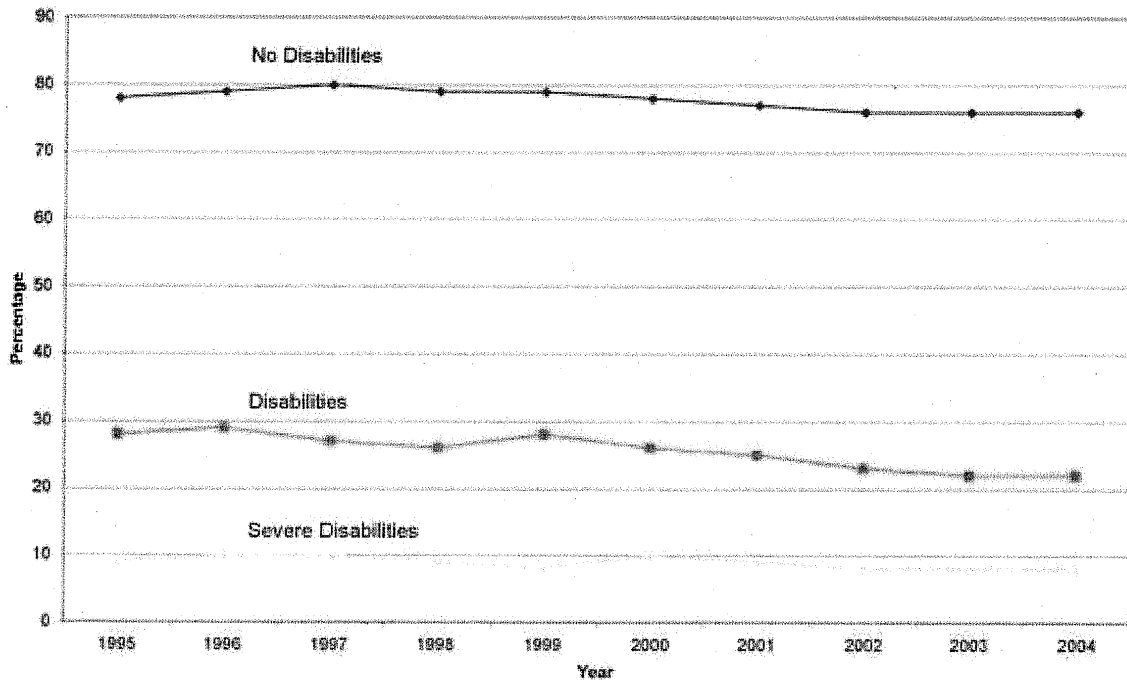


Figure 7. This graphic shows that employment among American adults aged 16 to 64 inclusive over the period 1995 to 2004 ranged from a low of 76% to a high of 80%. During the same time frame, employment among those with disabilities ranged from a low of 22% to a high of 29%. Among those with severe disabilities, the range was from a low of 7% to a high of 10%. The highs in this latter group were reached in 1997 (10%) and 2000 (9.6%).
Data Source: U.S. Bureau of the Census, Current Population Survey, Table 2 various years.

<http://www.census.gov/hhes/www/disability/disabcps.html>

In 2005, the most recent year for which CPS March Supplement data are available, the employment data for adults aged 16-64 with severe disabilities were these:

In the labor force	10%
Employed	8%
Full-time	3%
Unemployed	20%

To explain briefly:

“In the labor force” means working or actively looking for work. The counterpart term, “not in the labor force,” means neither working nor actively seeking employment.

“Employed” means holding a paying job, whether year-round full-time (YRFT) or not.

“Full time” means YRFT employment.

“Unemployed” means actively seeking a job, but not having one.

Accordingly, the fact that 10% of adults 16-64 with severe disabilities were “in the labor force” means that they were either working (80% of them, or 8% of the total) or looking for work (20% of them - the unemployment rate - or 2% of the total). Most of those who were working were not employed YRFT. On the other side of the same coin, the fact that 10% were in the labor force means that 90% were not (they were neither working nor actively seeking employment).

The portrait drawn by these statistics for 2005 is the one we see (with minor variations), in the entire 1995-2005 period (see Figure 7).

Could employment discrimination help to explain these dire statistics? In 2005, some researchers reported upon an in-depth analysis of all disability discrimination complaints filed from the effective date of ADA title I to late 2003 (McMahon, Edwards, Rumrill, & Hursh, 2005; Bowe, McMahon, Chang, & Louvi, 2005). We explored more than 600,000 allegations, focusing particularly upon 328,727 that had been closed (with official findings of discrimination or not) by the U.S. Equal Employment Opportunity Commission.

About one in every three allegations (103,777) were of unjust discharge (termination from employment), another one in five (58,448) were of failure to make reasonable accommodations, and the balance alleged a wide variety of other acts, such as harassment on the basis of disability (25,776). A total of 17,535, or 5% of all allegations, related to failure to hire.

These findings need some context. First, the most meritorious complaints of discrimination in employment tend to be settled within the company or organization itself (i.e., by a supervisor’s review, by a human resources staff investigation, etc.). Second, the fact that the EEOC ruled on 328,727 disability discrimination allegations suggests that a substantial number of adults with disabilities experienced discrimination in employment, or believed they did, in the years following the effective date of ADA title I.

On the other side of the coin, the EEOC failed to substantiate most of those complaints. That is, the agency did not find that discrimination had in fact occurred. In addition, the failure to hire total (17,535) is rather small. In addition to comprising just 5% of EEOC-closed allegations about disability discrimination

in employment, it represents an average of just 1,600 per year over the 11-year study period.

We conclude: Yes, employment discrimination is a factor, but it does not explain much of the low labor force participation that we see.

There is another aspect of employment discrimination not addressed in the EEOC data: Some adults with disabilities may be dissuaded from seeking employment because they fear, rightly or wrongly, that they will encounter discrimination in the workplace. They may be aware of the protections offered by the ADA. They may believe, however, that "those don't count for much in the real world". We cannot quantify that fear. We can, however, note it. It is there.

