

## 1. The Organization and Financing of Health Services for Persons with Disabilities

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OVER THE LAST 30 YEARS, THE NATION HAS witnessed a material change in the status of Americans with disabilities: no longer are they at the periphery of American political and social life but now are increasingly represented in the mainstream of American community life. What started almost as a quixotic social movement in the early 1970s has matured into a social and political force that has altered how most Americans view individuals with disabilities. The most widely known achievement of the movement is the 1990 Americans with Disabilities Act, commonly referred to as the “civil rights act for individuals with disabilities.”

Despite these successes and a decade of strong economic growth, people with disabilities lag behind in many areas of American life, especially employment and health care. About half of working-age individuals with disabilities report that they are not working, and for those persons with the most severe disabilities, this proportion is 69 percent (U.S. Department of Commerce 2001). People with disabilities are nearly three times as likely to live in households with a combined annual income below \$15,000 and thus require income support (NOD 2000). An increasing

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number of individuals meet the stringent eligibility requirements of the nation's two largest disability-related income maintenance programs, the Social Security Disability Insurance program and the Supplemental Security Income program, which together pay \$62.5 billion per year to 7.5 million persons with disabilities (*Federal Register* 2000; Social Security Administration 1999; U.S. General Accounting Office 2000). As we will note later, the employment and income status of individuals with disabilities also affects their participation in the nation's health care system.

The record in health care, as this article shows, is equally unsatisfactory. No matter how the population is segmented, individuals with disabilities report having significant problems with access, even though they are the largest group of health care users in the so-called vulnerable populations. Despite the enormous stake that people with disabilities have in the health care system, health plans and health service providers remain ill equipped to meet their needs. And despite their extensive analytic armamentarium, health services researchers tend to overlook this population.

This oversight cannot be attributed solely to the health care industry and the health services research community. For those in the vanguard of the independent living and disability rights movement, until the 1990s, health policy issues rarely were given the priority of other public policy issues such as personal assistance services, transportation, and housing policy, despite the well-above-average health care needs of the groups they represented. Movement leaders saw professional health care as a system that marginalized them, especially taking umbrage at the "medical model" and the "sick role" (DeJong 1979; Oliver 1996; Zola 1977). Encounters with the health care system, they argued, often reminded them of their second-class status.

Then in the 1990s, how individuals with disabilities viewed their stake in health policy issues changed. Four events or perceived threats mobilized the disability community: (1) Oregon's Medicaid waiver in which rationing was seen as undervaluing the disabled state, (2) the 1993–94 health care reform debate, (3) the physician-assisted suicide debate, and (4) the rise of managed care and capitated payment, especially in the Medicaid program on which many depended. The disability community is now organized and represented in almost every major health policy debate: Medicare reform, the patient bill of rights legislation, the prescription drug benefit issue, mental health benefit parity, and others.

In short, the disability community is much better prepared to address health services research-related issues than it was a few years ago.

This article outlines the principal challenges in health care organization, delivery, and financing for individuals with disabilities and how the health services research community might help meet these challenges. First we specify the size and scope of this population, the changing epidemiology and demography of disability, the variety of health care needs of people with disabilities, and the actual utilization of health care.

Some important health policy issues we touch on only briefly. First, we do not discuss mental health policy issues that, unlike issues related to physical disability, have attracted significant attention from health services researchers. Second, we do not examine developmental disabilities or childhood disabilities; these are the subject of another article in this issue (Perrin 2002).

## The Prevalence and Changing Epidemiology of Disability

The U.S. Census Bureau recently estimated that 52.6 million Americans have a disabling condition (U.S. Department of Commerce 2001). Advocates and those in marketing often use this large number to demonstrate political and economic heft. From a health services research perspective, though, this figure obscures as much as it enlightens, and it provides very little insight into the nature or scope of the health care needs of individuals with disabilities. In fact, some people who have a disabling impairment may not think of themselves as having a disability at all, and yet technically they meet a population-based survey definition of disability.

A more useful number of adults with disabilities is that from the 1997 National Health Interview Survey (NHIS) (National Center for Health Statistics 2000) and the 1999 Medical Expenditure Panel Survey (MEPS) (Agency for Healthcare Research and Quality 2000) (see table 1). These figures reveal the prevalence of disability or limitation by type of limitation and the nature of the underlying condition and allow us to compare the degrees of limitation for both working-age and retirement-age persons. Our analyses of the NHIS data indicate that the prevalence of disability in all adults varies from 5.2 percent to 18.2 percent, depending on the underlying condition. Our analyses of the MEPS data show that

TABLE 1  
Disability by Age Group for Adults Included in the 1997 National Health Interview Survey and the 1999  
Medical Expenditure Panel Survey

| Disability or Limitation                     | All Adults<br>18+ Years Old | Working-Age Adults<br>18–64 Years | Adults Age<br>65+ Years Old |
|--|-----------------------------|-----------------------------------|-----------------------------|
| 1997 National Health Interview Survey (NHIS) |                             |                                   |                             |
| Severe Mobility Limitation                   | 102,251 (5.2%)              | 4,737,342 (2.9%)                  | 5,487,759 (17.9%)           |
| Mild to Moderate Mobility Limitation         | 35,592,679 (18.2%)          | 23,962,275 (14.7%)                | 11,630,304 (36.3%)          |
| Depression or Emotional Limitation*          | 4,165,105 (6.3%)            | 3,710,109 (8.1%)                  | 454,996 (2.2%)              |
| Vision and/or Hearing Limitation†            | 24,165,708 (12.4%)          | 15,386,205 (9.4%)                 | 8,779,503 (27.4%)           |
| 1999 Medical Expenditure Panel Survey (MEPS) |                             |                                   |                             |
| Cognitive Limitation*                        | 7,196,466 (3.6%)            | 4,040,631 (2.4%)                  | 3,155,835 (9.9%)            |
| Physical Limitation*                         | 22,495,370 (11.4%)          | 12,282,521 (7.4%)                 | 10,212,849 (32.0%)          |
| ADL Limitation                               | 3,344,378 (1.7%)            | 1,278,435 (0.8%)                  | 2,065,943 (6.5%)            |
| IADL Limitation                              | 7,857,183 (4.0)             | 3,671,331 (2.2%)                  | 4,185,852 (13.1%)           |
| Major Activity Limitation*                   | 16,449,583 (8.3%)           | 9,981,792 (6.0%)                  | 6,467,791 (20.3%)           |
| Social Limitation                            | 9,899,910 (5.0%)            | 5,938,977 (3.6%)                  | 3,960,933 (12.4%)           |

Note: Raw sample sizes were weighted with the final annual basic weight for national, civilian noninstitutionalized population estimates.

\* Severe enough to substantially limit daily activities.

† With glasses and/or hearing aid.

Source: Data from National Center for Health Statistics 2000.

11.4 percent of all adults have some type of physical limitation and about 3.6 percent have some type of cognitive limitation.

Because older Americans have far higher percentages of disability and functional limitation, many people assume that more older Americans than working-age Americans have disabilities. Although this is true for some types of disabling conditions, overall more working-age individuals have disabilities because the working-age population is more than five times larger than the retirement-age population. While the health services research community has long been concerned with the health and long-term care needs of older Americans, it has not yet been able to address the health and long-term service needs of working-age individuals with disabilities.

Table 1 does not illustrate the enormous diversity within the population of people with disabilities in terms of its varying etiologies, underlying health conditions, degrees of activity limitation, ages of onset, natural histories, longevity, gender, ethnicity, and socioeconomic status. Although we cannot, in this article, explore the full extent of this diversity, we do want to make clear that this population is constantly changing and creating new and different demands on the nation's health care systems. We offer three broad observations or generalizations about the changing epidemiology of disability:

1. *In some instances, the nation has made important progress in reducing the incidence and/or prevalence of disability.* Overall, Americans have fewer occupational injuries (Bernard 1997; BLS 2000; CDC 2001; NIOSH 2000); fewer automobile-related deaths and injuries despite the increase in automobile driving (NHTSA 2000); reduced death and disability because of early and aggressive intervention provided by the nation's regional trauma care systems; less mental disability due to the effective use of pharmacologic agents used to manage schizophrenia, bipolar disorder, and depression; and less disability due to the use of less invasive surgeries (e.g., arthroscopy, laparoscopy). Accordingly, some of these conditions require fewer emergency room visits and fewer rehabilitation admissions.

