

The Financial Vulnerability of People with Disabilities: Assessing Poverty Risks

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The economic self-sufficiency and independence of people with disabilities depend largely on their capacity to maintain financial stability. As a group, such individuals have among the highest poverty rates, lowest educational levels, lowest average incomes, and highest out-of-pocket expenses of all population groups. Any substantial shock to the financial stability of people with disabilities can threaten their access to necessary housing, nutrition, medical care, and other resources, the absence of which may result in further vulnerability and possible poverty. This article offers a theoretical framework for understanding disability poverty risk. Empirical studies are needed to test this model, quantifying the specific risk factors and identifying coping mechanisms used by people with disabilities to reduce vulnerability. The results will have important implications at the individual, service provider, and policy levels.

Introduction

The Americans with Disabilities Act of 1990 states that "The Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals."¹ Thus, assisting the 54 million² Americans with disabilities (i.e., functional or activity limitations)³ to be self-sufficient and to live

independently in their communities are among the most important objectives of U.S. disability policy.⁴ To achieve these goals, people with disabilities need to be able to maintain financial stability, balancing their budgets and absorbing threatening shocks to their financial security such as the costs of illnesses and other short-term emergencies.

As a group, people with disabilities appear to be particularly vulnerable financially due to 1) reduced earning capacity often associated with functional limitations, 2) the often-substantial costs of accommodating these limitations, and 3) their high susceptibility to certain financial shocks (LaPlante, 1993; LaPlante et al., 1996a & b). Many people with disabilities live at or near the poverty line (Kaye, 1998). These individuals, who have virtually no financial reserves and extremely limited earning potential, have no financial "cushion" to help absorb short-term shocks, and are at high risk of poverty. Some are at substantial risk of homelessness, particularly individuals with mental illnesses. The capacity of people with disabilities living at a subsistence level to maintain independence can be compromised as a result of a single major adverse event.

However, such vulnerability also has profound implications for people with disabilities who are more financially secure, but whose resources are limited and whose expenses are extraordinary. Challenges to financial stability may threaten their abilities to maintain necessary housing, nutrition, medical care, and other key factors affecting health and survival. The absence of such resources may, in turn, result in further financial vulnerability. Failure to maintain financial stability may, therefore, trigger a downward spiral resulting in bankruptcy, diminished health (both physical and mental), financial dependence on family members and friends, and even homelessness or institutionalization if no family support is available.

Unfortunately, while financial stability is so important to people with disabilities, these individuals also appear to be disproportionately subject to extraordinary costs of living that compromise the ability to maintain stability. These include the high cost of personal assistance services (e.g., attendant care for people with quadriplegia, reader services for blind people, interpreter

services for people who are deaf), assistive technology (e.g., wheelchairs, augmentive communication devices, reading machines, and voice recognition computers), and transportation services for some people with disabilities (Nosek, 1991, 1993).

Exacerbating this situation, the inability of many people with disabilities to pay for extraordinary expenses such as personal assistance and transportation costs may increase their vulnerability to health-related financial shocks (Nosek, 1993). Due to their disabilities, many of these individuals have a thinner margin of health than people without disabilities (DeJong, Batavia and Griss, 1989). Any deprivation of needed resources can compromise their health, causing a major drain of limited financial resources.

Although people who address disability issues understand these factors and relationships in a general manner, such variables have never been studied systematically with the objective of developing insights for reducing financial vulnerability and increasing financial stability. Specifically, no comprehensive model for predicting disability poverty risks has been developed to date. This article constitutes a first effort to develop such a theoretical framework and research agenda for understanding the financial vulnerability of people with disabilities.

The Financial Status of People with Disabilities

As a group, people with disabilities are among the poorest of all Americans (Louis Harris and Associates, 1998, p. 5). Of course, the disabled population is extremely diverse, and there are broad ranges of educational status, employment status, income level, asset level and other economic indicators among people with disabilities (Louis Harris and Associates, 1986, 1998; Baldwin, 1999). Some, by virtue of their family circumstances, individual efforts, legal settlements, or other good fortune, are wealthy or at least secure in the middle class and not financially vulnerable (except perhaps in a relative sense compared with other people in their social class). However, the vast majority of people with disabilities are not so fortunate. The following parameters fairly characterize the financial circumstances

of the average individual with a major disability in the United States.

Poverty Rates

Based on data from the 1995 Current Population Survey (CPS), 38.3% of working-age adults with severe work disabilities (i.e., unable to work due to a disability)⁵ live in poverty, compared with 30% of those limited in their ability to work and 10.2% of those not limited in work (Kaye, 1998). The 1998 National Organization on Disability (NOD)/Harris survey found that 33% of people with disabilities live in households with incomes of less than \$15,000; only 12% of adults without disabilities live in such households (Louis Harris and Associates, 1998). According to these data, depending upon the extent of disability, people with disabilities are three to four times as likely to live in poverty as non-disabled people.

The 1992 National Health Interview Survey (NHIS) similarly suggests a significant discrepancy between the poverty rates of people with and without disabilities, though a somewhat smaller one. According to NHIS data, 17.1% of people limited in any activity live in poverty compared with 11.2% of people not limited in activity. Some 28.4% of children with a limitation in a life activity live in poverty compared with 17.8% of children who are not limited. Among the elderly population, 11.4% of those with disabilities live in poverty compared with 6.5% of those without disabilities (Kaye, 1998).