To this point, it is clear that title I of the ADA has had little discernible effect on employment among adults with severe disabilities who are enrolled in entitlement programs. SSI and SSDI are the two main such programs. Both are implemented by the Social Security Administration (SSA). Agency data show that the typical beneficiary comes onto the rolls in his/her 40s or early 50s (see, for example, Social Security Advisory Board, 2006b). Some, particularly in SSI, enter much sooner (in the teens or early 20s). The fact that the average age at entry is in middle age suggests that many of these individuals have not had life-long disabilities. In fact, especially with health and physical conditions, age at onset often is in the middle years.

Of the 32.5 million Americans of all ages who have severe disabilities, 16.9 million are in the 25-64 age range that we examine here. That is 52%, or just over half. Significantly for our purposes now, of these 16.9 million adults, 7.3 million, or 43%, are beneficiaries of SSI and/or SSDI. That is quite startling, given that program participation is the exception to the rule in the 25-45 cohort, or fully half of the 25-64 age range, meaning that program participation among those aged 45 to 64 is very common.

Program participation in entitlement programs, then, is a major factor in the lives of Americans with severe disabilities in 2006.

Program Participation

Nearly half (43%) of 25-64 year-old adults with severe disabilities are beneficiaries of Social Security Disability Insurance (SSDI) and/or Supplemental Security Income (SSI). These programs require persons to have disabilities that are, almost always, severe.

In 2005, 8 million adults with disabilities were on SSDI. All were under age 65. The vast majority also were over 45 years of age. That same year, 4 million adults with disabilities were on SSI. Significantly for our purposes here, enrollment in both programs has increased since the effective dates of Section 504 (1977) and ADA title I (1992/1994).

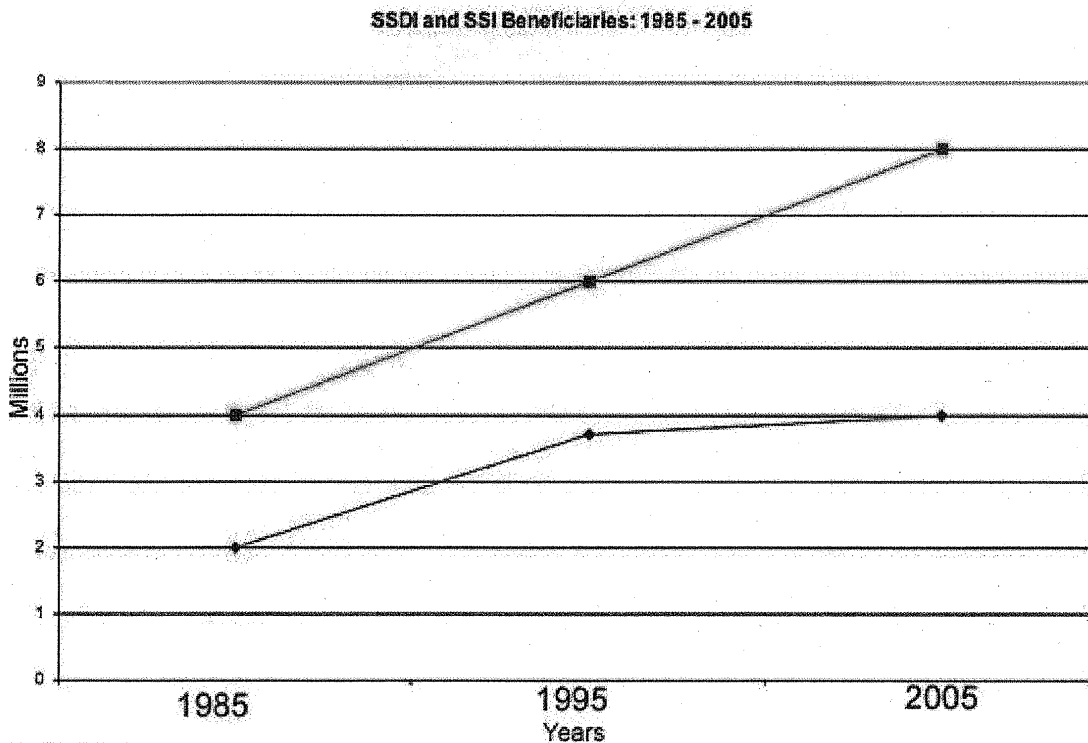


Figure 8. This chart shows that SSDI enrollment rose from about four million in 1985 to double that number, eight million, in 2005. In the same period, enrollment by adults with disabilities in SSI rose from two million to four million. *Data Source: Social Security Advisory Board (2006), Chart 20, p. 38.*

(Some people participate in both programs. This may happen when an individual works for a number of years, then stops due to disability. If his/her resources and income dwindle to the point of poverty subsistence, he/she may also become eligible for SSI.)

Participation in SSI by adults with disabilities has increased in every age group since 1980. Growth has been particularly striking among those aged 35-49 and 50-64. Beneficiaries receive, on average, about \$550 a month (some states

supplement this federal benefit amount). Adjusted for inflation, monthly benefits have remained unchanged since the program began in 1974.

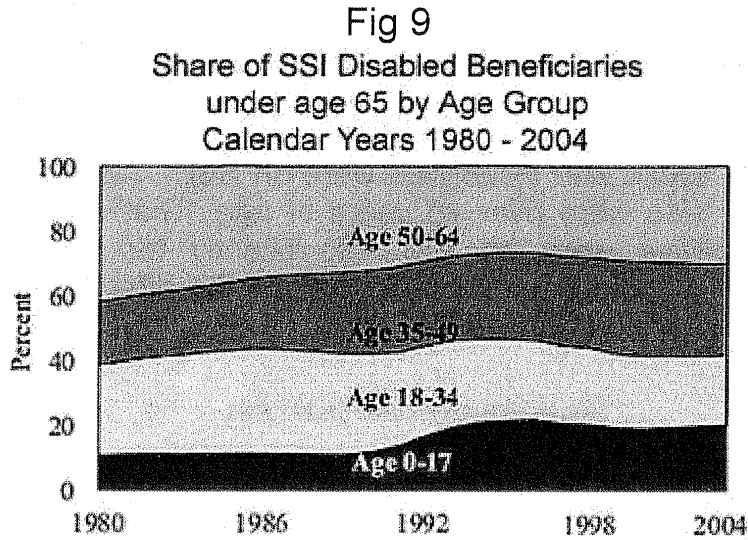


Figure 9. This graphic illustrates how enrollment in SSI has grown rapidly among persons in the middle years. Persons aged 35 to 49, for example, represented 28% of the total by 2004. Source: Social Security Advisory Board (2006), Chart 32, p. 50.

