The Personal Assistance Services and Direct-Support Workforce:
A Literature Review

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INTRODUCTION

Millions of Americans of all ages with disabilities or long-term illnesses need assistance with daily activities such as bathing and dressing. Family members and friends fill much of that need, but paid workers are also a critical source of home care and personal assistance services.

The need for assistance is increasing as our population ages and the number of younger people with disabilities grows. Yet the number of people available to provide care is growing slowly, if at all. For the past several years, many states have reported difficulties in attracting and retaining a sufficient number of direct-care workers to meet the demand for services. Now states are redesigning their long-term care systems to accommodate people with disabilities and long-term illnesses who want to live in the community. This will require an even larger supply of qualified personal assistance workers.

The Centers for Medicare and Medicaid Services funded this paper to summarize literature and research on the home care, home health, and personal assistance services workforce, highlighting issues raised and lessons learned. This literature review is part of a multifaceted report on the policies and practices that influence the availability and adequacy of personal assistance services and supports for people living in the community.[1]

WHO RECEIVES SERVICES

A disability is defined by the Americans with Disabilities Act of 1990 (ADA) as "a physical or mental impairment that substantially limits one or more of the major life activities of such individual." According to Jack McNeil of the United States Census Bureau (2001), disabilities may be in the area of ambulation (inability to walk without assistance), communication (impairment in sight, hearing, or speech), or cognition (learning disability, mental retardation, Alzheimer's disease or another form of dementia, or an emotional disorder such as severe depression, anxiety, or schizophrenia).

People with disabilities may need assistance with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs). ADLs include basic tasks such as moving from one place to another, getting up from a chair or out of a

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[1] For more information on this project or for additional resources, go to www.directcareclearinghouse.org/pas.

bed, bathing, dressing, eating, and toileting. IADLs include less primary but still important functions such as balancing a checkbook, preparing a meal, performing light housekeeping, taking medication, and using the telephone (McNeil 2001).

About 10.1 million people over the age of 18 in the United States, or 3.8 percent of the population, need another person's assistance to carry out activities such as bathing, feeding, cleaning, or grocery shopping (McNeil 2001). Within this group, it is estimated that 4.2 million are age 65 or older (USDHHS 2000).

Only a fraction of people with disabilities receive Medicaid-funded care or services. In a report based on 1995 Medicaid data, Pamela Doty, a senior policy analyst at the US Department of Health and Human Services, stated: "Medicaid home- and community-based services programs for the elderly and disabled…served a total of 1,847,369 recipients" (Doty 2000).

According to the Census Bureau, the number of Americans living with a disability or long-term illness keeps growing, "and that growth can be expected to accelerate in the coming decades" (1997). While there is general agreement that that number will grow, explanations of how growth will occur can be complex.

Researchers note that, while the number of elderly is increasing, the prevalence of disability among the elderly has dropped nearly 25 percent from 1982 through 1999 (Manton and Gu 2001). However, much of this decrease can be attributed to a decline in the need for assistance with IADLs, which is associated with a lower level of disability than a need for assistance with ADLs. In fact, the percent of the elderly who were severely impaired (receiving assistance with three to six ADLs) actually increased between 1984 and 1994, rising from 35.4 percent to 42.9 percent (AHRQ 2001).

In addition, two-fifths of those requiring personal assistance are under age 65. While the projected growth of this population is relatively small, the number of people in this age cohort is quite large compared to the number of elderly, so even a small growth rate translates to a large number of people. Furthermore, the percentage of young people requiring personal assistance rose between 1990 and 1994, going from 2.0 to 2.5 percent among those age 18 to 64 and from .3 to .5 percent among those age 5 through 17 (Kaye et. al. 1996).

At present, approximately four million people with mental retardation or another type of developmental disability live outside of institutional settings. Of these, an estimated 10 percent live in a non-familial supported residential setting and receive personal assistant services (USHHS 2000).

Elderly people with disabilities tend to want and need assistance different from that preferred by younger people with disabilities. In recent years, those differences have been the subject of considerable discussion among caregivers, advocates, and consumers. According to one report, these discussions "suggest differences concerning 1. the extent of reliance on unpaid caregivers, 2. the site of and rationale for providing care, 3. the extent of involvement of medical personnel in care arrangements and provision, and 4. the extent [to] which the disabled person directs and manages his or her services and assistants" (Eustis and Fischer 1992).