According to 1992 CPS data, women with severe work disabilities (i.e., conditions that prevent them from working) have the highest rates of poverty of all groups. Some 40.5% of such women live in poverty compared with 31% of men with severe work disabilities, 12.1% of women with no work disability, and 8.1% of men with no work disability (InfoUse, 1999).

Although these estimates of the extent of poverty among the disabled population differ, there is general consensus that a far larger percentage of people with disabilities live in poverty than people without disabilities. This conclusion is particularly disconcerting considering that about half of people who are unable to work due to a chronic disease or illness receive federal cash benefits under the Social Security Disability Insurance (SSDI)

program (32.7%), Supplemental Security Income (SSI) program (19.8%) or both (6%). These individuals also qualify for Medicare and Medicaid respectively. Thus, even though many people with disabilities have a stable source of program income and health insurance, they still remain in poverty at rates significantly higher than people without disabilities.

Education

People with disabilities have relatively low levels of education compared with the population generally. According to the NOD/Harris survey, 20% of people with disabilities do not complete high school, compared with 10% of those without disabilities (Louis Harris and Associates, 1998). Based on NHIS data, people with lower education levels consistently report higher levels of activity limitations, with 16.5% of those with 8 years of education or less unable to do their major life activity compared with 2.3% of those with 16 years or more (InfoUse, 1996). The relationship between disability and education is complex, and causation is likely to run in both directions.

Employment

According to the NOD/Harris survey, only about 30% of working-age adults with disabilities are employed full or part-time, compared with 80% of adults without disabilities (Louis Harris and Associates, 1998). Although 75% of unemployed individuals with disabilities consistently indicate that they would like to have a job, their employment situation has not improved, and may have worsened, in the past decade even with the implementation of legislation designed specifically to improve their economic viability such as the ADA. (Louis Harris and Associates, 1986, 1998; Budetti et al., 2001)

Other national surveys have yielded similar results. CPS data indicate that, of the 16.9 million working-age people with health conditions or impairments that limit their ability to work, 12.1 million people (72.1%) are unemployed (Kaye, 1998). Survey of Income and Program Participation (SIPP) data collected in 1994–95 indicate that 26.1% of people with severe disabilities⁶ are employed, compared with 76.9% of people with non-severe disabilities and 82.1% of people with no disabilities (McNeil, 1997).

The following percentages represent the proportion of people with certain disability characteristics who are employed: 22% of working-age wheelchair users; 27.5% of cane, crutch or walker users; 25% of people unable to climb stairs; 30.8% of people who are unable to see words or letters; and 35.1% of people with mental retardation (Kaye, 1998).

The poor levels of education and training of people with disabilities, combined with prejudicial attitudes and a history of dependence, often conspire to give many people with disabilities short or spotty job histories. This may make them less desirable to employers than other employees. Traditionally, disabled people have tended to make the most significant gains in the workforce when there is a shortage of available labor, or when disabled veterans return from a popular war (Berkowitz, 1980; Oberman, 1965; Renz-Beaulaurier, 1996, chap 2.). There is little evidence that the employment provisions of the ADA and other disability laws have changed the employment prospects of people with disabilities very much.

Earnings and Other Income

The major sources of income for people with disabilities are well known. They include a combination of conventional sources of income available to all people (e.g. employment, interest payments, dividends, TANF), as well as income transfer programs specifically targeted at disabled people such as SSI, SSDI and private disability insurance. Moreover, employer or government-subsidized benefits such as employment-based health insurance, Medicaid, Medicare, disability trust programs, and sliding scale service programs may serve as in-kind forms of income, or at least provide a way of limiting expenses (Batavia, 1998).

According to SIPP data, the median earnings of people with severe disabilities is about 60% of that for people without disabilities, and "[t]he presence of a disability is associated with an increased chance of having a low level of income" (McNeil, 1997, p. 3-4). For men between 21-64, median earnings for individuals with severe disabilities was \$1,262 per month, compared with \$2,190 for individuals with no disabilities. For women in this age range, the median earnings for disabled individuals was \$1,000 per month, compared with \$1,470 per month for women with

no disabilities. Some 42.2% of people with severe disabilities have incomes below the median income, compared with 13.3% of people with no disabilities (McNeil, 1997).

Individuals with very low incomes are, of course, particularly vulnerable to high costs of living and exposure to financial shocks. Those who are eligible for federal cash assistance under the federal disability programs, SSI and SSDI, are less vulnerable in part due to the cash payments, but mostly due to their resulting eligibility for Medicaid and Medicare respectively. Contrary to popular misconception, only 37.1% of people with severe disabilities receive means-tested government assistance (McNeil, 1997). Among those on the disability programs, work incentive provisions in these laws have further increased the earning potential of these individuals. However, the vast majority of people with disabilities still do not attempt to work, and remain trapped in a permanent state of subsistence (Batavia and Parker, 1995).

Expenses

The term "expenses" is used in this article to connote financial costs that must be paid out-of-pocket by the individual (as opposed to costs that may be paid by third parties). People with disabilities generally have the same categories of expenses as other people, as well as a few additional categories. These additional expenses may include housing and workplace modifications, special transportation needs, attendant care, interpreter services, reader services, periodic medical procedures or visits with specialists, and in some cases assistance in organizing care and services for their special needs. The need for personal assistance services increases with age (McNeil, 1997). Depending on their specific needs associated with their impairments and functional limitations, people with disabilities often bear financial burdens far beyond those of people without disabilities.