Most participants in SSDI and SSI have income from sources other than these two entitlement programs. That is less true of SSI recipients than of those on SSDI, who get, on average, about \$900/month. Significantly for our purposes here, SSA imposes a cap on other income in both programs. Recipients may not earn more than “substantial gainful activity” (roughly, minimum wage earnings in a 40-hour workweek) without jeopardizing eligibility. The SGA requirements have the effect of limiting work activity among beneficiaries. The chart below shows what proportion of their individual incomes are attributable to SSDI or SSI cash benefits.

Fig.10

**Benefit and Other Income,
SSDI and SSI Recipients**

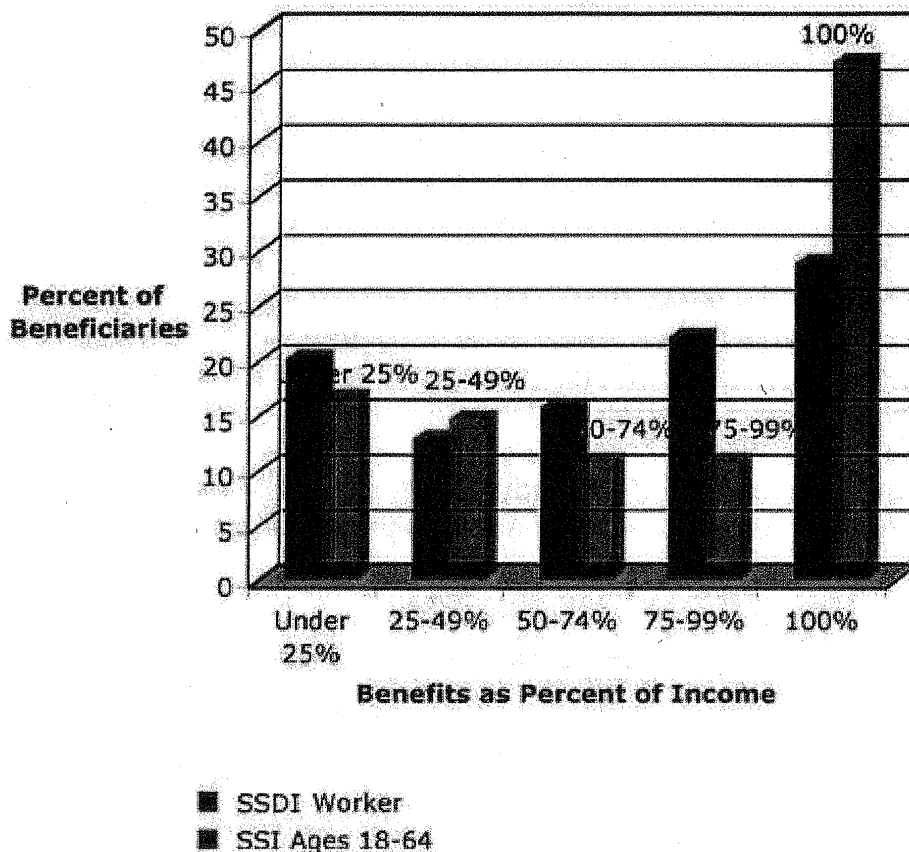


Figure 10. This chart shows that for nearly half (47%) of adults who are on SSI, the monthly benefit checks account for all of their individual incomes. Among those on SSDI, that is true of 29%. Benefits account for nearly all of income (three-fourths or more) for 23% of persons on SSDI and 11% of those on SSI.

Source: Social Security Advisory Board (2006), Chart 41, p. 56.

Why do so many Americans with severe disabilities enroll on SSDI or SSI if those programs confine them to near-poverty levels of income? The answer, according to the experts: because they need health insurance (National Council on Disability, 2005; Social Security Advisory Board, 2006).

The attraction for beneficiaries typically is not the monthly checks. To appreciate this, consider that Supplemental Security Income is intended to provide a guaranteed minimum income. That is, SSI brings a person's income up to the federal poverty level. The poverty guideline for an adult living alone in 2006 is \$9,800. That translates into \$817/month. Thus, the idea behind SSI is that if the person's monthly income (earned and unearned) is below about \$800/month, and the individual is eligible for SSI, a supplement is provided. With the supplement, the person's monthly income rises to about \$800. For the 2006 poverty

guidelines, see: <http://aspe.hhs.gov/poverty/06poverty.shtml>. This site has figures for households of two, three, etc., persons. For example, a household with two persons would be in poverty if income were under \$13,200. SSDI, as well, restricts non-beneficiary income for recipients to SGA. So persons enrolled on SSDI are also limited in how much they may make.

SGA is more or less the same as minimum wage. Thus, someone who makes minimum income and works 40 hours a week for 50 weeks of the year will earn $40 \times 50 \times$ about \$7/hour, or a total of \$14,000 a year.

Medical care is far more important to these people. Persons on SSDI are covered by Medicare, while those on SSI receive Medicaid (except in a few states, e.g., California where MediCal is provided). The prospect of being left without health insurance is understandably frightening for anyone, particularly for an individual who has a disability.

While four out of every five (81%) adults with no disabilities have private health insurance, that is true only of 45% of adults with severe disabilities.