WHO DELIVERS SERVICES

While many direct caregivers work in nursing homes and other institutions, this literature review is concerned only with those who work in home- and community-based settings.

Since the US Bureau of Labor Statistics (BLS) tracks data pertaining to personal care assistants and home health aides, and because job descriptions and responsibilities attached to these titles are widely accepted and used, labor statistics for these workers are relatively easy to generate. The government, which pays for most of the care these workers provide through either Medicare or Medicaid, oversees them via certification standards, training requirements, and other regulations.

The BLS estimated the number of home health aides and personal care assistants to be just over a million in the year 2000 (Hecker 2001)—an estimated rate of growth of 53 percent since 1996. The majority of these workers are women, and most are between the ages of 25 and 44. A little less than half have a high school education or GED (Stone 2001).

Those characteristics may be somewhat different for other types of direct-care workers. These workers, who may be found in group homes, assisted living, consumers' homes, and other community-based settings, are identified by a number of titles, including residential aide, personal assistant, home care attendant, and direct-support professional (the last is usually applied to people

who work with individuals with mental retardation or developmental disabilities). The lack of standardization in job descriptions and the proliferation of titles—over 155, according to a survey completed in North Carolina (Hewitt et al. 2001)—make it difficult to generalize about this population.

According to Marianne Taylor of the Human Services Research Institute (1999), no one knows just how many paid community-based direct-support workers there are. Statistics for these workers tend to be inexact, as they are generally extracted from a broad range of titles within the Human Services and Health Care part of the Services Sector BLS database.

Despite the lack of definitive statistics, recent estimates place the number of direct-support professionals between 600,000 and 750,000. Amy Hewitt and her colleagues estimate that there are 400,000 FTE positions in community residential settings and between 90,500 and 125,000 direct-support workers in supportive vocational programs (2001).

In a 1994 review of literature, Amy Hewitt, Sheryl Larson, and Charles Lakin of the University of Minnesota's Institute on Community Integration found that the median age was between 26.5 and 39, an estimated 68 to 83 percent were female, 73 to 93 percent were Caucasian, and between 17 and 48 percent held some type of college degree (Hewitt 1994; Gaylord et al. 1998). More recently, Hewitt and Lakin (2001) in a review of existent literature, described the direct-support workforce as consisting primarily of women below the age of 39 with at least some college experience. At least a third, they found, have a college degree.

Paid workers represent only a fraction of those assisting people with disabilities. At least four-fifths of all adults with disabilities in the United States who need personal assistance services—80 to 83 percent—receive assistance from unpaid caregivers, according to the Census Bureau (Bureau of the Census 1997; Simon-Rusinowitz et al. 1998). For adults with disabilities who are under the age of 65 and meet state and federally defined need for personal care, that estimate rises to 86 percent (USDHHS 2000).

"Informal care" is the term generally used for unpaid care provided voluntarily to a family member or friend who is ill or has a disability and lives in the community (USDHHS 1998). While it should be noted that some family caregivers object to the term, this review reflects its use in the literature, where it generally describes unpaid caregivers who are not federally- or state-certified or

licensed, and/or who have not completed training required by a government agency.

The National Survey of Families and Households (Wave 2/1992-4) estimates that 52 million people in the United States, including 37 million relatives and 15 million friends, act as informal caregivers during the course of a year (USDHHS 1998). Of these, 38 percent are adult children providing care to an aging parent; 11 percent are providing care to a spouse; 7 percent are parents caring for a severely disabled child; 20 percent are caring for a relative such as a grandparent, sibling, aunt or uncle; and 24 percent are caring for a neighbor or friend (USDHHS 1998). Estimates place the average hours of service provided at anywhere from 34 hours to upwards of 52 hours a week (USDHHS 2000).

The same survey revealed that the average age for informal caregivers is 43 and the majority are women, who provide roughly 50 percent more hours of care per week than their male counterparts. It also reported that 64 percent of informal caregivers are employed outside of the home (USDHHS 1998).

Increased attention is being paid to the similarities and differences between formal and informal care and services (Penning 2002). The line between the two is blurring as Medicaid, the traditional funder of long-term care services, begins to fund consumer-directed service delivery models and, in some instances, paying family caregivers to deliver care.