Obviously, if the individual's expenses exceed income for several years consecutively, this could deplete whatever net assets the individual may have accumulated. Even those people with disabilities who are highly educated and have substantial income levels may also be adversely affected by high costs and financial shocks. For example, an individual with an annual income of \$100,000 who requires extensive personal assistance services

and who is subject to occasional severe health problems (e.g., decubitus ulcers, severe infections) may be severely impacted in a particularly bad year.

Although it is clear that people with disabilities are subject to high costs of living, little is known about their specific expenses. By virtue of their functional limitations, they tend to be more dependent than other people on costly human assistance and assistive technology. The most expensive component of human assistance for these individuals is services specifically designed to address their disabilities, such as specialized medical services and personal assistance services. However, people with disabilities also tend to have an increased dependence on services also used by non-disabled people such as housekeepers, electricians, plumbers, auto mechanics, and handymen, because many are less able to engage in self-help activities that are physical in nature (e.g., make minor home or car repairs and modifications).

Assistive technology can range from relatively simple devices (e.g., canes, walkers) to highly sophisticated motorized wheelchairs, communication devices and environmental control units. The more expensive devices can cost tens of thousands of dollars, and are virtually unaffordable to those who are not wealthy or who do not have another significant source of payment (e.g., health insurance, workers' compensation, vocational rehabilitation, etc.). Many insurance plans do not cover assistive devices or cover them only upon very limited circumstances.

Stability of Income and Expenses

Almost as important as levels of income and expenses is their stability over time. An occasional dip in income or spike in expenses can have a dramatic effect on an individual's financial situation and risk of poverty. Expense stability may be conceptualized as a continuum, with a range based on stability of impairments, accommodations, housing and social supports. Almost all expenses are subject to fluctuation, and this can have a particularly adverse impact on people with disabilities.

Automobile expenses are a good example. While insurance, licensing and even maintenance costs may remain relatively stable, in some years it will be necessary to replace the car or make major repairs, creating extra financial instability. For a disabled person

driving a wheelchair-accessible conversion van, such "spikes" can be particularly dramatic due to the relatively high cost of the accessible vehicle itself (typically over \$35,000), as well as to the high cost of non-standard parts and high labor costs for specialized personnel. Moreover, a person with special transportation needs may not easily be able to find another means of transportation while the van is being repaired. Unlike non-disabled individuals, people with disabilities may not be able to simply rent a car, even if their insurance will pay for them to do so. This can lead to additional expenses or even a loss in employment or employment-related income.

The nature of disability can also influence stability of expenses. Some disabilities change over time and require different adaptations and therefore different expenses over time. Some disabilities are degenerative in nature (e.g., multiple sclerosis, muscular dystrophy), and inherently result in major changes in needs and expenses as the impairment and disability progress. Yet, even people with relatively stable impairments (e.g., spinal cord injury) can have increased expenses over time as they age with their disabilities and develop secondary conditions (e.g., joint deterioration, muscle deterioration, skin breakdown, arthritis, scoliosis).

Like expense stability, income stability may be conceptualized as a continuum, ranging from very stable sources of income to very unstable sources. Some forms of income, such as entitlement program income (e.g. SSI, SSDI) and trust payments are very stable. Most work-related benefits, however are limited roughly to the time one is working, and are therefore of limited duration when a person is unable to work. Because people with disabilities have greater susceptibility to health problems, their risk of losing employment due to health problems is probably also above average. If this is true, income fluctuations are likely to be relatively high for people with disabilities.

Assets and Net Worth

The financial net worth (i.e. assets minus liabilities) of an individual offers an assessment of the individual's financial cushion at any point in time. This cushion can protect the individual during a period of financial shock, such as a severe medical problem.

Personal savings and liquifiable assets remain the chief way in which people of all abilities prepare for the possibility of financial burdens and shocks. Many people with disabilities have almost no financial assets, and even a single year of financial shocks or one substantial shock, can put the individual in poverty.

There are few direct data on the net worth of people with disabilities. However, we know that many have almost no net assets by the significant and growing number of SSI and TANF recipients with disabilities. For the most part, assistance under these programs is not designed to allow these individuals to increase what little reserve they may have. In order to qualify, it is generally necessary to show both low income and minimum assets. Once in poverty, financial recovery is extremely difficult.

Health-Related Financial Consequences

All aspects of a person's finances are affected by a substantial disability. However, financial consequences related to health problems deserve specific attention. Numerous studies demonstrate the high susceptibility of many people with disabilities to major health problems (DeJong, Batavia and Griss, 1989; LaPlante, 1993; Max et al., 1995). Estimates of their health care expenses vary in part based on the definition of disability used. One study found that people with an activity limitation due to a chronic condition spend over four times more than non-disabled people on health care (InfoUse, 1996). The high-risk status of this population has a double impact on the potential for financial stability—an effect on income and on expenses.

First, health problems can substantially affect income in any given year, particularly for the many people with disabilities who have little or no job security (such as individuals who work for wages or on a part-time basis). A major health problem can result in unemployment and/or loss of income even for people with full-time employment.

Second, high susceptibility to health problems has obvious implications for the expenses of people with disabilities. To the extent an individual does not have access to group insurance coverage and is not eligible for government coverage, an individual policy will be extremely expensive and often unaffordable.