Fig. 11a

Health Insurance: Adults with Severe Disabilities

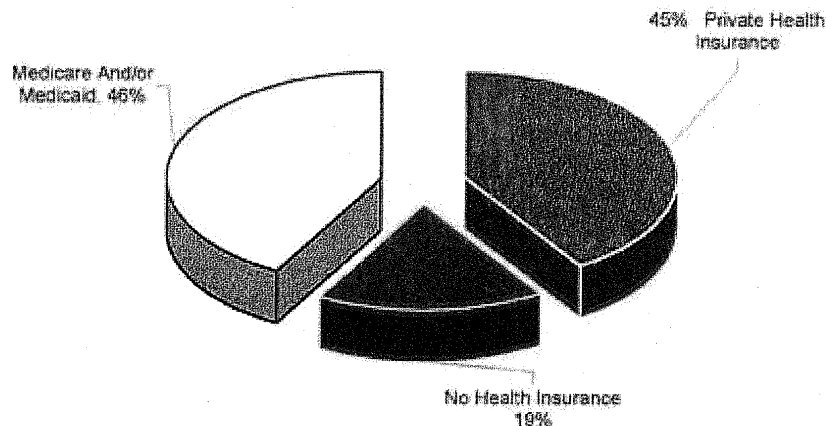


Fig. 11b

Health Insurance: No Disabilities

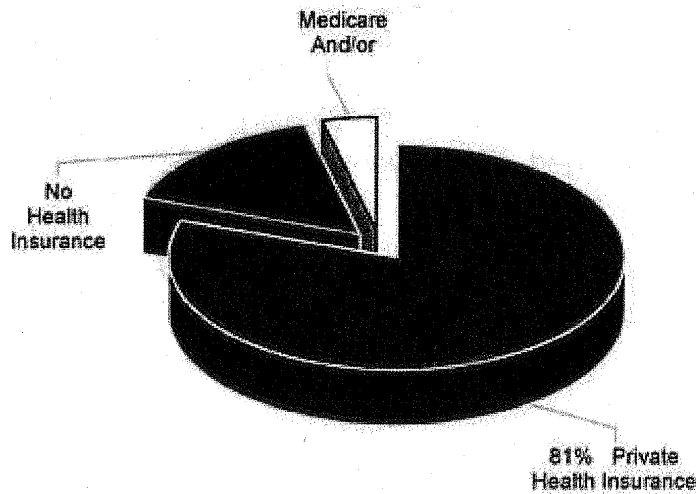


Figure 11(a,b). These charts demonstrate that private health insurance is far more common among American adults who have no disabilities than it is among those with severe disabilities. Among those without disabilities, 81% have private health insurance, 16% have public health coverage, and 4% are without any health insurance. By contrast, among those with severe disabilities, 45% have private health insurance, 46% have public coverage (Medicare and/or Medicaid), and 19% have no coverage at all. The numbers are not additive (do not total 100) because some individuals have both private and public health insurance coverage.

Source: U.S. Bureau of the Census (2006), Table 4.

Private health insurance is most available today in well-paying jobs that require considerable education and training. Few entry-level and/or minimum-wage jobs provide employer-paid coverage.

Many American adults with severe disabilities lack the education needed to qualify for those jobs. This is one reason they depend so heavily upon Medicaid and Medicare.

We explore below education through high school and then college. Too many adults with severe disabilities lack even a HS diploma, the "union card" for most jobs. Few have any college education. Increasingly, at least some college is required for the kinds of jobs that carry health insurance.

Education

We turn now to education as another factor helping us to understand why so many American adults with severe disabilities are poor. With respect to education, 2006 is nearly 30 years after IDEA took effect. Passed in 1975, this landmark federal law first applied to K-12 schools in the 1977-1978 school year. Thus, by now, virtually all adults aged 35 or younger have benefited from the IDEA since kindergarten; those aged 35 to 46 benefited during some of their school years; and those aged 47 or over did not benefit from IDEA, because it took effect following their school years.

What is now IDEA requires all American public school districts to offer a free appropriate public education (abbreviated FAPE) to all children and youth with disabilities. Accordingly, education through HS has been a right for individuals with disabilities since 1977.

Figure 12a

Never Finished High School, Adults with Severe Disabilities

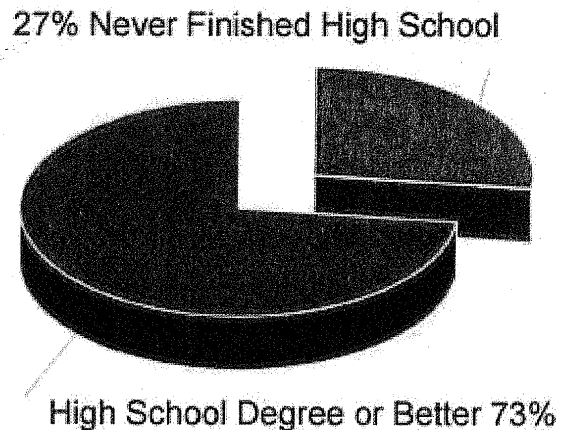
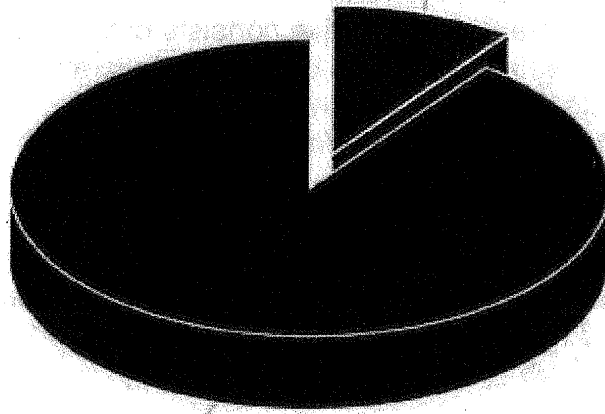


Fig. 12b

Never Finished High School, No Disabilities

10% Never Finished High School



High School Degree or Better 90%

Figure 12. (a,b) These charts show that as of 2003, 27% of adults aged 25-64 with severe disabilities had never completed HS. Among adults with no disabilities, the proportion is just 10%. *Data source: Wagner et al. (2005).*

In today's economy, not having a HS diploma is a real bar to employment. A job-seeker with a severe disability may be attractive to employers as long as he/she has education and training; however, when he/she lacks that credential, the applicant's attractiveness to employers is greatly reduced.