WHO PAYS FOR CARE

Although out-of-pocket spending and private long-term care insurance, Medicare and other federal agencies, and state and local governments pay for some home- and community-based services (HCBS), Medicaid funds the great majority. Medicaid spending on HCBS totaled $17.9 billion in 1999, approximately 28 percent of the $63.9 billion spent on all Medicaid-funded long-term care services. That average is deceptive, however, since it is boosted by exceptionally high rates of HCBS usage in five states (Oregon and New York top the list at 40 percent and 50 percent respectively.) In most states, the percentage of Medicaid long-term care spending going to HCBS was below 28 percent (USDHHS 2000).

According to a US Department of Health and Human Services (USDHHS) primer on Medicaid, the program allows states "considerable flexibility to cover virtually all long-term care services that people with disabilities need to live

independently in home and community settings," but that wasn't always the case.

According to the USDHHS, Medicaid did not cover home health care at all until 1970, when the federal government changed its rules in response to the high cost of nursing facility care and criticism of the program's institutional bias. States are now required to offer Medicaid-funded home health services for beneficiaries entitled to nursing home care. (They may also cover other Medicaid beneficiaries, but are not required to.) The services covered include nursing, home health aides, medical supplies, medical equipment, and appliances suited for use in the home. States may also opt to provide therapeutic services including physical therapy, occupational therapy, speech pathology, and audiology services. All services must be deemed medically necessary and authorized on a physician's plan of care.

Medicaid pays for home care aides and personal assistants primarily through two means. The first is the main program's personal care services option. The second is the home and community-based services waiver program. As of June 2000, 27 states offered the personal services option. All 50 offered HCBS waiver programs and many had more than one, for a total of 242 (USDHHS 2000).

Medicaid's Personal Care Services Option
Any state offering this option must make the same coverage (amount, duration, and scope) available to all of its Medicaid beneficiaries. Initially, this option required a doctor's prescription, supervision by a registered nurse, and delivery in accordance with a care plan in the person's home. It primarily covered assistance with ADLs, offering assistance with IADLs only on a limited basis and in conjunction with ADL assistance (USDHHS 2000).

Over the last decade, coverage guidelines have been revised to be less medically oriented and more inclusive. A doctor's prescription and nurse supervision are no longer required. Services can be delivered outside a person's home and can include a broader array of service including assistance with IADLs such as personal hygiene, light housework, laundry, and meal preparation. Consumers can direct their own services and hire relatives to provide it, although legally responsible relatives (spouses and parents or guardians of minor children) are usually ineligible for pay (USDHHS 2000).

While these changes have the potential to broaden coverage, states must amend their Medicaid state plan to take advantage of them. In fact, coverage under this

option has grown slowly in recent years, in part because states looking to expand coverage often opt for more flexible HCBS waivers instead (USDHHS 2000).

Medicaid Waivers
Unlike the personal care services option, waivers allow states to target particular segments of the Medicaid-eligible population, such as people with certain diagnoses or residents of specific areas.

In 1981, Medicaid began to permit states to cover services that had not previously been covered by Medicaid but were needed to keep beneficiaries at home. These services are provided under the Home and Community Based Services, or 1915(c), waiver program. They include case management; homemaker, home health aide, and personal care services; adult day services and partial hospitalization; and psychosocial habilitation. As of 1998, about 40 percent of HCBS waivers served people with developmental disabilities, 57 percent served people with other disabilities, and 3 percent served other populations, including people with HIV/AIDS, people with brain injury, and children with medical disabilities (USDHHS 2000).

In addition to HCBS waivers, some states use 1115 waivers to provide home- and community-based services. These so-called demonstration waivers are available to states to test innovative approaches to financing and delivery of medical and supportive services. One example of such an approach is New York State's Medicaid-only Managed Long-Term Care demonstration program (Nadash 2001-2002). Another is the Cash and Counseling demonstrations in Florida, Arkansas, and New Jersey (University of Maryland Center on Aging 2001).

Much of the debate over whether to fund more HCBS revolves around whether it costs more than facility-based care. Recent research suggests that community placement is not necessarily less costly than institutional placement (Walsh et al. 2003). Some studies show that home- and community-based programs are more cost-effective (Polivka 2001). North Dakota's average payment through the Family Home Care program, for instance, is between $186 and $700 a month, while the average cost of institutionalization in the state is upwards of $3,200 a month (MEDSTAT Group). A 2002 analysis by the Research and Training Center on Community Living/ Institute on Community Integration found that the average cost to care for a person in the MR/DD population in an institutional setting was $121,406 annually; in the same population the annual Medicaid expenditure per person per year in a home and community based waiver program was on average $35,309 (Prouty et al. 2002).