Moreover, individual policies typically have inadequate coverage, particularly for the needs of people with disabilities. Even if the individual has a good group policy, out-of-pocket expenses can be extremely burdensome in a year in which the individual has a major health problem. The federal tax system attempts to reduce the burden of some health care costs. However, only those qualified health-related expenses that exceed 7.5% of income may be deducted. Therefore, individuals with disabilities often have to bear the burden of thousands of dollars directly out-of-pocket without any tax relief.

The consequences of increased susceptibility to health problems are major sources of financial shock for people with disabilities. One study found that persons with both musculoskeletal conditions and comorbidity report 18% lower family earnings, 15% lower family income, and 35% fewer assets than the average among all persons their ages, while those with such conditions and no comorbidity have earnings, incomes, and assets closer to the average among their peers (Yelin, 1997).

Another study indicates that 89% of an inception cohort of 186 people with rheumatoid arthritis (mean disease duration 3 years) was affected in at least one socioeconomic area (work capability, income, rest during the daytime, leisure time activity, transport mobility, housing and social support), and 58% were impacted in at least three of these areas simultaneously. Overall, work disability was 4–15 times higher among these individuals than the general population, with 42% registered as work disabled after 3 years (Albers et al., 1999). However, we must also recognize that there are enormous differences among people with different impairments, and even among people with the same impairment, with respect to health problems that increase poverty risks (Baldwin, 1999).

It is apparent that health, income and expenses are very closely related for people with disabilities—even more so than for people without disabilities—and any comprehensive policy addressed at reducing poverty among the disabled population must address their health as well. Conversely, health care policy generally must be concerned about providing adequate access to quality care at a reasonable cost for people with disabilities and ensuring that the burden of health care expenses does not

render such individuals disproportionately financially vulnerable (Batavia, 1993b).

Theoretical Framework

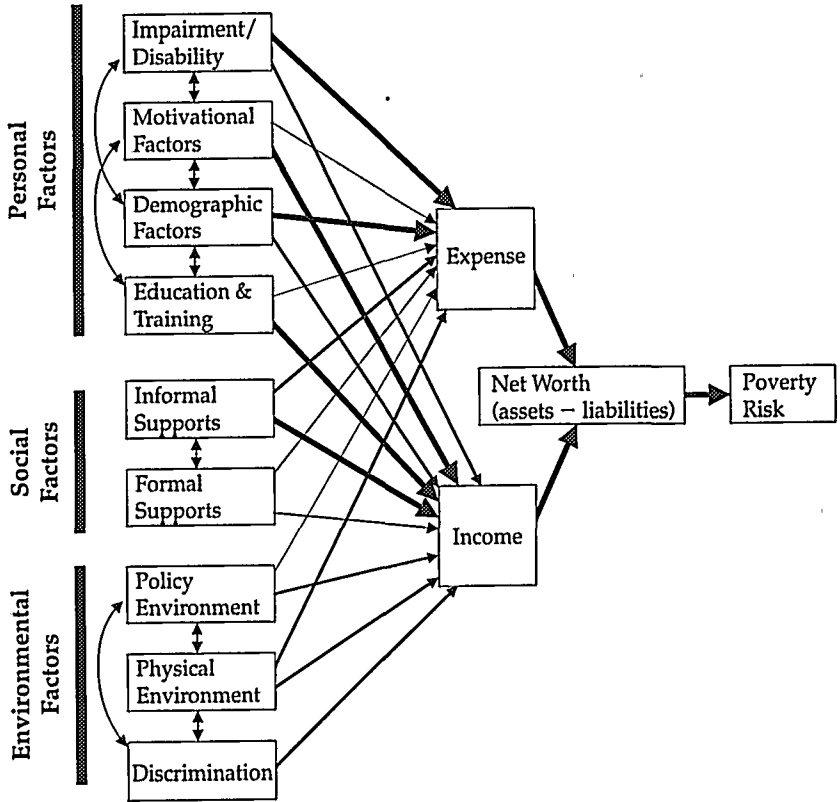
A rough assessment of the financial situation of people with disabilities may be depicted through income statements and statements of net worth. However, such a purely financial analysis by itself will not be sufficient to predict an individual's long-term financial security. In order to make such predictions, we must understand those factors that affect income, expenses, assets and liabilities over time. The risk of poverty, and consequent loss of financial security, is best depicted as the complex interaction of several personal, social and environmental factors. As illustrated in figure 1, each of these factors may be expected to have a weak, moderate or strong effect (characterized by the narrow, medium and broad lines respectively) on income and expenses, and consequently assets and liabilities.

Personal Factors

Among the personal factors that could potentially affect the individual's financial condition are impairment, disability, personality, values, intellectual ability, education, skills, adaptability and motivation. Some of these are innate in the individual, such as impairment and intelligence. Others are more subject to modification, such as education and motivation. All of these personal factors interact in affecting individuals' abilities to manage their disabilities in a manner that allows them to function in the economy—whether that means attempting to balance their budgets based on program income or attaining optimal productivity to succeed in a competitive environment.

Managing a disability is not an easy task. Effective management typically involves the highly-complex financing and coordination of many resources which must work in concert to compensate for the individual's functional limitations and/or to adapt the individual's environment to his or her needs. In most cases, people with disabilities, or their agents, will need to spend considerable time at these management necessities. Moreover, since the best laid plans often go awry due to extrinsic factors,

Figure 1
 Framework for Predicting Disability Poverty Risk



the individual or agent will also spend considerable time troubleshooting when one or more parts of their accommodation strategy develops problems.