For older adults with severe disabilities, the lack of a HS diploma may be understandable – FAPE was not required of public schools until 1977-1978. But what about adults under age 46 and especially those younger than 35 in 2006? For most of these adults, a HS diploma should have been attainable.

The reality is that, even today, education at the elementary and secondary levels does not equally benefit students with and without disabilities. The word “appropriate” in IDEA does not mean “excellent” or even “good” - rather, it means that the education provided is designed to meet the child's needs and to be of sufficient quality to enable to student to advance from grade to grade.

Of course, some students have disabilities that are so significant educationally that they require substantially more instruction than do other students.

Elementary and secondary students with disabilities tend to be about two years behind their non-disabled peers in academic achievement (English and Language Arts, math, social studies, science, etc.) (Blackorby et al., 2005; U.S. Department of Education, 2003;Wagner et al., 2005).

While some students with disabilities do well in school, many struggle. Overall, students with disabilities are in the lowest quartile 50% of the time (applied math) and 40% (calculation). The lowest quartile consists of the poorest-achieving 25% of students. NLTS2 found similar levels of performance among high-school-age students. *Data sources: <http://www.sri.com/seels> and http://www.nlts2.org/search/tables/5/ndaAP_PRfrm.html.*

In fact, even in elementary school, large numbers are “held back” (retained in grade) once or even twice. The typical 9 year-old is in 4th grade. However, just 4% of 9 year-olds with disabilities are there. More than half (61%) are in 3rd grade and another 31% are still in 2nd grade. *Data source: SEELS School Survey, in U.S. Department of Education (2003).*

Among those in high school, we see as much, if not more, retention in grade. As illustrated below, most 15 year-old students with disabilities are not, as one might expect, in 10th grade. Rather, a majority (57%) are in 9th grade and more than a quarter (27%) are still in 8th grade. *Data source: NLTS2 School Survey, in U.S. Department of Education (2003).*

Fig. 13

Proportion of 15 Year-olds in 10th Grade: Students with Disabilities

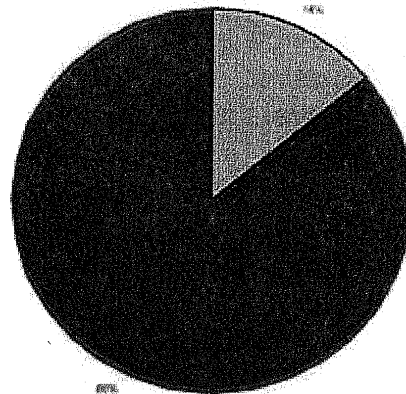


Figure 13. This chart looks at grade level for 15 year-olds with disabilities. Just 14% are in 10th grade, where the typical non-disabled 15 year-old is. The vast majority (86%) are in lower grades.

There is some good news on education. Recall that what is now the IDEA took effect in 1977-1978. By 1986, then, we could see some effects. About half of

secondary students with disabilities that year were successful in completing high school. Looking back from 2003, we see more progress.

Fig. 14

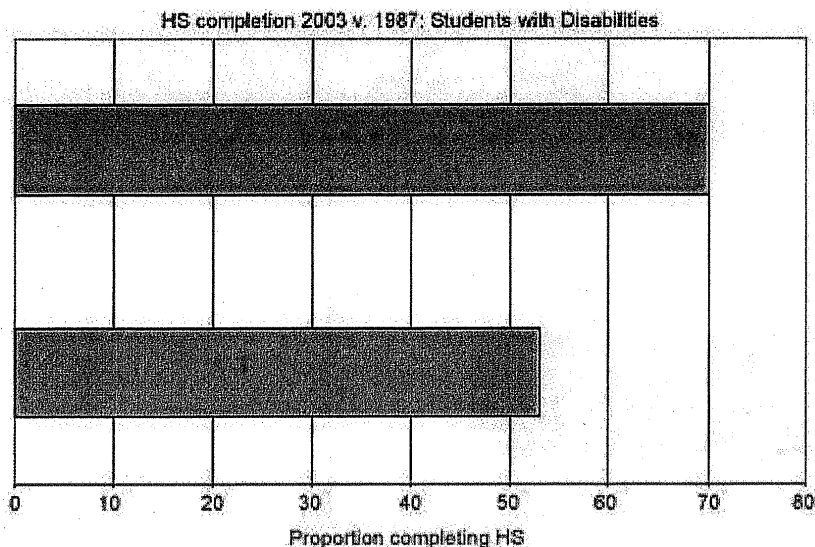


Figure 14. This chart compares HS completion rates among persons with disabilities in 1986 v. 2003. The rate in 2003 was 70%, much better than the 53% rate in 1986.

Data source: Wagner et al. (2005).

We are also seeing progress in postsecondary education. In 2003, 19% of youth who had completed HS at least two years earlier were attending college. While that was half the rate among peers without disabilities, it is nonetheless heartening. We also know, from another source (Ward & Merves [in press]) that persons with disabilities comprised 6.8% of all full-time freshmen attending four-year colleges and universities in 2004.

While that is lower than the 11% rate that we see in K-12 schools, it nonetheless shows real progress over past years. And it shows, again, the long-lasting effects of Section 504, which has required colleges and universities across the nation to offer non-discriminatory admission and educational services to applicants and students with disabilities since 1977.