2. *The incidence and prevalence of disability is growing because of the nation's failures.* While the nation is gaining ground in workplace and highway safety and trauma care and surgical management, it is losing ground in avoiding preventable causes of disability. The increases in both child and adult obesity and in Type-2 diabetes—major risk factors for disabling conditions such as coronary heart disease, stroke, and numerous

orthopedic and soft-tissue complications—are alarming (Grundy 2000; Lean 2000; Simons-Morton, Hogan, Dunn, et al. 2000). The prevalence of both child and adult-onset asthma is rising as well, despite cleaner air and less cigarette smoking (Clark and Cochrane 1999; Laszlo, Nicholson, Denison, et al. 2000; Toren and Lindholm 1996). Common to all the conditions mentioned here—obesity, diabetes, and asthma—is their disproportionate prevalence among low-income and minority groups, who often lack the education and resources to manage their new condition and thus to make it less disabling.

3. *The incidence and prevalence of disability are increasing because of the nation's successes.* The incidence and prevalence of disability are rising because the nation has succeeded, not because it has failed. A few examples illustrate. First, consider the nation's successes in neonatal intensive care which have, over the last few decades, improved the survival rates of premature infants (those born before 37 weeks gestation). This success is accompanied, however, by a greater risk of disabling neurologic conditions such as cerebral palsy and mental retardation (Bhushan, Paneth, and Kiely 1993; Horbar and Lucey 1995; Lorenz, Wooliever, Jetton, et al. 1998) and visual difficulties (Sauve, Robertson, Etches, et al. 1998). Second, consider the advances in trauma medicine that have sometimes enabled individuals to survive but with greater residual disabilities, as in the case of ventilator-dependent individuals with spinal injuries. Third, consider the advances in managing HIV/AIDS that in recent years have made HIV/AIDS less a fatal disease and more a chronic and potentially disabling condition because it can be managed with the aggressive use of antiretroviral drugs.

At this time, researchers do not fully understand how these trends have affected the numbers of persons with disabilities and their health needs. We recommend that federal agencies sponsor studies and develop models to enable us to better understand the changing epidemiology and demography of disabilities and their implications for the organization, delivery, and financing of health services.

## Health Care Needs of Individuals with Disabilities

The diversity and constantly changing epidemiology of disability should serve as a warning about overgeneralizing the needs of people with

disabilities. But if researchers and policymakers are to understand better the health care needs of individuals with disabilities, they nonetheless do need to make some generalizations. The following, therefore, are eight observations about the health care needs of individuals with disabilities (ACRM 1993; Bockenek, Mann, Lanig, et al. 1998; DeJong 1997). Note that they do not apply to all individuals with disabilities and, in some cases, may not apply at all.

First, people with disabilities often have what we call a “thinner margin of health” which must be guarded carefully in order to avoid medical problems (Institute of Medicine 1991). This observation applies to health conditions that people with disabilities share with the nondisabled population (e.g., upper respiratory infection, pneumonia) as well as conditions more likely to appear among people with disabilities (e.g., urinary tract infections, pressure sores). We should emphasize that people with disabilities are not “sick” and that most are generally in good health. Their impairments and functional limitations, however, often make them more vulnerable to certain health problems.

Second, people with disabilities often do not have the same opportunities for health maintenance and preventive health as do those without disabilities. For example, people with mobility limitations usually have fewer opportunities to participate in aerobic activities needed for good cardiovascular health (Institute of Medicine 1991).

Third, people with disabilities who acquired their impairment early in life may experience an earlier onset of chronic health conditions than do those without disabilities. For example, people with long-standing mobility limitations are believed to experience an earlier onset of coronary heart disease than do those without disabilities. Likewise, people with mobility limitations may experience an earlier onset of adult diabetes (Bauman, Adkins, Spungen, et al. 1999) because of obesity and may experience an earlier onset of renal disease (e.g., pyelonephritis) because of a neurogenic bladder.

Fourth, people with disabilities who acquire a new health condition apart from their original impairment are also likely to experience secondary functional losses. For example, someone with a spinal cord injury who acquires arthritis in his upper extremity may have to move from a manual wheelchair to a power wheelchair and from an automobile to a ramped van. Thus, the functional consequences of a new chronic health condition are usually more serious for a person who already has a disabling impairment.

Fifth, people with disabilities may require more complicated and prolonged treatment for a particular health problem than do people without disabilities. Likewise, a person with a disability may require a longer recovery period after an episode of acute illness or injury because of preexisting functional limitations that limit her participation in various therapies (e.g., using a treadmill or exercise bicycle following an acute myocardial infarction).

Sixth, some individuals with disabilities may require sustained pharmacologic support, as in the case of long-term mental illness.

Seventh, people with disabilities may need durable medical equipment and other assistive technologies.

Eighth, individuals with disabilities may require long-term services such as personal assistance and continuous medical supervision.

Even these eight characterizations cannot fully capture the health care needs of individuals with disabilities. They may have health care needs that are specific to their underlying impairments or health conditions, such as multiple sclerosis, muscular dystrophy, arthritis, sickle cell, and bipolar depression.

We should emphasize that people with disabilities also have most of the same health conditions as do people without disabilities. Persons with disabilities are, however, at greater risk for certain common health conditions than are those in the general population, and they often experience these conditions differently and may require a somewhat different and extended therapeutic regime that takes into account both their underlying impairment and their functional limitations.

## Health Care Utilization and Expenditures

We analyzed the 1996 Medical Expenditure Panel Survey (MEPS) to create an overview of the health care utilization and expenditure experience of adults with certain functional limitations, which served as a proxy for disability (Tepper, Sutton, Beatty, et al. 1997). Using the variables available in the MEPS, we defined a person as having a disability if he or she met any one of the following criteria: (1) uses mobility aids or equipment; (2) has difficulty bending lifting, or stooping; (3) is limited in a major activity; or (4) requires help or supervision with at least one ADL (activity of daily living) or IADL (instrumental activity of daily living). This definition of disability is based mainly on functional limitation and



is sufficiently broad to include people who have disabilities associated with most physical, sensory, or cognitive impairments.

This definition of disability applies to approximately 16 percent of the adult population (age 18+). In 1996, such persons accounted for about 34 percent of all adults' visits to a physician, 41 percent of all adult prescriptions (including refills), nearly half of all hospital discharges, 62 percent of all nights spent in the hospital by adults, and 46 percent of all adult-related health care expenditures (see figure 1).

These figures are also reflected in estimates of the utilization and expenditure experience of *individual* adults with disabilities. While only 3 percent of adults with disabilities had no health care expenditures in 1996, 16 percent of individuals without disabilities had no health care expenditures. Of those who spent at least \$1 on health care, the median expenditure for people with disabilities was \$2,489, compared with

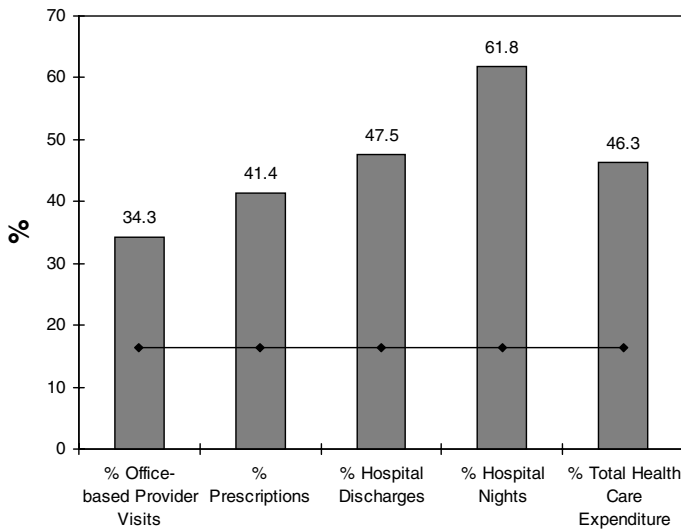


FIG. 1. Percent of total health care utilization and expenditures by adults with a functional limitation, United States, 1996. A person is defined as having a functional limitation if they fulfill at least one of the following criteria: (1) use mobility aids; (2) have difficulty bending, lifting, or stooping; (3) are limited in their major activity; (4) require help or supervision with ADL/IADL. ■ = % of total utilization or expenditure by adults with functional limitations; ◆ = people with functional limitations comprise 16.3% of the adult population. Source: Computed by the NRH Center for Health and Disability Research from the March 1996 Medical Expenditure Panel Survey (MEPS).