People who experience financial crises typically adapt by making contingency plans. If you cannot drive to work, you take the bus. If you cannot afford to eat out, you eat in. However, for many people with disabilities, there is a limited array of viable substitute options. If your personal assistant doesn't show up, or your customized wheelchair breaks, or your guide dog dies, what do you do? Even the best managed contingency systems break down on occasion, resulting in particular frustration when

contingency options are limited. This suggests that many people with disabilities may not only be close to the margin financially, but also emotionally, in their capacity to maintain independence. Several factors appear important, including the ability to plan in a flexible manner, the ability to deal with stress and frustration, the ability to invest by delaying gratification, and the ability to follow through in ensuring a successful long-term outcome.

The following are our hypotheses concerning how various factors inherent in the individual will affect the individual's income and expenses:

1. *Disability (i.e., functional deficit) is a moderate negative predictor of income.*

Advocates of disability rights and independent living like to claim that the functional limitations of people with disabilities do not cause reduced employment and income, but rather the interaction between the disability and the environment causes such problems. Although environmental factors appear to impose the most significant barriers to inclusion in all aspects of life for people with disabilities, including employment, the impairments and related disabilities of individuals can inherently preclude employment, either entirely or with respect to certain occupations, or can simply reduce productivity.

A perceptive commentator once observed, "Disability steals time." This insight has substantial implications for both the income-earning potential and spending requirements of people with disabilities. To the extent that the limitations associated with disability require an individual to spend more time on a given task than the task would require in the absence of the limitations, disability reduces the individual's productivity and earning potential. Of course, depending on relative aptitude, skills, attitude, motivation and a variety of other factors, the individual could still be significantly more productive than his or her peers. The point is that, relative to the individual's potential without the disability, productivity may be reduced to some extent.

Thus, disability deprives the individual with the disability of needed income associated with the lost time, or alternatively deprives the individual of spare time and energy necessary to compensate for the lost time. The type and extent of disability,

and the availability of assistive technology to compensate for functional losses, will determine the extent of the lost income.

2. *Age is a moderate positive predictor of income.*

Age is among the most important demographic factors affecting poverty risk. All other factors held constant, increased age and related life experience are probably associated with increased income.

3. *Motivation is a strong positive predictor of income.*

Perhaps the personal factor that is most difficult to understand or measure is motivation. Some people with disabilities who have every financial advantage completely lack the motivation to become self-sufficient. Others who have no advantages have succeeded admirably. In other words, people with disabilities are not basically different from non-disabled people in this important regard, except that the consequences of their motivation or lack thereof may be greater for people with disabilities. Motivation is certainly affected by values and upbringing, but it also has a strong unpredictable element. It is not unusual to hear successful people with disabilities say that they succeeded to prove their ability to all those who doubted it.

Motivation in people with disabilities is likely to be affected by several factors, including perceptions about stability of their income and expenses, and about the prospects that the future will be as good or better than the present. For example, if individuals believe their hard work will be "rewarded" by a reduction in government benefits, motivation is likely to be diminished. This is probably the strongest reason that very few people ever leave the Social Security disability rolls (Batavia and Parker, 1995). The individual's degree of commitment to the independent living philosophy is also likely to affect his or her motivation to become financially self-sufficient.

4. *Education is a strong positive predictor of income.*

It is practically a truism that a good education is the road to opportunity and economic success. This appears to be particularly true for people with significant disabilities, because the skills and knowledge gained through education can compensate

for lost functional capacity or can otherwise offer employment opportunities that would not have been available to the individual. For example, obviously a person who is legally blind cannot be employed as a taxi driver (except possibly in Miami). However, such an individual, with the appropriate education, can be employed as an attorney or a banker. Therefore, education is not only the most promising strategy for employment for many people with disabilities; it is also the strategy with the highest return in terms of income. Unfortunately, as indicated above, people with disabilities do not achieve levels of education comparable to people without disabilities. Clearly, education is a key variable in any model for predicting financial vulnerability of people with disabilities.

5. *Functional deficit is a strong positive predictor of expenses.*

In addition to adversely affecting income, disability is likely to increase expenses. This may result from increased costs of rehabilitative care, personal assistance services and assistive devices. Also, to the extent individuals have limited time available to meet those needs they are capable of addressing independently, they must live with needs unattended or must pay for them. For example, a person with a disability who is capable of doing housework may still need to hire a housekeeper if all his time and energy are consumed managing his disability.

6. *Age is strong positive predictor of expenses.*

All other factors constant, increasing age is likely to exacerbate the costs associated with a disability. A growing literature on aging with a disability indicates that, as people with disabilities age, their functional and health problems tend to increase (DeJong, Batavia, & Griss, 1989). These problems often require expensive medical attention or personal assistance.

7. *Motivation is a weak negative predictor of expenses.*

Motivated individuals may find ways in which to fulfill their responsibilities without incurring additional expenses.

8. *Education is a weak negative predictor of expenses.*

Educated individuals may have skills or access to informational resources that can assist them in containing their expenses.