Fig. 15
College Attendance: Youth with and without Disabilities: 2003

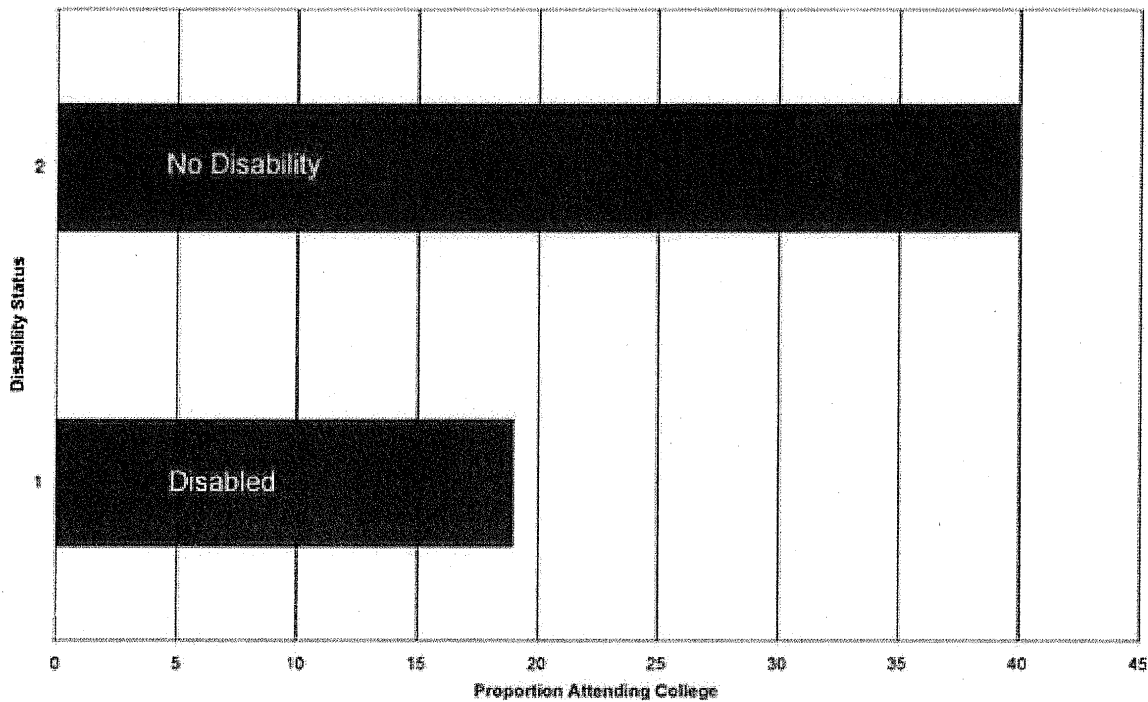


Figure 15. This chart compares college attendance rates two or more years after completion of high school. Among youth and young adults with disabilities, the rate in 2003 was 19%. Among those with no disabilities, it was 40%.

Data source: Wagner et al. (2005).

As salutary as is higher levels of college attendance, what matters most is a college degree. There, much more progress is needed. The U.S. Department of Education estimates that only one out of every seven (15%) of college students with disabilities obtain a B.A. or B.S. degree within six years of beginning their coursework.

Where from Here?

This report concludes with "Reflections" – a few pages of meditation on all of these numbers and figures.

For me personally, this has been a painful exercise. I wanted very much to see more progress than the data demonstrate. I am proud to have played a role in the ADA and, especially, in Section 504. These civil rights laws have made a difference in the quality of life of millions of Americans with disabilities. Section 504's long lasting effects are most apparent in postsecondary education (they changed things for the better in 3,000 institutions of higher learning), in access to government services, in airports, and in public libraries. ADA has made small, but important, changes in tens of millions of stores, hotels, and other private businesses (e.g., Bagenstos, 2004).

Still, employment is so much a key to the middle class that I wish we had data specifically on "qualified individuals with disabilities" so that we could see how ADA and Section 504 have supported with disabilities in the workplace.

The data we do have, which look at individuals with severe disabilities, many of whom are on entitlement programs, show that too many such persons have had to make a choice -- between the security of knowing that one has medical insurance, on the one hand, and the freedom to pursue the American Dream, on the other. "**Disability Benefits 101**" illustrates how the choice is made.

The bottom line, for me, is that they should not have to make that choice. We should be able to provide public or publicly guaranteed health coverage for people with disabilities – completely divorced from any ties to SSDI and SSI. This may follow the model given to us by Massachusetts in April, 2006. This universal health care program is innovative and comprehensive. It calls upon employers to provide health insurance on the job, yet also protects persons who cannot work. Another possibility is what we might call "medical insurance from Mom and Dad". A number of states now allow adult children to "piggyback" on their parents' health coverage. In New Jersey, for example, adults age 30 or under who reside in the state and have no children of their own may continue to be covered by one or both parents' policies (Lee, 2006). A third possibility is government reinsurance (Swartz, 2006). Were federal and/or state governments to reinsure (back) private health insurance, thus assuming some of the risk of high medical costs, we might see health coverage become far more universal than it is today.

The key is to free people with disabilities from the constraints under which many feel they must manage. The result, I believe, would be a tremendous unleashing of energy and creativity. We have a precedent for such social change. In fact, we have two. In "Reflections," I look briefly at these and draw some lessons.

Reflections

What is the take-home message from these charts? Here, I leave the realm of objective statistics and delve into that of personal opinion. Readers who shared the journey with me to this point may find their views now diverging from mine. Some will be with me the rest of the way. Others will strongly disagree. That's fine – this section of the report is, frankly (to coin a term) political. That is because these are policy questions, and they have policy answers.

If more Americans with disabilities are to live rewarding and productive lives, more need to become YRFT employees and at jobs that pay a living wage. This has been a goal of advocates since at least the early 1970s. There are steps we can take. They will, however, require a major shift in national priorities.

What's Right

Nondiscrimination in employment is the norm today. Dating back a dozen or more years, title I of the Americans with Disabilities Act (ADA) offers protection against unjust treatment in interviews, in hiring, in promotion, and in benefits. The reach of title I is broad: it covers millions of American employers, those with 15 or more workers. That is an order of magnitude greater than the protections offered by Sections 504 (in not-for-profit organizations and agencies) and 503 (in very large corporations having contracts with federal agencies).

These kinds of jobs require, in today's economy, at least some college education. The good news is that the doors to postsecondary education are wide open for people with disabilities. Section 504 (from 1977) and titles II and III of the ADA (from early 1992) assure equality of opportunity in admission and in matriculation toward a degree. Indeed, we have seen over the years an increase in the number and proportion of young people with disabilities who pursue postsecondary education.