However, other studies point out that such figures neglect to account for the costs associated with informal caregiving. In a study conducted by the Montefiore Medical Center, the United Hospital Fund, and the Albert Einstein College of Medicine, the economic value of informal caregiving in the US in 1997 was placed at $196 billion (Arno et al. 1999). In addition, these do not include hidden costs such as the increased health care costs incurred by physically and emotionally strained informal caregivers, decreased government tax revenues and increased likelihood of dependency on public assistance from their forgone employment income and benefits and lower worker productivity by those distracted by caregiving responsibilities (Fast and Frederick 1999). The report, *Informal Caregiving: Compassion in Action,* warns: "We cannot take informal caregiving for granted," because "we could not, as individuals or as a society, afford to pay the costs of replacing all informal caregivers with paid personnel" (USDHHS 1998).

Informal caregivers also need supports. According to an NCOA report, a survey by the Family Caregiver Alliance found that 76 percent of family caregivers need some type of support to help them care for their loved ones at home (NCOA 2001). Available services include respite care (hourly paid caregivers, temporary nursing home placement, or adult day services), chore services (volunteer or paid workers to do housekeeping and other chores), home-delivered meals, caregiver support groups, caregiver registries, and case management services. The report documents five "best practice" programs around the country that offer such supports.

Another factor to consider is that institutional care includes housing, food, and other costs unrelated to medical care or personal assistance services. Researchers A.R. Prouty and K.C. Lakin (2002) of the University of Minnesota note that day program costs for those being served under HCBS fall into educational budgets and room and board costs paid out of Social Security disability payments usually are not taken into account when estimating the cost of home-based services for those in the MR/DD population.

Some policymakers fear that paying informal caregivers will boost costs without providing more care, as people will simply start providing less unpaid care (Stone 1999). However, researcher Margaret J. Penning found no evidence of that in a study of the substitution of formal for informal in-home care. On the contrary, Penning (2002) notes: "The findings revealed no evidence to indicate

that greater use of formal services is associated with less extensive informal care."

WHERE SERVICES ARE DELIVERED

Government-funded long-term care programs have traditionally delivered services predominantly in institutional settings. Yet, if given a choice, consumers almost always prefer to stay in their own homes. A 2001 study conducted by *NewsHour with Jim Lehrer, the Kaiser Family Foundation, and the Harvard School of Public Health* of over 300 adults over the age of 45 who have "substantial nursing home experience" found that 90 percent of those surveyed would have difficulty accepting placement in a nursing home. Of those, 43 percent feel that nursing home placement would be "totally unacceptable." An earlier survey of over 1,200 Americans also revealed a strong preference for home-based care. When asked for their first choice for providing long-term care services, 49 percent chose family and friends, 38 percent chose home care agencies, and only 8 percent chose a nursing home or other residential setting (Kassner and Bectel 1998).

 The tension between policymakers' needs to contain costs and individuals' desire for home-based care led to the independent living movement of the 1970s and the establishment of research and advocacy organizations such as the World Institute on Disability and ADAPT (American Disabled for Attendant Programs Today). As Hanson (1999) notes, the independent living movement advocated "consumer sovereignty – the idea that the disabled person, not professionals, should choose which services best fulfill the needs and interest of the individual."

Prior to the independent living movement, most people requiring assistance had no choice in the type of service they received or where that service was rendered unless they could afford to pay for it themselves. People with disabilities were generally institutionalized in a nursing home, developmental center, or psychiatric facility (Eustis and Fischer 1992).

Independent living advocates demanded and got more and better systems to support consumers living in the community. New services, which were funded mainly through Medicaid waivers, included home care, home health services, home attendant services, personal care services, homemaker programs, and adult day services (Penning 2002; Polivka 2001). This led to developments like the following:

- Between 1980 and 1993, the number of individuals with developmental disabilities living in state institutions declined by 44 percent (Hewitt and Larson 1994).

- The population at large state institutions for MR/DD population continues to fall. Between June 2000 and June 2001, there was 2.9 percent decrease (Prouty et al. 2002).