Social factors

When most people with disabilities experience fiscal shocks and other sorts of crises, there are a variety of social resources that they are able to access. These constitute our society's formal and informal safety net. They include informal support from family and friends, and formal support through federal, state, local and not-for-profit programs (DeJong, Batavia & McKnew, 1989). Informal support, which is uncompensated, is often inadequate to assist people with disabilities to achieve economic security and the capacity for independent living. The high costs of many special accommodations are beyond the financial capacity of most families. The direct provision of personal assistance services by family members may reduce their capacity to earn income that would benefit the household, including the disabled individual.

There are considerable differences among families with regard to how they cope with crises (McCubbin & Patterson, 1983). By the same token, naturally-occurring community supports (as defined by Pinderhughes, 1994), such as churches and social organizations, frequently are not be able to accommodate the often-extensive needs of people with disabilities. Therefore, although informal supports are an essential component of the mix of resources needed by people with disabilities to survive economically, they will never be adequate for the vast majority of people with significant disabilities.

Like all Americans, those with disabilities are potentially eligible for all the government poverty-reduction programs, assuming that they satisfy the programs' non-disability-related eligibility criteria. In addition, there are some programs such as SSI for which disability itself is a primary eligibility criterion. Often, however, use of these programs comes at the cost of increased dependence, or limitations on independence. For example, in order to receive SSI, it is necessary to prove that the individual is basically unemployable. Other programs may have other restrictions as well. For example, subsidized attendant care may be available in some areas only if the individual is willing to accept highly restrictive conditions (DeJong, Batavia & McKnew, 1992; Doty, Kasper & Litvak, 1996; Egley, 1994).

The following are our hypotheses concerning how various factors associated with the individual's social relationships and support networks will affect the individual's income and expenses:

1. *Informal social support is a strong positive predictor of income.*

Support provided by family members and friends is probably one of the most important factors in assisting a person with a disability to be able to seek gainful employment, and to work at a higher level of productivity than without such support. For example, an individual without informal support may not have adequate personal assistance services or transportation to allow the individual to get to work.

2. *Formal social support is a weak positive predictor of income.*

Obviously, formal support from social programs provides direct income or the equivalent in in-kind benefits (e.g., Medicare, Medicaid) for those who are eligible. However, this factor is somewhat ambiguous in its effect because such formal support can create a disincentive to seek gainful employment. On balance, formal support is probably a weak predictor of income.

3. *Informal social support is a moderate negative predictor of expenses.*

Informal support from friends and family can directly decrease the expenses of an individual with a disability by providing services that the individual would otherwise have to pay out-of-pocket (e.g., personal assistance and transportation).

4. *Formal social support is a weak negative predictor of expenses.*

Formal support from government programs may increase the individual's ability to care for himself or herself, and thereby contain health care costs.

Environmental Factors

Disability rights advocates often argue that the problems of disabled people have more to do with environmental factors, including discrimination and negative attitudes, than with their physical impairments (Fine & Asch, 1990; Meyerson, 1990). According to this perspective, their problems may be ameliorated or

eliminated entirely through environmental modifications, including the use of assistive technology. Unfortunately, many people with disabilities who are working or wish to work do not have access to optimal assistive devices, and work in environments that have not been adapted to their needs. Consequently, many such individuals are performing at a level that is below their optimal potential. In a competitive economy, in which incomes reflect productivity, it is likely that these workers are being paid less than what they would earn if accommodated more appropriately.⁷

To some extent, environmental factors and social factors overlap, particularly when we consider how formal and informal supports often affect the environments of people with disabilities. For example, some government programs provide some funding specifically for assistive devices and environmental accommodations. Other programs provide general funds that may be used by individuals or businesses for such purposes. Still, for purposes of conceptualizing financial vulnerability factors, it is valuable to consider the environment as a separate but overlapping category.

The following are our hypotheses concerning how various factors inherent in the individual's environment will affect the individual's income and expenses:

1. *Policy accessibility is a moderate positive predictor of income.*

An environment of laws and policies supporting the aspirations of people with disabilities is likely to enhance the individual's ability to attain and maintain gainful employment. To the extent that some states, such as California and Wisconsin, have supportive policy environments, we would predict that people with disabilities in such states will have advantages in seeking employment relative to people with disabilities in less supportive states.

2. *Physical accessibility is a moderate positive predictor of income.*

An optimally accessible environment is likely to enhance the individual's ability to attain and maintain gainful employment. Conversely, an inaccessible environment can impose an insurmountable barrier to employment. As the ADA has enhanced the accessibility of our country, physical accessibility is less of a barrier now than it has ever been.

3. *Discrimination is a moderate negative predictor of income.*

Employment discrimination may prevent the individual from being hired or advancing to a higher level of employment. However, it is not deemed a strong factor, in that many individuals have been able to overcome discrimination to become successful in employment.

4. *Policy accessibility is a weak negative predictor of expenses.*

A policy environment amenable to the needs of people with disabilities may reduce their burden of managing their disabilities, and could therefore reduce avoidable expenses.

5. *Physical accessibility is a moderate negative predictor of expenses.*

An accessible environment is likely to reduce the individual's need for costly assistance. For example, an environment with a highly accessible public transportation system, such as Washington, DC, will significantly reduce the individual's transportation expenses.

Conclusions

People with disabilities appear to be among the most financially vulnerable Americans due to their low levels of education, employment, income, and assets. They are also among the people most in need of financial security due to often extraordinary and unstable expenses. There has been no systematic effort to research the relationships among personal, social and environmental factors and financial vulnerability of people with disabilities. A variety of factors, including social support, environmental modifications, and attitudes about community living, may serve to moderate the effects of impairments and disabilities even in the face of financial crisis.