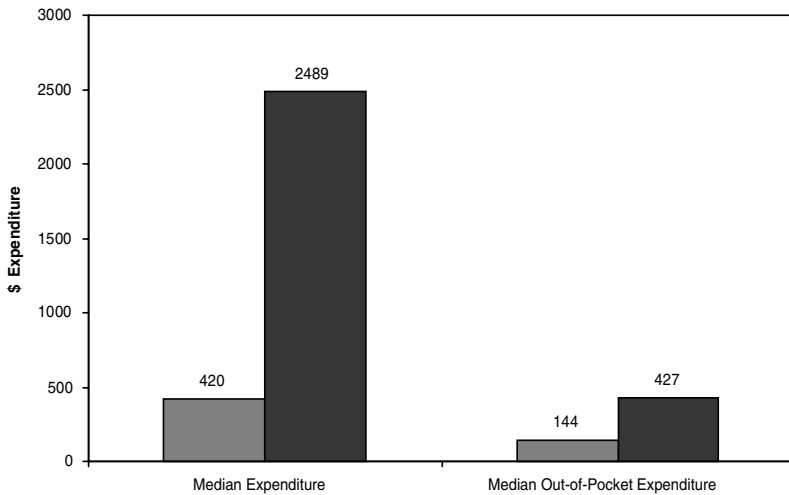


FIG. 2. Median total and out-of-pocket expenditures for adults, by functional limitation, United States, 1996. Expenditures were computed separately from among individuals with at least a \$1 expenditure. A person is defined as having a functional limitation if they fulfill at least one of the following criteria: (1) use mobility aids; (2) have difficulty bending, lifting, or stooping; (3) are limited in their major activity; (4) require help or supervision with ADL/IADL. ■ = adults without functional limitations; ■ = adults with functional limitation. *Source:* Computed by the NRH Center for Health and Disability Research from the Medical Expenditure Panel Surveys.

\$420 for people without disabilities. According to these median figures, the out-of-pocket expenses (\$427) for the health care of adults with disabilities were typically more than the expenses for the nondisabled paid from all sources (\$420). The median out-of-pocket expenditure for adults without limitations was \$144 (The median total and out-of-pocket expenditures were calculated only for those who had at least a \$1 total or \$1 in out-of-pocket expenses, respectively. Out-of-pocket expenditures do not include health plan premiums.) (see figure 2).

### Health Care Access and Coordination

Despite their well-above-average use of health care services, individuals with disabilities face greater barriers to access than does the rest of the population.

Access is a multidimensional concept, especially for people with disabilities. We have chosen to address the issue of access in three ways. First, we present two sets of barriers: (a) physical, social, and communication barriers; and (b) financial and health plan coverage barriers. Second, we address access to specific health related services (i.e., primary care and preventive services, specialty care, rehabilitation, durable medical equipment (DME) and assistive technology (AT), prescription drugs, and long-term services) that are especially needed by individuals with disabilities. And between these two topics, we address the cross-cutting issue of medical necessity—both its definitional and operational problems.

### *Two Sets of Barriers*

*Physical, Social, and Communication Barriers.* Disability is commonly described as a function of the interaction between a person and his or her environment. In health care, the physical and social environments often impede access to timely and appropriate health care services for people with disabling health conditions. Individuals with disabilities, especially those with mobility impairments, observe that physicians' offices and other health care facilities are not easily accessible, despite the requirements of the Americans with Disabilities Act (Anderlik and Wilkinson 2000; Gans, Mann, and Becker 1993). People with disabilities often find that even if a medical facility is physically accessible, the examination equipment (e.g., tables, scales) are not (Iezzoni, McCarthy, Davis, et al. 2000; Nosek 2000; Thierry 1998). Moreover, office staff often are unskilled in transferring a patient from a wheelchair onto an examining table.

A recurring access problem is accessible transportation for individuals with mobility impairments, which frustrates both consumers and providers on account of missed appointments and the need for rescheduling. Public transportation may not be available, and paratransit is often problematic. Health care organizations catering to persons with disabilities sometimes make transportation part of their service delivery program.

Social barriers are more subtle. In focus groups and other venues, wheelchair users and individuals with communication impairments report that office staff often ignore them and speak instead with their attendant rather than make eye contact with them (O'Day, Palsbo, Dhont,

et al. 2002). Perhaps the most commonly reported barrier is the physician's lack of knowledge about the health care needs of individuals with disabilities. Consumers with disabilities tell us that they must often educate their physicians about the health-related issues associated with their impairment. They also observe that many physicians see the impairment as the principal diagnosis, not the presenting complaint (DeJong 1997; O'Day et al. 2002). This problem is a result of inadequate medical training and a health care system that is oriented to diagnoses and human body systems (Anderson and Knickman 2001).

To rectify these issues, health plans and providers need to become what we call "disability literate," that is, knowledgeable about the accessibility and the health care needs of individuals with disabilities, including the requirements of the Americans with Disabilities Act (ADA). Research, with substantial input from consumers, is needed to define what it means to be disability literate in a health care environment, to identify shortcomings in health care that lead to disability illiteracy, and to evaluate alternative educational tools to introduce disability literacy to health plans and providers.

*Financial and Health Plan Coverage Barriers.* Working-age persons with functional activity limitations are uninsured at roughly the same rate as those in the general population (see figure 3). Moreover, about one-fifth of persons with activity limitations do not belong to a health plan, public or private. Because of their relatively low rate of participation in the labor force, individuals with activity limitations are much less likely to belong to an employer-sponsored health plan and are more likely to participate in the Medicare or Medicaid programs (see figures 3 and 4).

Those persons with the most severe disabilities—indicated by the presence of an ADL (activity of daily living) limitation—are much less likely than those without ADL limitations to be uninsured. Roughly 9 percent of individuals with ADL limitations have no insurance, compared with 22 percent of those without limitations. Persons with the most severe disabilities are also more likely than those without limitations, or those with less severe activity limitations, to be covered by Medicare or Medicaid (see figures 3 and 4).

Medicare provides the least coverage and Medicaid provides the best coverage among public and private payers for many of the services that individuals with disabilities are likely to need (Anderson and Knickman 2001). Employer-sponsored plans tend to fall between the two public programs in terms of coverage. The problem for people with disabilities

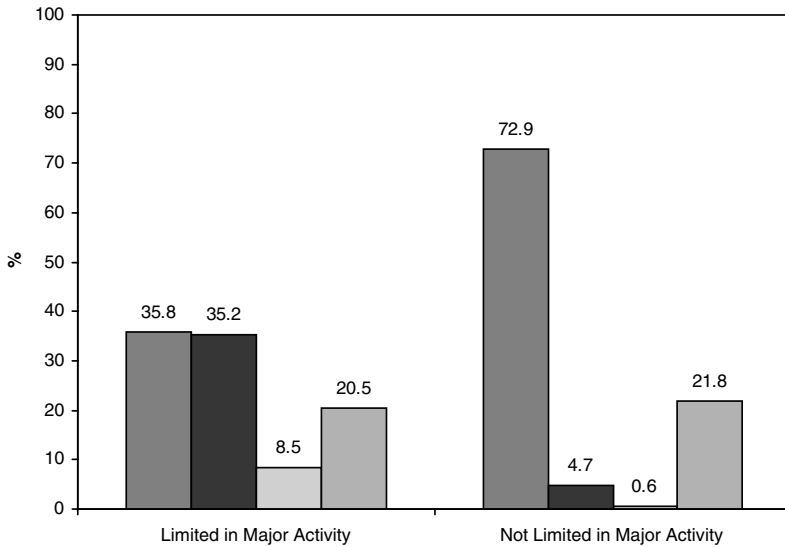


FIG. 3. Payer type by activity limitation among working-age adults, United States, 1996. “Public” insurance coverage refers to Medicare or Medicaid. A person is defined as having an “activity limitation” if they report being limited in their major activity. Approximately 14% of the working-age population is limited in major activity. ■ = private; ■ = public; ■ = private and public; ■ = uninsured. *Source:* Computed by the NRH Center for Health and Disability Research from the Medical Expenditure Panel Surveys.

is that their higher health care needs also expose them to much higher out-of-pocket expenses, especially if they participate in Medicare or an employer-sponsored plan (Anderson and Knickman 2001).