- Between 1994 and 1999, spending on home- and community-based services through Medicaid waivers increased by 14.6 percent, a much higher growth rate than that for institutional care (Fox-Grage et al. 2001).

Despite this shift, 73 percent of the long-term care portion of Medicaid spending in 1999 went to institutional care—almost three times the amount spent on home- and community-based services (Fox-Grage et al. 2001).

One of the most significant and earliest federal factors to affect the shift toward community-based service was the Omnibus Reconciliation Act of 1987. OBRA '87 allowed funding to flow from nursing homes to community-based agencies, which in turn allowed more adults with disabilities to remain at home or return to the community. Also significant was 1993's Family and Medical Leave Act, which requires businesses of a certain size to grant employees unpaid leave in order to care for family members.

The Supreme Court provided another push in 1999. In *Olmstead v. L.C.*, the court ruled that public entities are required to administer their programs "in the most integrated setting appropriate to the needs of qualified individuals with disabilities" under Title II of the American with Disabilities Act (Fox-Grage et al. 2001). Executive Order 13217, issued by President George W. Bush on June 18, 2001, followed by his NewFreedom Initiative, bolstered that decision. Reiterating that "unjustified isolation or segregation of qualified individuals with disabilities through institutionalization is a form of disability-based discrimination," the executive order said states must ensure the existence of effective community-based programs and foster the independence and community participation of people with disabilities (Bush 2001).

Proposed federal legislation would further expand home- and community-based services. The Medicaid Community Attendant Services and Supports Act (MiCASSA) would allow any Medicaid beneficiary entitled to nursing home care facility to use those funds to pay for community services and supports instead.

While no action has been taken on the legislation to date, it enjoys significant support among disability advocacy groups and is expected to be reintroduced in the 108th Congress.

CONSUMER-DIRECTED CARE

A related trend is consumer direction, which allows people with disabilities or long-term illnesses to take a more active role in their care management. Unlike in agency-directed home care, where aides and personal assistants are generally assigned to a consumer with little or no allowance for personal preferences (Casebolt and Gilson 2000), self-directing consumers hire, train, and supervise their own assistants. What's more, the people they choose often have no formal training in caregiving. In fact, they may be relatives or friends.

While some states require Medicaid-funded services to be provided through state-licensed home care agencies, federal law requires agency involvement only if those services are provided under the home health benefit (USDHHS 2000). Meanwhile, notes Larry Polivka (2001), director of the Florida Policy Exchange Center on Aging, "Support is growing for publicly funded payments to informal caregivers (relatives and friends)."

Polivka (2001) estimates that close to 70 percent of the states pay informal caregivers to provide care in consumer-directed community-based models. A survey of states' involvement in personal care and home health programs revealed that 34 of the 41 responding states offered some form of paid informal caregiving through consumer-directed models (Niesz 2001).

"Paying caregivers through consumer-directed models represents a paradigm shift in the objectives and management of long-term care services," writes Polivka (2001). He identified three types of state and federally funded programs that pay informal caregivers: 1) caregiver allowance programs, in which caregivers are paid small monthly stipends of $100 to $200 to compensate for out-of pocket costs; 2) consumer-directed attendant care programs, in which caregivers are paid an hourly, taxable wage for their work; and 3) mixed model programs, which are some variation on the two (2001). Examples of programs that pay informal caregivers include California's In Home Supportive Services Program, Iowa's Elderly Waiver Program, and Michigan's Home Help Program.

A 2001 study by the National Council on the Aging (NCOA) found that more than 75 percent of consumer-directed care programs allow consumers to choose personal attendants with no formal training in caregiving.

Medicaid regulations generally do not allow people to be paid to assist their own children or spouses. However, exceptions may be made under the following circumstances:

1. If the legally liable relative provides skilled nursing care outside what is "normally" expected by someone in this role (USDHHS 2000). This would apply, for instance, if a registered nurse provided care to a spouse or child under a Medicaid service agreement.

2. If the state has been granted a waiver from this requirement. The Robert Wood Johnson Foundation and the US Department of Health and Human Services are funding a Cash and Counseling demonstration project in three states under Medicaid 1115 waivers. Two of these states—New Jersey and Florida—allow payment to anyone providing informal care, including legally liable relatives (University of Maryland Center on Aging 2001).