Significant empirical research is needed to determine factors that affect the financial vulnerability of people with disabilities and implications for economic self-sufficiency and independent living. Specifically what is called for initially is exploratory and descriptive research that can chart in detail how people with disabilities view their financial circumstances. These studies should identify the relevant vulnerability factors, including those that

impose extraordinary costs on people with disabilities. Discerning this information is probably best achieved through qualitative research methods using focus groups of people with different disabilities (e.g., quadriplegia, paraplegia, deafness, blindness, mental illness, etc.), including an adequate representation of individuals who are living in or near poverty. Subsequently, once specific factors are identified, they must be operationalized as key variables and tested on the broader disability population to determine whether they are generalizable.

The findings of such studies will have important implications at several different levels. At the individual level, they can provide valuable insight for people with disabilities and their families to recognize sources of financial vulnerability and how to avoid them, including coping strategies of successful people with disabilities. At the clinical level, this research can also provide similar information to professionals such as social workers and rehabilitation professionals to assist them in empowering their clients with disabilities to gain financial security and avoid poverty. At the broader policy level, such studies will have implications for income maintenance policy, employment policy, health care policy, tax policy, and civil litigation. By reducing the financial vulnerability of people with disabilities, we can help them to improve their lives and enhance their independence and self-sufficiency.

NOTES

1. Section 2 (a) (8) of the ADA (42 U.S.C. 12101(a) (8)).
2. The estimate of 54 million Americans with disabilities, representing 20.6% of the population, is based on a broad definition of disability including an array of functional and activity limitations. It is estimated that approximately 26 million, or 9.9% of the population, have a severe disability. Approximately 6 million use wheelchairs, 5.2 million use other mobility aides (e.g., cane, crutches, walker), 1.6 million are unable to see, and 1 million are unable to hear (McNeil, 1997).
3. The term disability is used differently by different people and in different contexts. Some people use the term to connote the relationship between the individual's environment and any impairment (e.g., severed spinal cord) or functional limitation (e.g., paraplegia) the individual has—the extent to which the individual is disadvantaged socially (i.e., "handicapped"). For purposes of this paper, we use the Nagi terminology in which disability

- is synonymous with functional limitation, and does not necessarily imply a social disadvantage (Batavia, 1993a).
4. The philosophy of independent living, which has served as the ideological foundation of the independent living movement of the 1970s, includes strong emphasis on consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy (DeJong, 1979). See section 701 of the Rehabilitation Act of 1973 (29 U.S.C. 796).
 5. Specifically, the CPS classifies people as having a "severe work disability" if (1) they did not work in the survey week because of a long-term physical or mental illness that prevents the performance of any kind of work, (2) they did not work at all in the previous year because of illness or disability, (3) they are under 65 years of age and covered by Medicare, or (4) they are either 65 years of age and a recipient of SSI.
 6. The SIPP regards a person who is unable to perform, or needs the help of another person to perform, one or more of the following list of physical functional activities as having a severe functional limitation: 1) seeing ordinary newspaper print (with glasses or contacts if normally used); (2) hearing normal conversation (using hearing aid if normally used); (3) having speech understood; (4) lifting or carrying 10 pounds; (5) walking a quarter of a mile without resting; (6) climbing a flight of stairs without resting; (7) getting around outside; (8) getting around inside; and (9) getting in and out of bed.
 7. This is also true of other workers without disabilities who are not accommodated adequately to meet their individual needs. However, due to the functional limitations of people with disabilities, the potential productivity gain of adequate accommodations is likely to be greater for them.

References

- Albers J. M., Kuper H. H., van Riel P. L., Prevoo M. L., van 't Hof M. A., van Gestel A. M., Severens J.L. (1999) "Socio-economic consequences of rheumatoid arthritis in the first years of the disease." *Rheumatology* 1999 May; 38(5):423-30.
- Baldwin M. L., (1999) "The effects of impairments on employment and wages: estimates from the 1984 and 1990 SIPP," *Behav Sci Law*. 1999; 17(1):7-27.
- Batavia, A. I. (1993a) "Relating Disability Policy to Broader Public Policy: Understanding the Concept of Handicap," *Policy Studies Journal*. 21(4): 735-39.
- Batavia, A. I. (1993b) "Health Care Reform and People With Disabilities," *Health Affairs* 12(1): 40-57, Spring 1993.
- Batavia, A. I. (1996). "Health Care, Personal Assistance, and Assistive Technology: Are In-Kind Benefits Key to Independence or Dependence for People with Disabilities?," In *Disability, Cash Benefits and Work*, J. L. Mashaw, et al., (eds.), Kalamazoo, MI: W. E. Upjohn Institute for Employment Research.
- Batavia, A. I., and S. Parker. (1995). "From Disability Rolls to Payrolls: A Proposal for Social Security Program Reform," *Journal of Disability Policy Studies* 6(1): 73-86, August 1995.