Health plan coverage for those who are eligible for both Medicare and Medicaid is complicated. Persons with this dual eligibility must enroll in two plans and deal with two sets of benefit packages and two sets of payment policies. Because dual eligibility often means fragmented care for those who need health care the most, several alternatives have been created to improve the quality of their care. For example, the Minnesota Model, called Senior Health Options, provides comprehensive benefits and is accountable to both the state and federal government (HCFA 1995). This project is trying to expand its coverage to people with disabilities. In addition, the Robert Wood Johnson Foundation is currently funding the Medicare/Medicaid Integration Program (MMIP), and several New England states have sought waivers that would enable them

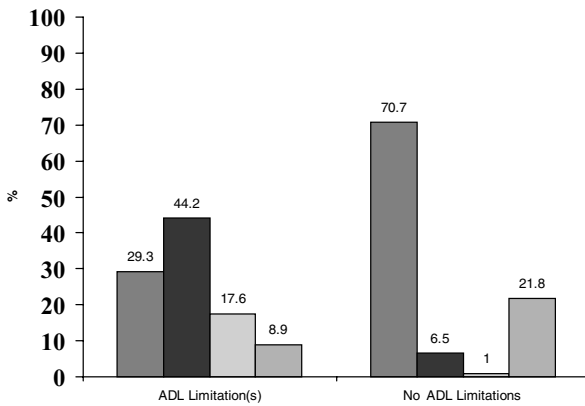


FIG. 4. Payer type by ADL limitation among working-age adults, United States, 1996. “Public” insurance coverage refers to Medicare or Medicaid. A person is defined as having an “ADL limitation” if they report needing assistance with at least one of six activities of daily living: bathing, dressing, grooming, toileting, eating, and getting around inside the home. Approximately 1% of the working-age population has an ADL limitation. ■ = private; ■ = public; ■ = private and public; ■ = uninsured. *Source:* Computed by the NRH Center for Health and Disability Research from the Medical Expenditure Panel Surveys.

to integrate their Medicare/Medicaid plans and streamline delivery for dual eligibles (HCFA 1995).

### *Medical Necessity*

Benefit packages often do not reveal what a health plan does or does not cover. Health plans, especially managed care plans that use case managers or physician gatekeepers, may include a particular benefit that may not be accessible unless it is deemed “medically necessary” and is preauthorized by a case manager or health plan medical director. This is a problem especially for consumers with disabilities who are more likely to need the services of specialists and postacute providers. And because the need for these services is often not well understood by those who authorize them, individuals with disabilities sometimes have difficulty obtaining the services they need.

Medical necessity is an important issue. Most definitions of medical necessity use an acute model of health care and do not consider the

ongoing health and functional maintenance needs of individuals with disabilities. Thus, most definitions of medical necessity recognize the need to restore function following the onset of a major disabling condition but do not recognize the need to maintain or enhance function in people with progressive conditions who want to function more independently in their home or community (Ireys, Wehr, and Cooke 1999; Jacobson, Asch, Glassman, et al. 1997).

Research is needed on how different definitions of medical necessity affect individuals with disabilities, how health plans determine medical necessity, and the long-range costs and benefits of alternative definitions. One or more federal agencies should also sponsor a major consensus conference on the issue of medical necessity, with the goal of creating a more standardized set of definitions.

While more managed and organized care may be good for people with disabilities (Sutton and DeJong 1998), there is evidence that managed care coverage and preauthorization policies restrict access to “downstream” specialty and postacute services (Huntt and Growick 1997; Kassirer 1994; Wholey, Burns, and Lavizzo-Mourey 1998). Traditional fee-for-service coverage may supply all or most needed services, but the higher premiums and deductible amounts may restrict access financially (Wholey, Burns, and Lavizzo-Mourey 1998).

### *Access to Specific Health Care Services*

*Primary Care and Preventive Services.* Most primary care physicians are not adequately prepared to address the health care needs of individuals with disabilities, partly because they see so few persons with any one disabling condition in their practices except for individuals with more common, but less severe, conditions, such as intermittent low-back pain (ACRM 1993; Batavia, DeJong, Burns, et al. 1989; DeJong 1997). In fact, many primary care physicians regard individuals with disabilities as patients who require more time than a physician’s productivity and compensation schedule allows and who complicate a busy office practice. Persons with disabilities need more assistance with dressing and undressing, and they may have speech, hearing, and cognitive limitations that slow communication and understanding. In short, primary care settings often exhibit many of the physical, social, and communication barriers mentioned earlier (Bockenek, Mann, Lanig, et al. 1998).

The research to date on people with disabilities covered by managed care and fee-for-service plans indicates either that access to primary care does not differ by plan type (Beinecke, Pfeifer, Pfeifer, et al. 1997) or that access to primary care is easier for those enrolled in managed care plans (Wholey, Burns, and Lavizzo-Mourey 1998). A national survey of people with spinal cord injuries, cerebral palsy, multiple sclerosis, or arthritis showed that 71 percent reported a need for primary care services over a six-month period. Approximately three-fourths of those reporting such needs received primary care services every time they were needed (Beatty, Hagglund, Neri, et al. 2001).

Preventive health services are as, if not more, important to individuals with disabilities than to people without disabling conditions, because of the “thinner margin of health” cited earlier by many people with disabilities (Iezzoni et al. 2000; Jones and Beatty 2002). Preventive services include (1) health screenings such as blood pressure checks, cholesterol screening, and mammography; (2) immunizations such as flu and pneumonia shots; and (3) health behavior assessments and counseling such as inquiries about smoking, alcohol use, sexually transmitted diseases, and participation in physical activities (Burton, Paglia, German, et al. 1995; Iezzoni et al. 2000; McGinnis and Rothstein 1994; Phillips, Meyer, and Aday 2000).

In a recent study of preventive service utilization among working-age adults with mobility limitations, researchers at the National Rehabilitation Hospital's Center for Health and Disability Research (NRH-CHDR) analyzed data from the 1994 National Health Interview Survey Disability Supplement (NHIS-D) and 1994 NHIS data files tracking *Healthy People 2010* objectives (Jones and Beatty 2002). The national survey data are mixed: persons with severe mobility limitations were more likely than nondisabled adults to receive a physical exam but less likely than persons without mobility limitations to receive other health screenings, such as cholesterol checks, during their exam. Repeated reports from our many focus groups of individuals with disabilities suggest that primary care providers may be too “disability focused” in their interactions with people with disabilities, choosing to address disability-related health concerns during office visits and overlooking or skipping preventive services commonly offered to patients without disabilities.

The NHIS data also indicate that women with severe mobility limitations were less likely than their nonlimited counterparts to receive pap smears, breast exams, and mammograms. People with mobility



limitations were more likely than nonlimited adults to receive immunizations but less likely than people without these limitations to receive counseling on health risks.

*Specialty Care.* Access to specialists is particularly important to people with disabilities, especially those with relatively rare conditions that may not be well understood by primary care physicians. Disabling conditions often involve multiple body systems or comorbidities that complicate assessment and treatment processes that require the knowledge and skill of specialists. There is evidence that people with disabilities (Beatty et al. 2001) and chronic conditions (Wholey, Burns, and Lavizzo-Mourey 1998) in managed care plans have less access to specialty care compared with those in traditional fee-for-service plans. We do not know whether the lack of access to specialty care is due mainly to coverage issues or to gatekeeping and preauthorization hurdles.