What's Not

What is now unavoidably obvious, but for most of the past 30 years was only dimly perceived, is that these opportunities are only part of the story. Yes, the door is open. But more needs to be done to encourage individuals with disabilities to move through to pursue the American Dream.

I refer, of course, to the Supplemental Security Income (SSI) program dating from 1972 and the Social Security Disability Insurance (SSDI) program going

back to 1956. As unforgettably demonstrated in the well-illustrated May 2006 report of the Social Security Advisory Board, *Disability Decision Making: Data and Materials* (<http://www.ssab.gov>), these programs define disability as inability to engage in productive work. This definition of disability forces many Americans with disabilities to make life-altering decisions – and to comport with a mind-boggling maze of confusing rules, particularly for SSI (<http://www.socialsecurity.gov/notices/supplemental-security-income/text-understanding-ssi.htm>). In a book published in 1981, former HEW Secretary Joseph A. Califano, Jr., noted that what is now SSA had to employ more administrative law judges (ALJs) to process hearings and complaints than were employed in the rest of the federal court system combined. It's worse today.

SSI enrolls about 4,000,000 adults with disabilities. They represent about 15% of all American such adults, as estimated by the Census Bureau. Beneficiaries receive, on average, about \$450/month. As for SSDI, some 8,000,000 adults with disabilities and their dependents are on the rolls. They receive some \$900/month (<http://www.socialsecurity.gov/cgi-bin/currentpay.cgi>). The annual cost, at the federal level, is over \$30 billion a year (the states supplement that, at tens of billions of dollars more). As of 2004, SSDI costs the federal government some \$70 billion/year.

The effects of these two programs on the spirits and dreams of Americans with disabilities would not be anywhere as massive as they now are were these programs not tied to two others. People with disabilities apply for SSI and/or SSDI primarily to get the health insurance that is attached to eligibility.

Once on the aid rolls, they seldom leave. Year after year, fewer than 1% of SSI beneficiaries with disabilities, or those on SSDI, leave (see, for example, National Council on Disability, 2005). Going on, and remaining on, these rolls is not always, or even usually, by choice. Year after year, vast majorities of adults with disabilities say they would rather be on pay rolls than on aid rolls (see, among other sources, National Organization on Disability, 2004).

The Centers for Medicare & Medicaid Services (CMS), in the U.S. Department of Health and Human Services (HHS), administer Medicaid and Medicare (<http://www.cms.hhs.gov>). Medicaid spending has increased greatly in recent years. In the past five years alone, Medicaid costs have jumped 63%. Medicaid is now larger than Medicare, at \$300 billion annually (state and federal combined). In fact, Medicaid is more expensive than elementary and secondary education combined. That simple fact suggests that something is amiss. Here is another: In 2003, Medicaid costs for persons with disabilities added up to \$80 billion (Gleckman & Palmer, 2005).

In 2004, the U.S. Governmental Accountability Office (GAO), Congress' watchdog, projected that "Medicare, Medicaid, and Social Security will nearly double as a share of the economy by 2035". This fact, too, signals trouble ahead.

Last year, the author was one of a number of individuals convened by the National Council on Disability to review entitlement programs for individuals with disabilities. The two-day session was a dispiriting one. The Council's report reflects our sense of discouragement: there are no quick fixes, so easy solutions. The Social Security Advisory Board (2006a,b), as well, recognizes that systemic reform is required.

What Now?

We find ourselves in 2006 spending several hundred billion dollars "for" adults with disabilities. The word for is in quotes because the benefits are dubious at best for many of these citizens. Yes, these people are able to subsist. Lives are preserved. But at what I regard as an awful cost.

Suppose we were to change direction. Let us think about it, at least.

In a 20-year period (1950-1970), the United States made a massive, and hugely successful, investment in the abilities, talents and energies of Americans with disabilities (Bowe, 2006). We did this through the federal-state partnership known as vocational rehabilitation (VR). In 1950, just one dozen rehabilitation counselors were graduated nationwide. By 1970, the total was 5,000. Similarly, in 1950, VR successfully rehabilitated 60,000 adults with disabilities. Twenty years later, the figure was 240,000.

What made the difference? We put money into human resources, instead of into entitlements. We supported VR programs which, in turn, subsidized postsecondary education for many youth and adults with disabilities. Armed with education and training, they went to work. Many entered – and stayed in – the middle class. It is not an accident, in my view, that SSI did not even exist. It came along in federal legislation that was enacted in 1972.

Suppose we were to take some of the money now spent on entitlements and turn it, instead, toward postsecondary education and vocational training for Americans with disabilities. Suppose we were to take some (much less!) of it and put it toward real enforcement of ADA title I by the Equal Employment Opportunity Commission (EEOC). And suppose we were to take some (more) of it and partially subsidize employer-provided health insurance, as an incentive for hiring adults with disabilities.

Certainly, the argument cannot be made that "we can't afford to do this". We already are paying out a couple hundred billion dollars annually. This modest proposal would re-direct some of that money toward what I regard as more socially productive use: investing in our people.

I am willing to bet, as I did in 1980, that the investment will pay off. When tens or hundreds of thousands, or even millions, of adults with disabilities have private jobs, with private health insurance, they can support themselves and their families. And government need no longer shell out so massively large amounts of tax revenues in entitlement spending.

I think Americans with disabilities, on the whole, will be happier. I think the country will be, as well.

To quote Joe Califano once more: This is doing well by doing good.

Two Precedents

We have two recent precedents for social change that offer encouragement that we will succeed in doing good well.

The first is the 1996 Personal Responsibility and Work Opportunity Reconciliation Act, better known as “welfare reform”. In the ten years since president Clinton signed it into law on August 22, 1996, this law has helped many people to escape dependency and poverty. Welfare rolls fell from 12 million to 4 million. We have also seen large drops in childhood poverty. The Temporary Assistance for Needy Families (TANF) program this law created, replacing Aid to Families with Dependent Children (AFDC), has led to employment by many women. Once working, they gained in self-respect and in social connections. Their “culture” altered from one of victimhood to one emphasizing personal responsibility.