- Batavia, A. I., G. DeJong, and L. McKnew. (1991) "Toward a National Personal Assistance Program: The Independent Living Model of Long-Term Care for Persons with Disabilities," *Journal of Health Politics, Policy and Law* 16(3): 525-547.
- Berkowitz, E. D. (1980). *Rehabilitation: The Federal Government's Response to Disability 1935-1954*. New York: Arno Press.
- Budetti, P., Burkhauser, R., Gregory, J. and Hunt, H. A. (2001). *Ensuring health and security for an aging workforce*. W. E. Upjohn Institute for Employment Research.
- DeJong, G. (1979) "Independent Living: From Social Movement to Analytic Paradigm." *Archives of Physical Medicine and Rehabilitation* 60: 435-446.
- DeJong, G., A.I. Batavia, & R. Griss. (1989) "America's Neglected Health Minority: Working-Age Persons with Disabilities." *The Milbank Quarterly*, 67 (Supplement 2, Part 2): 311-351.
- Doty, P., J. Kasper and S. Litvak. (1996) "Consumer-Directed Models of Personal Care: Lessons from Medicaid." *Milbank Memorial Fund* 74(3):377-409, 1996.
- Egley, L. (1994) *Program Models Providing Personal Assistance Services (PAS) for Independent Living*, Oakland, CA: World Institute on Disability, 1994.
- Fine, M., & Asch, A. (1990). Disability Beyond Stigma: Social Interaction, Discrimination and Activism. In M. Nagler (Ed.), *Perspectives on Disability* (pp. 61-74). Palo Alto, CA: Health Markets Research.
- InfoUse (1996). *Chartbook on Disability in the United States*, Washington, DC: National Institute on Disability and Rehabilitation Research.
- InfoUse (1999). *Chartbook on Women and Disability in the United States*, Washington, DC: National Institute on Disability and Rehabilitation Research.
- Louis Harris and Associates. (1998) *NOD/Harris Survey of Americans with Disabilities*. Washington, DC: Author, 1998.
- Louis Harris and Associates. (1986) *NOD/Harris Survey of Americans with Disabilities*. Washington, DC: Author, 1986.
- Kaye, H. S. (1998) *The Status of People with Disabilities in the United States: A Report of Disability Rights Advocates, Inc.*, Volcano Press, Volcano, California.
- LaPlante, M. P. (1993). *Disability, Health Insurance Coverage, and Utilization of Acute Health Services in the United States*. Disability Statistics Report (9). Washington, DC: U.S. Department of Health and Human Services.
- LaPlante, M., Kennedy, J., and Trupin, L. (1996). *Income and Program Participation of People with Work Disabilities*. Disability Statistics Report, (9). Washington, DC: U.S. Department of Education, National Institute on Disability and Rehabilitation Research.
- LaPlante, M. P., Carlson, D., Kaye, S., Bradsher J. E. (1996). *Families with Disabilities in the United States*. Disability Statistics Report (8). Washington, DC: National Institute on Disability and Rehabilitation Research.
- Max, W., Rice, D. P., Trupin, L. (1995). *Medical Expenditures for People with Disabilities*. Disability Statistics Report (12). Disability Statistics Rehabilitation Research and Training Center. Washington, DC: National Institute on Disability and Rehabilitation Research.

- Meyerson, L. (1990). The Social Psychology of Physical Disability: 1948 and 1988. In M. Nagler (Ed.), *Perspectives on Disability* (pp. 13-23). Palo Alto, CA: Health Markets Research.
- McCubbin, H. I., & Patterson, J. M. (1983). Family transitions: Adaptations to stress. In H. I. McCubbin & C. R. Figley (Eds.), *Coping with Normative Transitions* (Vol. 1, pp. 5-25). New York: Brunner/Mazel.
- McNeil, J. M. (1997). *Americans with Disabilities: 1994-95*. U.S. Bureau of the Census, Current Population Reports, P7 70-61. Washington, DC: U.S. Department of Commerce.
- Nosek, M. (1991) "Personal Assistance Services: A Review of Literature and Analysis of Policy Implications." *Journal of Disability Policy Studies* 2(2):1-17.
- Nosek, M. (1993) "Personal Assistance: Its Effect on the Long-term Health of a Rehabilitation Hospital Population." *Archives of Physical Medicine and Rehabilitation* 74(2): 127-32.
- Oberman, C. E. (1965). *A History of Vocational Rehabilitation in America*. Minneapolis, MN: T. S. Denison & Company.
- Pinderhughes, E. (1994). Empowerment as an intervention goal: Early ideas. In L. Gutiérrez & P. Nurius (Eds.), *Education and Research for Empowerment Practice* (pp. 17-30). Seattle, WA: Center for Policy and Practice Research.
- Renz-Beaulaurier, R. L. (1996). *Health social workers' perspectives on practice with people with disabilities in the era of the Americans with Disabilities Act: An exploratory-descriptive study*. Unpublished Doctoral Dissertation, University of Southern California, Los Angeles, CA.
- Trupin, L., Sebesta, D. S., Yelin, E., and LaPlante, M. P. (1997). *Trends in labor force participation among persons with disabilities, 1983-1994*. Disability Statistics Report, (10). Washington, DC: U.S. Department of Education, National Institute on Disability and Rehabilitation Research.
- Trupin, L. and Yelin, E. H. (1999). *The Employment Experience of Persons with Limitations in Physical Functioning: An Analysis of the 1996 California Work and Health Survey*. Disability Statistics Report (12). Washington DC: U.S. Department of Education, National Institute on Disability and Rehabilitation Research.
- Yelin E., "The earnings, income, and assets of persons aged 51-61 with and without musculoskeletal conditions." *J Rheumatol*. 1997 Oct; 24(10):2024-30.

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