Some people with disabilities prefer to have a specialist serve as their principal care provider. For example, persons with multiple sclerosis sometimes want a neurologist as their principal care provider. Individuals with a spinal cord injury often maintain long-term relationships with the physiatrist whom they first met while an inpatient in a rehabilitation center. The extent to which specialists should also be primary care providers is an enduring issue within and between medical specialties.

*Rehabilitation.* Not all persons with disabilities need rehabilitation. Those who do have a variety of pathways to rehabilitation. Those who experience a major disabling event (e.g., stroke, hip fracture, spinal cord injury) may require an inpatient stay in a rehabilitation center. They may also need follow-up outpatient rehabilitation or outpatient services because of new functional losses. Those with a less life-altering disabling condition (e.g., low-back injury, sports injury, work-related injury) may need only outpatient rehabilitation.

Access to these different rehabilitation venues varies with the health plan's payment policies for postacute care (Clement, Retchin, Brown, et al. 1994; Retchin, Brown, Yeh, et al. 1997). Medicare remains the single largest payer of rehabilitation services, and as we discuss later, Medicare payment policies continue to have a major impact on the willingness of providers to supply rehabilitation in various venues (U.S. General Accounting Office 1999; Wheatley, DeJong, and Sutton 1998). Likewise, as private employer-sponsored health plans have shifted to managed care, health plans often direct individuals with disabilities to less intense settings such as "subacute" or SNF-based rehabilitation instead of "acute" or

hospital-based rehabilitation (Wheatley, DeJong, and Sutton 1998). We know that the public and private payers have had a major impact on the supply side of the market, but we do not know the magnitude or the impact or how supply-side changes have affected access—in either denying services altogether or merely shifting rehabilitation to alternative venues (DeJong, Wheatley, and Sutton 1996).

Access to rehabilitation also pertains to the medical necessity issue cited earlier, whether a person's rehabilitation needs meet the payer's definition of medical necessity. Providers must often go to great lengths to prove that the rehabilitation service in question is indeed medically necessary.

*Durable Medical Equipment and Assistive Technology.* People with disabilities often need durable medical equipment (DME) or assistive technology (AT) to maintain their health, functional ability, and independence. All health plans have complex policies and guidelines regarding the kinds of equipment or technology they cover. Recent research suggests that when DME is not received in a timely manner, people with disabilities are likely to experience detrimental and potentially costly health care consequences (Neri, Scheer, and Kroll 2001). Additional research is needed to determine the impact of DME coverage decisions on the health of consumers with disabilities and on the long-term financial consequences for health plans and programs.

Along with restrictive health plan decisions regarding the coverage and medical necessity of equipment, financial barriers are the most common reason for not having needed assistive equipment (O'Day and Corcoran 1994). About half of people with assistive equipment and more than three-fourths of those with home modifications bought them themselves, without help from third-party payers (LaPlante, Hendershot, and Moss 1992).

A recent study of medical necessity decisions by managed care organizations in California found that requests for DME are among the most likely to be denied on the basis of medical necessity (Singer, Bergthold, Vorhaus, et al. 1999). This finding strongly suggests that people with disabilities are disproportionately affected by restrictive medical necessity definitions and decision-making processes.

Health plan policies can make obtaining DME and AT an arduous task, even for people skilled in navigating health plan coverage issues (Batavia 1999). For example, wheelchairs have a life expectancy of five to seven years before they must be replaced, and users are often unable to convince

health plans that a new one might be needed *before* the current one becomes inoperable. Once a chair does break down, it may take several months to obtain a custom-fitted chair. In the meantime, the use of a poorly functioning or inadequate wheelchair can lead to a decline in physical health and a more frequent use of downstream health care services like physical therapy (Neri, Scheer, and Kroll 2001).

To determine which pieces of equipment and AT should be covered and for whom, the research on the long-term impact of health plans' coverage and medical necessity decisions should be expanded. This research should look at health outcomes and the cost consequences for both the individuals and health programs associated with these coverage and medical necessity decisions. Health programs like the U.S. Department of Defense's TRICARE plan (Public Law 107-107) recently expanded its coverage to include a wider range of DME. Programs and health plans that have a relatively wide range of coverage for DME present opportunities for research that can provide a greater understanding of the link between DME provision and the long-term health consequences for individuals with disabilities and can help inform the debate of what constitutes medical necessity.

*Prescription Drugs.* Research consistently shows that the high cost of medications, coupled with limited prescription drug coverage from health care plans, have been major barriers for those who need prescription drugs, such as individuals with low incomes, the elderly, and the disabled (Reutzell 1993; White House National Economic Council 2000). People with disabilities, on average, tend to use more prescription drugs because of their complex medical needs, many of which respond to drug therapies. In addition, those who need more prescription drugs appear less likely to be able to afford them (DeJong, Jones, and Beatty 2000; White House National Economic Council 2000). Out-of-pocket expenditures for working-age Medicare beneficiaries are 15 times higher than those of the working-age population without disabilities (DeJong, Jones, and Beatty 2000).

Most of the research on prescription drugs has looked at access for the elderly Medicare population. Compared with elderly Medicare beneficiaries, working-age beneficiaries with disabilities fill 40 percent more prescriptions and spend 50 percent more on prescription drugs (White House National Economic Council 2000). About one-third of all working-age Medicare beneficiaries with disabilities do not have prescription drug coverage.

Prescription drug coverage is limited and premiums are expensive even for those who do have supplemental Medigap policies. Of the ten Medigap policies, only three offer prescription drug coverage, and compared with other Medigap plans, the costs of these plans are high. These three plans still cover only 50 percent of drug costs, up to a maximum of \$1,250 or \$3,000, depending on the plan (MedPac 2000). For persons with disabilities enrolled in Medicare, who tend to have relatively high out-of-pocket drug expenses, supplemental insurance policies such as Medigap are not always available or affordable and offer only limited assistance with prescription drug costs (DeJong, Jones, and Beatty 2000; Gross, Alecxih, Gibson, et al. 1999).

*Long-Term Care and Personal Assistance Services.* Many people with disabilities need long-term assistance with the basic activities of daily living (ADLs), such as bathing, grooming, dressing, using the bathroom, eating, and simply getting around. Independent living and disability rights advocates promote consumer-directed long-term care, commonly known as “personal assistance services,” or PAS. These services enable the user to hire and manage their own personal assistants without the supervision of a home care agency. Over the last three decades, PAS has remained the foremost public policy issue for independent living adherents, for two reasons.

First, PAS is deemed essential to maintaining health. If bathing, grooming, dressing, using the bathroom, or eating is neglected for long, health difficulties are inevitable. Moreover, research suggests that PAS can have a positive impact on health (Nosek 1993; Prince, Manley, and Whiteneck 1998). Second, the consumer-directed nature of PAS encourages personal autonomy, social integration, productivity, and overall well-being (Benjamin 2001; DeJong, Batavia, and McKnew 1992; DeJong and Wenker 1979; Kane, Kane, and Ladd 1998).

Approximately 30 states offer consumer-directed long-term care programs, many expanded through home and community-based waivers under the Medicaid program (Benjamin 2001). Studies of these state-level programs indicate that recipients of consumer-directed home- and community-based services were more likely than recipients of traditional agency-directed services to be satisfied with them (Beatty, Richmond, Tepper, et al. 1998; Benjamin, Matthias, and Franke 2000). Consumer-directed services also promise lower costs than agency-directed long-term care models, through the reduction or elimination of administrative costs for home care agencies (Batavia 2002).

The programs vary enormously from state to state, owing mainly to the many ways in which the states use Medicaid and other state monies to fund these services. Further research is needed on a wide variety of issues: needs assessment methods, the benefits of consumer direction, the merits of hiring family members as care providers, assessment of quality, long-term outcomes of health and societal participation, program costs relative to other models of long-term care, and alternative payment methods.

Consumer-directed models of personal assistance are also gaining acceptance among older Americans and their advocates and, as a result, are being increasingly viewed as a mainstream long-term care policy issue (Kane and Kane 2001; Simon-Rusinowitz and Hofland 1993). Even so, the state-by-state, waiver-by-waiver approach to consumer-directed models of care has resulted in a highly fragmented system of care. In the short term, this fragmentation enables experimentation and research, but in the long term, sound research should produce greater policy coherence and integration.