Some states fund programs solely with their own funds, allowing them to devise their own eligibility rules. One study found that 10 states have self-funded programs that allow payment to spouses and parents of minor children (Niesz 2001). Another source of funding is the Veterans Administration, whose Housebound Program and Aide and Attendance Program provide cash to consumers for supportive services and other needs. Both programs allow consumers to pay spouses (Simon-Rusinowitz et al. 1998).

Studies of this relatively new phenomenon are limited, but a few show that consumers who opt for this model enjoy the additional choice and control it gives them (Velgouse and Dize 2000; Polivka 2001).

Other studies show problematic working conditions for care providers hired under the consumer-directed model, noting that the consumer's lack of knowledge of how to supervise and/or express their needs bears the potential to hinder the working relationship, and that a consumer's lack of knowledge of training and support resources may thwart a caregiver's skill potential (Yamada 2001).

SUPPLY AND DEMAND

The demand for paid home- and community-based workers is increasing (Hewitt and Lakin 2001), due in part to an increase in the number of people with disabilities requiring assistance. The move toward de-institutionalizing care is another factor, since more direct-care workers are needed to assist 10 people if each lives in his or her own home than if they lived together in a facility.

The Bureau of Labor Statistics projects a 62.5 percent increase in demand for home care and personal care aides and a 47.3 percent increase in demand for home health aides between 2000 and 2010 (Hecker 2001). The number of home health aides and personal care aides is expected to rise to 1.5 million by the year 2010, up from just over one million in 2000 (Hecker 2001). That category is projected to be the eighth fastest-growing occupation between 2000 and 2010, requiring an estimated 874,000 additional workers to keep up with increasing demand (PHI and NCDHHS 2002).

Organizations and agencies are already feeling the strain of labor vacancies (Cramer et al. 1999; Dixon 2001; Workforce Training and Education Coordinating Board 2002; Gilbert 1988). Managers of residential programs have consistently identified the recruitment, training, and retention of high-quality staff as "among the most challenging problems they face" (Ford and Honnor 2000). In Minnesota, Medicaid waiver resources are being unspent in consumer-directed care models because families are finding it increasingly difficult to find in-home supports, not because those supports are not needed (Taylor 2002).

"Our community support system is highly vulnerable due to the increased pressure on counties to serve more people with less money," write Jennifer Ondrejka and Howard Mandeville of the Wisconsin Council on Developmental Disabilities (2002). Budgetary challenges exist at the state level as well. The National Governors Association reports that nearly every state is in fiscal crisis as a result of the slowing of the national economy. State revenues are shrinking while spending pressures—particularly for Medicaid and other health care—mount. According to the report, virtually all states have either taken action in fiscal year 2002 or plan to take action in 2003 to control Medicaid costs to respond to these fiscal pressures (National Governors Association 2002).

Adding to the pressure to find workers are legal actions being taken against states for maintaining lengthy waiting lists for home- and community-based

services. As of summer 2002, litigation had been filed against 21 states for "failure to provide prompt access to Medicaid long term services" (Taylor 2002).

As Jerry Ford and Jill Honnor (2000) observe, "Recruiting new workers is a major human resource barrier to providing adequate community services to people with developmental disabilities." Competition in recruiting in the human resource field is expected to grow, and potential workers are being drawn into less demanding, higher paying positions (Ford and Honnor 2000; Hewitt and Lakin 2001; Feldman 1994; Cramer et al. 1999). Relatively low employment rates, difficulty in accessing transportation and affordable child care, and other systemic problems exacerbate the problem (Cramer et al. 1999; Bratesman 2000).

Immigration continues to supply a steady stream of direct-care workers. According to a November 2002 report published by the Center for Immigration Studies, "There is no evidence that the economic slowdown that began in 2000 or the terrorist attacks in 2001 has significantly slowed the rate of immigration. More than 3.3 million legal and illegal immigrants entered the country between January 2000 and March 2002" (Camarota 2002).

Yet even before September 11, Robyn Stone (2001) argues, immigrants were unable to fill all the openings in long-term care: "Analysis of the data from 1950 to 1990 indicates that although immigration's impact has contributed to high worker-to-elderly ratios, the amount of immigration over the past decades has been insufficient to counteract the much stronger impact of populations aging."