TANF is a success. Importantly, it provided job training, child care, and other supports that have been vital in enabling mothers of young children to sustain labor-force participation. Notably, too, it works hand-in-hand with the Earned Income Tax Credit, food stamps, and other programs.

Individuals with disabilities, too, have access to vocational preparation through the Rehabilitation Act, as well as to EITC and food stamps.

The other precedent is even larger in scope. Over the past 30 years, we have seen a tremendous change in the education and work ambitions of girls and women. An early impetus was the 1972 amendments to the Higher Education Act that are known as Title IX. Its 34th anniversary was June 23. It prohibited discrimination on the basis of gender in education.

The changes it helped to unleash are breathtaking. Girls in high schools see doors open for them, and they take advantage. Today, more girls than boys graduate. Their grades are higher; it is quite common for both valedictorian and

salutatorian to be female. More go to college, and more graduate with bachelors degrees. More get graduate and professional degrees.

Put simply, girls and women were empowered. Boys and men are doing about what they always were – for them, the rules have not changed.

We can do much the same for Americans with disabilities. Key is to free them from the shackles of “substantial gainful activity” by de-linking essential medical insurance coverage from earned income limits.

Only then will we realize the full promise of ADA title I – and only then will tens of millions of Americans with disabilities feel free to pursue the American Dream.

Technical Notes

1. The demography of disability in the United States is treacherous territory. Take the seemingly simple matter of definition. What do we mean by “disability”? The answer varies from survey to survey. It even varies within survey, from year to year. Counting Americans with disabilities, it turns out, is far more challenging than is counting males or 16-to-24 year-olds. This fact introduces a note of caution. When we compare figures from, say, 1986 and 2003, the methodology behind the numbers may not be the same in each case. This is fact, and there is no getting around it. That being said, when one takes a bird’s eye view, as we do here, the divergences are manageable. That is, the differences are not so great as to make the comparisons meaningless. We do need to alert the reader, however, and that’s the purpose of this Technical Note 1. For more on the technical issues involved, see McNeil (2000), Stern (2006), Stapleton and Burkhauser (2003) and Silverstein, Julnes, and Nolan (2005).

2. The numbers in this report are averages. Many are means, but some are medians. As is always the case with averages, considerable deviation from the mean exists in virtually every case. Thus, while we can, and do, report that X percent of adults with disabilities work year-round full-time (YRFT), the proportion varies considerably by disability category. YRFT employment is higher with persons who are deaf than it is with individuals who have mental illness, for example. Earnings, too, vary greatly. There are people with disabilities whose annual earned incomes exceed one million dollars. And there are persons with disabilities whose earnings are below federal minimum-wage levels. This being a bird’s eye view, we focus on the averages so as not to clutter up the report with all of the variabilities. Again, however, we need to caution the reader that each mean is associated with variation.

3. In some instances, as with data on employment, the technical issues relating to Notes 1. and 2. are particularly vexing. The Social Security Administration (SSA), to illustrate, defines disability in terms of inability to perform substantial gainful activity (SGA), by which it means “work”. The Census Bureau, too, refers to ability to work when determining whether or not someone has a disability. This, it turns out, is quite a methodological quagmire. The author, for example, is deaf. Do I have a disability? To my mind, unquestionably. Does it limit the amount or kind of work I can do? Not really. I have worked YRFT for more than 30 years. Does it prevent me from working? No - as long as the work is something I can do without my ears. Accordingly, were the Census Bureau to come calling and ask me questions, I might well tell them, “No - I do not have a work disability” (as they define it). This would, of course, exclude me from their tabulations of “adults with work disability”. This point is made, too, by Silverstein et al. (2005).

4. Errors of measurement of another kind are also possible in these surveys, and undoubtedly occur. Census Bureau and SSA survey takers are, of course, representatives of the U.S. Government. Someone being interviewed who is

anxious to qualify for government benefits might be tempted to report more severe limitations than actually exist, in a misguided effort to enhance his or her prospects for benefits.

5. This report focuses upon Americans with "severe" disabilities. The Census Bureau and other sponsors of surveys identify persons with disabilities by asking a series of questions. Typically, these are self-report surveys. Respondents do not categorize themselves into "severe" and "non-severe" groups. Rather, that is done by the demographers on the basis of respondents' answers to questions. That being said, the reader needs to bear firmly in mind that civil rights laws such as Section 504 and the ADA do not reference this segment of the population. They prohibit discrimination against "qualified" individuals with disabilities. We have no national database, nor regularly conducted surveys, of that protected group as such (see, for example, Gould [2006] and Silverstein et al. [2005]). This is yet another troubling aspect of disability demographics today.

6. In writing about the demography of disability for more than a quarter century, the author has always distinguished between "impairments" by which is meant sensory, health, mental, emotional, and/or physical conditions that do not limit people in significant activities from "disabilities" which do (see, for example, Bowe, 1978). Experience has convinced me that what is meaningful when we talk about disability in America is what the demographers mean by "severe" disabilities. A few examples may help. People may have impairments of vision. If those are corrected with glasses, is it accurate to say that they have disabilities? I think not. In that instance, disability means blindness or low vision. Similarly, people may have impairments of hearing, but if a hearing aid corrects hearing, completely or nearly so, I would not use the term "disabilities". Rather, I reserve that term for people who are deaf or severely hard of hearing. With respect to the current report, the population that I consider to be "Americans with disabilities" is the 32,532,000 total identified by the Census Bureau as having "severe" disabilities - and not the 18,703,000 additional individuals in the survey who do not have severe disabilities. That is why this report mentions the 51,235,000 total in the May 2006 Census Bureau report, but considers that total to comprise persons with impairments as well as those with disabilities, and concentrates, instead, on the 32.5 million who have disabilities. The underlying surveys do not always break out data by severe v. non-severe disabilities (as with data on college attendance), but where such segmentation is possible, this publication applies it.

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