## Upheaval in Postacute Care

Postacute care applies to a wide array of services, from postoperative physical therapy to inpatient rehabilitation, skilled nursing, home health, and long-term residential care. Rehabilitation and personal assistance services, already mentioned, are only two such services. Persons with disabilities have a major stake in the viability of American postacute health care. After years of rapid growth, this sector of American health care underwent a tremendous upheaval during the late 1990s owing to the consolidation of providers, changes in federal payment policy, and the financial collapse of several large provider chains, particularly those with large holdings in the skilled nursing and home health industries. This sector is still far from stable, although it is starting to sort itself out as companies reorganize, in some instances, under bankruptcy court supervision. Given the unsettled state of affairs, we give this sector additional consideration here.

### *Growth and Consolidation in Postacute Care*

Medicare payment policies have had a great impact on postacute care in the past 20 years. When Congress implemented the prospective payment

system (PPS) for acute care hospitals in 1983, the postacute care system remained based on the reimbursement of costs. This acted as a “safety valve” by increasing the willingness of providers to accept Medicare beneficiaries who had more complex health care needs. In addition, Congress expanded Medicare coverage for skilled nursing facilities (SNFs) and home health care. The twin financial opportunities of cost-based reimbursement and expanded benefits led to a major expansion of the skilled nursing and home health industries. In addition, home health providers used new technologies and more highly trained personnel to provide care to patients in their homes that previously had been available only in institutions (Manard, Perrone, Kaplan, et al. 1995). Between 1988 and 1994, Medicare spending for postacute care services increased at an average rate of 34 percent per year (DeJong and Sutton 1997).

By 1997, one-quarter of Medicare acute care discharges used postacute care services within one day of leaving the hospital (MedPAC 2001). Skilled nursing facilities were used for more than half this time (53%), home health agencies about one-third of the time (32%), and rehabilitation facilities about one-tenth of the time (11%), with psychiatric facilities and long-term hospitals accounting for the remainder.

With access to private capital and a booming stock market, for-profit health care companies added new facilities and services to meet the market opportunity created by Medicare. From 1993 through 1998, the major for-profit chains traveled the classic industry growth cycle, consolidating from thousands of individual operations into a few dozen major players. Among rehabilitation hospitals, for example, by 1998 one major for-profit chain owned two-thirds of the 200 freestanding rehabilitation hospitals, with most of the remaining hospitals maintaining nonprofit status (Wheatley, DeJong, and Sutton 1998). Long-term hospitals underwent a similar consolidation. The skilled nursing and home health industries also consolidated rapidly.

### *Reversing Growth*

In the mid-1990s, Congress started to slow the growth in Medicare expenditures for postacute care by requiring prospective payment systems for the various postacute industries. With the Balanced Budget Act of 1997 (BBA'97), SNFs came under a Medicare PPS in 1998; home health services came under a PPS in October 2000 (after living with

an interim payment system); and inpatient rehabilitation facilities are now scheduled to come under a PPS in 2002. There is yet no PPS for “long-term hospitals,” an eclectic group of about 200 hospitals whose average length of stay is 25 days or more. In addition, BBA’97 placed a \$1,500 per-year per-beneficiary cap for occupational therapy and a similar \$1,500 cap for physical and speech therapy combined. These caps were later suspended but not eliminated.

The clampdown on Medicare payment is having a great effect on postacute care. First, providers are dropping those businesses with narrow or negative margins. For example, many SNFs have left the rehabilitation business. Rehabilitation patients once diverted to SNFs are again appearing in more traditional, hospital-based rehabilitation programs.

Second, many home health agencies and SNFs have filed for bankruptcy or have gone out of business. Between 1998 and 2001, for example, several of the largest SNF chains—Vencor (recently renamed Kindred), Mariner Post-acute Healthcare, NovaCare, Sun Healthcare, and Integrated Health Services—filed for bankruptcy protection or closed shop. Once favored by Wall Street, these companies’ financial problems stem from changes in payment policy under BBA’97 and from unsound business plans that relied heavily on rapid acquisitions or “roll-ups,” leveraged financing, and overly optimistic revenue projections.

Researchers do not know whether these changes have reduced access to postacute services for individuals with disabilities. In markets where one or more chains were dominant, there may well be shortages that shift the burden of care onto family, friends, and community organizations. A challenging issue for health services researchers is to determine the impact of these industry and market changes on the well-being of persons who need postacute care.

The United States lacks a coherent postacute health policy. The drivers of the policy we do have are the Medicare program’s payment and related policies. The Health Care Financing Administration (HCFA), which was renamed the Centers for Medicare & Medicaid Services (CMS) in 2001, tried to create a common patient metric and a common payment system that would apply to all settings of postacute care and thus presumably create a level playing field for all provider types and direct prospective patients to the most appropriate level of care. At the center of the HCFA strategy was the creation of a patient assessment tool, the minimum data set (MDS) or a variation thereof and the development of resource utilization groups (RUGs) that would become the basis for payment, as DRGs

(diagnostic related groups) did for acute care hospitals. The one-size-fits-all strategy has not succeeded. With more than 400 data items, the MDS is anything but minimal, and the RUGs-based payment method has had implementation problems, including accumulating evidence that it misclassifies beneficiaries (MedPAC 2001). When HCFA tried to export these policy tools from skilled nursing to hospital-based rehabilitation, the rehabilitation industry resisted in favor of a homegrown patient classification system, which HCFA/CMS eventually adopted.

HCFA's approach to postacute policy was anchored where it was most experienced, at the long-term care end of the postacute care continuum where clinical goals are less restorative and lengths of stay are more indefinite. Historically, rehabilitation research and patient assessment methods have not been a part of HCFA's policy research tradition. HCFA's policies assumed that SNF- and hospital-based rehabilitation were largely substitutable services, which in some instances they are.

HCFA's difficulties, we believe, have their origins in factors that are not necessarily specific to HCFA/CMS but are far more generic. One of these factors is the tendency of health services researchers and rehabilitation researchers to operate somewhat in isolation from one another for a variety of long-standing institutional reasons. Fortunately, this isolation is breaking down as the two communities of interest begin to discover the strengths of their respective traditions.

Recent postacute history poses larger issues with respect to research and policy development. Some researchers believe that payments for postacute services should be "bundled" into a single payment system, leaving it to the provider to determine the most suitable setting of care. Others recommend that postacute payments be bundled with acute care payments. Still others have urged using payment methods based on rehabilitation assessment and patient classification methods whenever postacute goals are restorative rather than custodial.

The recent upheaval in postacute care begs for a long-term health policy research agenda that can produce options for future postacute care reforms. This research agenda should include (1) the regular monitoring of industry size and volume by setting of care; (2) studies of postacute organization and consolidation; (3) the development of new and efficient assessment technologies to measure patient acuity, functional status, and service outcomes; (4) taxonomies of rehabilitation and postacute interventions in order to identify the effects of specific therapies in outcome studies; (5) studies of access to postacute venues following discharge from



acute care; (6) the evaluation of new payment systems authorized under BBA'97 for each of the different postacute settings of care, such as home health care, skilled nursing facilities, and hospital-based rehabilitation centers; (7) the development of new or enhanced case-mix adjusters for both payments and outcomes; (8) the development of new payment models based on outcome and quality as a possible adjunct to, or substitute for, payments based on service utilization or patient characteristics upon admission; and (9) strategies for outcome and quality disclosure that will enable both consumers and payers to make more informed postacute care choices.

### Measuring the Quality of Health Care for Persons with Disabilities

Most quality-of-care issues are the same for persons with and without disabilities. Even so, across the health care continuum, measuring the quality of care for persons with disabilities faces challenges above and beyond those for the general population.

The challenges arise in regard to population-based measures of care. Now that more states are mandating the enrollment of Medicaid beneficiaries with disabilities into managed care programs, deriving valid and reliable population-based measures takes on new urgency. Most states and CMS will probably want to start from existing measurement tools: outcomes and process-oriented report cards such as CAHPS<sup>®</sup> and HEDIS<sup>®</sup>; and the more structurally based accreditation processes of the CMS, the National Committee on Quality Assurance (NCQA), and CARE, the accreditation agency for rehabilitation and behavioral health. These efforts will confront several operational issues.