THE CHALLENGE AHEAD

Hundreds of thousands of additional workers will be needed to provide home- and community-based personal assistance services over the coming decade. Further, the skills needed by these workers may be somewhat different than those required of long-term care workers to date. As Amy Hewitt and Susan O'Nell of the Institute on Community Integration point out, the shift from traditional institutional care to home- and community-based care created changes in the location of service delivery (geography), expectations of those who have disabilities, and the skills required to support people with disabilities (Gaylord et al. 1998).

The challenges facing those who want to strengthen the direct-care workforce can be divided into five areas: recruitment, retention, wages, benefits, and training.

Recruitment
Recruiting personal assistants can be a difficult task.

Newspaper ads, the traditional means of recruiting, tend to be ineffective at attracting workers who will remain in their positions for more than a few months (Gaylord et al. 1998). It can also be difficult to judge such matters as who will be trustworthy and whether a candidate can deliver safe and high-quality care (Casebolt and Gilson 2000).

Debra Burdsall (n.d.), a Community Liaison for the Spinal Cord Injury Project at Santa Clara Valley Medical Center, recommends that self-directing consumers contact local independent living centers, post advertisement on hospital bulletin boards and community college or university career center bulletin boards, or advertise in weekly church publications. Community colleges are more appealing choices than universities, as students are usually local residents and "may be available year-round" (Casebolt and Gilson 2000).

Other places worth trying include the local welfare department; local offices for the federal or state office of Housing and Urban Development; supermarkets, shopping centers, and other stores; the local public housing authority; community organizations that serve immigrants, the elderly and disabled, victims of domestic abuse, or other underserved populations; GED and other educational programs; health clinics; laundromats; and unemployment offices (Paraprofessional Healthcare Institute 2003; Paraprofessional Healthcare Institute 2000).

In their consumer guide to training personal assistants, Gordon Casebolt and Stephen Gilson (2000) stress the need for a thorough screening process including a written application, a criminal background check, reference checks, and a comprehensive description of the job given either verbally or in writing to the applicant. Marianne Taylor (2000) of the Human Services Research Institute echoes this, saying that providing a "realistic job preview" is essential to recruiting a quality worker, and subsequently, retaining that worker.

Another key to success is screening for the right kind of person. Successful direct-care workers tend to be mature, reliable, sensitive to other people's preferences and needs, and good at prioritizing tasks, solving problems, and negotiating sticky situations. Depending on the client's needs, the job may also

require specific technical skills, such as monitoring vital signs or complex medical equipment (Paraprofessional Healthcare Institute 2003).

Retention
Turnover rates are high for direct-care workers in long-term care. The national average is estimated to be between 40 and 75 percent, depending on the facility or service type (Mesirow et al. 1998). Most workers leave their jobs within the first year (Bratesman 2000).

Poor benefits, low wages, and inflexible work hours are among the key causes of this high turnover rate. Other factors include a perceived lack of respect, limited decision-making capacity, and not being treated as a professional (Dixon 2001; Ford and Honnor 2000). The main reasons cited by direct-support professionals for leaving their jobs, according to Hewitt and Lakin (2001), are "difficulty getting along with co-workers, inadequate pay, and issues with their supervisors."

Limited opportunities for advancement often contribute to turnover (Barrett and Riggar 1997), as well as workers being too busy with their own families' personal care or medical tasks to offer needed emotional support or forge close personal relationships with clients—two of the primary rewards that motivate committed caregivers (Stone 1999; Yee 1994). In addition, worker stress and "burnout" have been shown to contribute to high turnover rates among direct-support professionals in residential and rehabilitative settings (Dixon 2001; Rhoades and McFarland 1999; Workforce Training and Education Coordinating Board 2002). A Kansas meta-analysis on turnover rates found a statistical correlation between turnover and job satisfaction, organizational commitment, and supervisory skills (Taylor 2002).

Turnover is expensive. One study estimates that the increased managerial expenses, lost productivity, and recruitment and training costs involved in replacing a direct-care worker add up to between $1,400 and $4,300 (Dawson and Surpin 2001). Marianne Taylor, senior project director at the Human Services Research Institute, finds that the cost ranges from $2,000 to $5,000 per recruit, depending on geographic differences, unemployment rates, managerial and training expenses, and advertisement costs, among other factors (Taylor 2002).