The first issue is the content of the existing instruments. Our research suggests that surveys on consumer-based measures of quality should include more items about the health plan's administration of durable medical equipment benefits, obtaining prescriptions for off-formulary pharmacological agents, and rapid access to specialty care when needed (O'Day et al. 2002).

The second issue concerns the structure, modality, and ordering of questions of existing instruments. The preliminary research suggests that people with cognitive impairments and low literacy levels have difficulty understanding some of the key questions on CAHPS<sup>®</sup>, even when

they are given a list of acceptable answers (Gruman, Curry, and Porter 2000). Telephone administration of surveys is problematic or impossible for people with speech impairments, and paper-and-pen surveys are difficult or impossible for some people with visual impairments or impaired manual dexterity. An example of poor question ordering can be found in the SF-36, which asks questions about “walking” various distances. A person who cannot walk at all has to explain this for one mile, a few blocks, and then again for one block. Moreover, this same person may be able to travel a mile using an assistive mobility device (Meyers and Andresen 2000).

Third is the issue of case finding, particularly when measuring the care of people with disabilities who are commingled in administrative data sets with people who are not impaired. Research needs to determine the feasibility of using medical claims data to develop disability registries that can be used to generate disability specific HEDIS<sup>®</sup> reports.

An interesting research question is the degree to which the care provided by an organized health care system for people with disabilities indicates overall system quality. People with complex and chronic health care needs have more frequent contact with their health plan than does the general population, and they use more health plan benefits (Allen and Croke 2000). Even though this group may constitute a small proportion of the plan’s enrollment, they may have a more comprehensive picture of care as it is provided on a day-to-day basis. Research can show us if the HEDIS<sup>®</sup> and CAHPS<sup>®</sup> scores for subgroups of people with disabilities show more variation within and among health plans than do the scores for people without disabilities. Researchers should also investigate how closely the quality scores for people with disabilities match the quality scores for the entire population served.

Researchers could look at whether fewer core questions in the existing instruments could serve as markers for a plan that is providing high-quality care for people with disabilities. For example, the HEDIS<sup>®</sup> measure of screening for colon cancer with people with cognitive, sensory, or mobility impairments in the denominator might be a valid marker of access to preventive services for each of these subpopulations.

Finally, communicating information to people with disabilities is another area warranting further research, particularly because past research suggests that they want more details and in a medium that accommodates their disability (O’Day *et al.* 2002). The two main methods of reporting measures to consumers are printed materials that compare health plan

scores with one another and Web sites such as the one posted by the state of Maryland. Although only 10 percent of people with disabilities use the Internet (Kaye 2000), they may want information about people like themselves that can be found only on the Internet. Printed material may be difficult or impossible for people with visual impairments or limited hand use to read and may be difficult for people with cognitive impairments to comprehend.

### Opportunities for Innovation, Experimentation, and Evaluation

As the health care needs of people with disabilities become better known, the interest in meeting these needs in more targeted and innovative ways has increased. These include new managed care solutions and the use of telemedicine and e-health. Likewise, changes in the larger policy environment also create new opportunities for innovation and experimentation. These include the conversion of state Medicaid programs into managed care systems, the U.S. Supreme Court's *Olmstead* decision, and the Ticket to Work and Work Incentive Improvement Act (TWWIIA).

#### *More Targeted and Innovative Solutions*

*Innovative Managed Care Solutions.* In meeting the health care needs of smaller target populations such as individuals with particular disabilities, large health plans and provider systems have not always offered the most innovative health care solutions. Over the last two decades, several niche health care programs directed at individuals with disabilities have appeared (Batavia et al. 1989; Master and Eng 2001; Meyers, Bisbee, and Winter 1999; Meyers, Glover, and Master 1997). Scattered throughout the nation, they all stem from the common frustration that mainline health care has not been responsive to the health care needs of individuals with disabilities. Among the better known of these niche programs is the Community Medical Alliance in Boston, now part of the Harvard Pilgrim system, and the Wisconsin Partnership Program in Madison.

One of the common elements of all these programs is their Medicaid sponsorship, which was made possible in part by sections 1115 and 1915 waiver authorities. The Robert Wood Johnson Foundation has helped fund all these programs, and they include one or more key managed

care concepts, including care coordination and the use of partial or full financial risk. Most also use nurse practitioners or similar physician extenders. One hallmark of these programs is the aggressive monitoring of health status and the substitution of benefits where needed in order to avoid more serious health issues later.

Most of these programs are Medicaid “carve-outs” in which the target population is separated, or “carved out,” from the rest of the Medicaid population. Another research question is how the care-management principles of successful programs can be carried over to larger health plans in a manner that will allow health plans to address larger populations of individuals with disabilities.

*Telemedicine and e-Health.* A long-standing yet growing movement in the disability and patients’ rights communities is enabling people to take charge of their own health care. Telemedicine and especially e-health (i.e., health information and services acquired on the Internet) are becoming important tools for people with disabilities and complex health needs to take a more central role in their health care decision making.

Long used in rural health, military, space, and prison medicine, telemedicine is starting to be used as a modality for some rehabilitation therapies. Most current activities are centered on psychological and vocational rehabilitation, such as job coaching. Research on physical and occupational therapy is just beginning (Palsbo and Bauer 2000). Tele-rehabilitation can help people with temporary or permanent mobility impairments to surmount many transportation barriers and to schedule encounters with a specialist with a shorter waiting period. It also enables the monitoring of wounds and pressure ulcers when the patient is at home. Four recent developments have made telemedicine a more viable option.

The first development is technological: the rapid expansion of broadband technologies and inexpensive hardware that makes live video contact over telephones and the Internet more readily available.

The second is the Consolidated Appropriations Act of 2001 (CAA); H.R. 5661, section 223, passed in December 2000, which expands Medicare reimbursement for telemedicine services and became effective in October 2001. The CAA authorizes the reimbursement of the consulting practitioner as if the care had been provided in person; authorizes the reimbursement of the referring practitioner, who does not need to be present during the tele-encounter but qualifies for a facility fee of

\$20; expands eligible originating sites from rural Health Practice Shortage Areas to all rural counties and entities that are federal telemedicine demonstration projects; and allows Medicare payment for routine evaluation and management and some types of psychiatry visits. Except in Alaska and Hawaii, all visits must be “live” rather than “store and forward.”

Third, under Medicare’s fixed payment PPS for home health agencies mentioned earlier, home health agencies are financially motivated to use less expensive modalities of care and support. Telemedicine is not excluded as a modality in this venue, and there is no limit on how many visits an agency can provide to any one patient. The home care industry has increasingly used computer technology and telecommunication equipment to monitor vital signs and also to facilitate patient care at home, rather than relying solely on in-person care. Researchers need to explore opportunities for telerehabilitation provided through home health agencies.

Fourth, the Joint Commission on Accreditation of Health Care Organizations (JCAHO) began to develop standards for telemedicine in the late 1990s. The JCAHO standards apply to practitioners who diagnose or treat patients via a telemedicine link between two medical institutions or organizations. More specifically, the standard applies to people who provide direct care (doctor to patient) via telemedicine. These standards establish a baseline for the development of standards applying to the provision of therapy via telerehabilitation.

Another promising development is e-health, by which individuals can obtain information on the Internet about health issues, health plans, and health care providers. Consumers already can obtain health-related information from any of the major health content providers such as Healtheon, WebMD, and HealthAtoZ. More promising, we believe, are the interactive Web sites organized around specific health conditions or types of providers. Because individuals with disabilities value peer contact and peer-vetted information, additional virtual communities of interest will undoubtedly organize around specific health conditions or groups of related conditions.

Both telemedicine and e-health present several research challenges. The first is the need to evaluate the clinical and cost effectiveness of the timing, place, and modality of telehealth programs. The research programs should lead to the development of clinical guidelines for appropriate settings and use of telerehabilitation. The second challenge is

the need to evaluate the Interdisciplinary Telehealth Standards Working Group and its principles of telemedicine (ITSWG 1998). These principles address standards of professional conduct, clinical standards, scope of practice, technical standards, certification, technical proficiency, client assessment and management, confidentiality, and informed consent.

The third challenge is the need to identify these technologies as empowerment tools by which individuals with disabilities can maintain and manage their health care.

The fourth is the need to assess the impact of telemedicine on the social integration of people with various types of disabilities: does telemedicine help them extend their network of contacts beyond their immediate circle? Or does it further isolate them in their home?

### *Policy Innovation*

Recent developments in national disability policy are creating opportunities for people with disabilities to work and receive health services in the community. Two substantial disability policy developments are the *Olmstead* decision by the U.S. Supreme Court and the 1999 Ticket to Work and Work Incentive Improvement Act (TWWIIA). These recent policy developments have implications for the financing and delivery of health care services and raise a number of broad and targeted research questions.

*The Olmstead Decision.* In the *Olmstead* decision (*Olmstead vs. L.C.*, 119 S.Ct. 2176 [1999]), the U.S. Supreme Court ruled that states not providing services “in the most integrated setting appropriate to the needs of qualified individuals with disabilities” are violating the Americans with Disabilities Act. The Court reasoned that “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.”

The entry of formally institutionalized people into the community requires changes in the structure of health care delivery systems, including more funding for community health centers, improved transportation services for people with mobility limitations, and the inclusion of people with disabilities in service planning and delivery. The Bazelon Center for Mental Health Law and other disability groups note that these changes provide opportunities to expand community health systems. In a letter to state Medicaid directors, CMS reminded states of the

opportunity—and, in some cases, legal responsibility—to make changes in their service delivery system that will accommodate not only persons leaving institutions but also those already residing in the community but facing institutionalization (CMS 2000; Westmoreland 2000).

*Ticket to Work and Work Incentive Improvement Act (TWWIIA).* By enabling SSDI and SSI participants with disabilities to retain Medicare or Medicaid benefits for a longer period of time, TWWIIA substantially improved the work incentive provisions of the Social Security Act. Previously, program participants with disabilities were often discouraged from seeking or accepting gainful employment for fear that their new income status would deprive them of their health benefits under the Medicare and Medicaid programs. TWWIIA also provides individuals with a return-to-work “ticket” or voucher that they can deposit with a service provider who then is responsible for helping them obtain employment and the accommodations needed to remain employed. In return, the service provider receives a portion of savings resulting from the lower SSDI and SSI income payments.

Research is needed to evaluate the TWWIIA’s effects on the employment status of individuals with disabilities, the use of public and employer-sponsored health plans, the development of innovative strategies undertaken by service providers, and the provision of rehabilitation and health-related services needed to keep these people employed.

## Disability and Health Care Reform

Although comprehensive national health care reform is not currently on the horizon, policymakers and researchers still need to think of systemwide reforms as new programs are designed and implemented incrementally in the private and public sectors. The United States has recently seen comprehensive changes in state Medicaid programs as states converted their Medicaid programs into managed health plans. In the near future, we are likely to see a major debate about the future of the Medicare program and the desire of some lawmakers to convert Medicare into a “premium-support” program whose members will purchase their own health care coverage from private health plans in the open market with the aid of Medicare dollars. Research is needed to inform policy discussions about the potential impact of new programs on people with different kinds of impairments and complex health care needs. In fact,

individuals with disabilities represent an excellent test case in determining whether proposed reforms will perform as intended.

For better or worse, the analytic point of departure for nearly all health care reform discussion is managed competition theory, the notion that imperfect health care markets can be made to function more like “normal” markets through the introduction of rules and conditions that govern the behavior of health plans and providers in the marketplace. Four health care market conditions are of special interest to individuals with disabilities: (1) a meaningful choice of health plans, (2) greater standardization of benefit packages and definitions of medical necessity, (3) relevant and accessible information about health plan and provider quality, and (4) risk adjustment for health plan payment. These four conditions also offer a partial framework and agenda for future disability-related health services research priorities.

Conditions 1 and 2, meaningful choice and greater standardization, suggest that we need research on the benefits and services that are helpful to individuals with disabilities. We need focus groups and surveys to tell us what health care goods and services are important to them and how they would rank the importance of each. We also need research on the different definitions of medical necessity, how health plans use their definitions, and a consensus process by which we standardize the definitions in order to reduce the uncertainty and haggling over benefits and payment that now dominate so much of the interaction among consumers, providers, and health plans. Condition 3, relevant information about health plan and provider quality, was addressed earlier in this article.

Condition 4, risk adjustment for health plan payment, is perhaps the single most health care reform issue for persons with disabilities (Batavia and DeJong 2001). Without adequate risk adjustment, health plans and providers have financial incentives to avoid and underserve individuals with disabilities. With adequate risk adjustment, health plans especially are more likely to compete on price and quality instead of price and risk.

Some risk adjustment methods are simply too crude to function effectively for populations that include people with significant disabilities. A case in point is the old Medicare AAPCC (adjusted average per capita cost) formula that adjusted health plan payments according to age, gender, institutional status, and geographic location. This system is gradually being replaced by PIP-DCGs (principal inpatient diagnostic cost groups) that risk-adjust health plan payments based on their enrollees’



main diagnosis if they were in a hospital the previous year (Ash, Ellis, Yu, et al. 1998). A model for people with disabilities who are under age 65 is used by some state prepaid Medicaid plans to adjust for risk. The Chronic Illness and Disability Payment System (CDPS), developed by Richard Kronick and colleagues, categorizes state Medicaid expenditures into 20 payment categories, based on body system or type of diagnosis (Kronick, Gilmer, Dreyfus, et al. 2000).

The limiting factor in all risk adjustment systems is the ready availability of data on which to adjust risk. In almost every instance, the propensity is to use more readily accessible data such as demographic data, claims data, or hospital data—if they are adequate. Research is needed on how to capture enrollment and encounter-level data that provide a more adequate but unobtrusive profile of individual risk. Research is also needed on how risk adjustment systems actually work and on how those people with the most serious impairments fare under various risk adjustment systems.

## The Coming of Age of Disability and Health Services Research

In the past, as we noted earlier, the disability/rehabilitation research and health services research communities have seldom intersected. Indeed, the isolation of these communities from each other mirrors, to some extent, the previously devalued status of individuals with disabilities. In the process, both communities lost some of the benefits of the other. Most important, people with disabilities have missed out on the benefits that these two research communities together could bring to national and state health policy.

If disability-related health services research is to mature as an intellectual endeavor, the nation will also have to invest in capacity building, similar to the steps now being undertaken in addressing health disparities among the nation's racial and ethnic minorities. In fiscal year 2002 Congress allocated more than \$150 million to support the newly established National Center on Minority Health and Health Disparities (NCMHD). A comparable level of effort is needed for the health issues of persons with disabilities. Such an effort will entail the creation of research training opportunities, the establishment of centers of research excellence, grants for investigator-initiated studies, the sponsorship of

innovative payment and service delivery mechanisms, and opportunities for collaboration among researchers, consumers, and other stakeholders.

The creation of the NCMHD is but one example of how health policymakers at all levels have increased their attention in recent years to the health status and health access issues of ethnic and racial minorities and other “vulnerable” subpopulations. This article has presented the case for giving individuals with disabilities the same kind of attention given to other groups. The AHRQ deserves credit for identifying persons with disabilities as a “priority population” and thus giving them the long overdue attention they deserve. The National Institute on Disability and Rehabilitation Research (NIDRR) in the U.S. Department of Education has a modest portfolio of disability-related health services research in addition to its more substantial rehabilitation research program. A health services research focus on individuals with disabilities is, however, not solely an AHRQ or NIDRR responsibility but also the responsibility of other federal, state, and private funding sources with research domains that clearly intersect, and should intersect, with those of these two agencies.

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*Acknowledgments:* An earlier version of this article was prepared for the Agency for Healthcare Research and Quality and presented to the “Status of Health Services Research Associated with Disability” conference, April 9–10, 2001, Rockville, Md. The article was made possible in part with the resources of the Rehabilitation Research and Training Center on Managed Care and Disability sponsored by the National Institute on Disability and Rehabilitation Research (grant H133B70003-01B). The authors wish to acknowledge the assistance and support of their colleagues Liz Hayes, David Bauer, and Melissa McNeil.

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