One study estimated the average cost in Alaska to be $2,341 per worker (Johnston 1998). Another, looking at nursing homes and home health agencies in Ohio, found the average self-reported turnover costs per employee ranging from

$952 to $2,100 for different categories of long-term care employers. The report noted only 17% of the providers surveyed had ever calculated turnover costs and, of those that did, most had likely underestimated the cost based on an early study that found an average cost of $3,200 for each frontline worker replaced using careful accounting estimates (Straker and Atchley, 1999). The annual cost of replacing staff in an average-sized rehabilitative center (116.5 full-time equivalent employees) was estimated to be $165,000 (Barrett and Riggar 1997). Finally, a study of residential care settings for people with developmental disabilities found the cost of recruiting, training, and supervising replacement staff to be between $80 and $100 million nationwide in 1993 (Gaylord et al. 1998).

The toll on human emotions and well-being is harder to measure. Turnover disrupts the continuity of care for people with disabilities (Ford and Honnor 2000; Hewitt and Lakin 2001; Mesirow et al.; Feldman 1994; Dawson and Surpin 2001). As Penny Feldman (1994) of the Visiting Nurse Services of New York points out, "Lack of continuity makes it extremely difficult to develop and sustain the trusting and familiar relationships that foster personal growth, independence, and self-direction." Those relationships are "fundamental" to the success and well-being of people with disabilities (Dawson and Surpin 2001). When relationships end repeatedly due to high turnover rates, "there is a loss that people with disabilities and their families must face over and over" (Turner 2002). Clients become reluctant to form bonds because of high turnover (Lombardi 2001).

Hewitt and Lakin (2001) note that clients often feel angry, confused, and/or sad when a worker leaves, yet service providers tend to expect consumers to "get used to five or more employees coming into their home." They also note that the most detrimental effects of turnover on people receiving community supports are decreased ability to: "1) develop and maintain relationships of support, 2) understand and develop mutual respect, and 3) develop trust with every new support staff person that enters the person's life."

Some organizations have managed to slow the revolving door. A 41-month study of the San Francisco In-Home Supportive Services Program compared the number of workers and turnover rates at the start and the end of the project. The number of workers increased by 39 percent, and "there was extraordinary constancy in measures of workforce stability, including turnover and the length of match between consumer and provider" (Howes 2002). Candace Howes, researcher on this project, attributes the outcomes to wage increases and the unionization of these workers.

Wages

Improving wages and benefits would improve retention for direct-care workers (Ondrejka and Mandeville 2002; Gardner 2001; Hewitt and Lakin 2001; Dawson and Surpin 2001; Cramer et al. 1999; Holzer 2001; Close and Estes 1994; Wenger 2002; Gaylord et al. 1998, MacAdam 1989; Gilbert 1988; Lombardi 2001). Researcher Margaret MacAdam (1993) states: "Labor theory holds that if there are no significant barriers to entry, such as limitation on numbers of job openings or extensive educational or training requirements, long-term worker shortages exist because employers are not able to raise wages to competitive levels."

Because long-term care services are primarily funded with state and federal money, wages are directly tied to public and political support. Marianne Taylor (2002) of the Human Services Research Institute asserts, "Growing human service needs and costs have forced politicians to 'hold the line' on raising wages, improving benefits and providing wage adjustments indexed to the cost of living."

Direct-care wages are generally low throughout long-term care, but home- and community-based workers tend to make less than those in institutional settings (Hewitt and Lakin 2001). This makes it harder to expand services in community-based settings (Gould et al. 1988). Some observers believe the disparity is due to the lack of union representation in home care, noting that only 1 percent of home care workers are represented, as compared to 10 percent of institutional workers (Close and Estes 1994).

Larson and colleagues (2001) surveyed mean starting wages for direct-support workers in residential settings nationally between 1998 and 2000. They found that "by June 2000 the starting wage for direct-care workers had risen to $9.19 (an increase of 5.9 percent) while the mean wage had increased to $11.57, an increase of 7.1 percent in two years."

The average starting wage for direct-support workers ranged from $5.62 per hour in Louisiana to $14.86 per hour in Connecticut (Larson et al. 2001). Another review of literature by Hewitt and Lakin (2001) revealed that direct-support professionals in home- and community-based settings averaged $9.14 per hour, according to 1998 data.

The median hourly wages received by home health aides in 2000 ranged from $6.60 in Texas to $11.45 in Connecticut, according to a report by Susan Harmuth

of the North Carolina Department of Health and Human Services and the Paraprofessional Healthcare Institute (2002). The average of all the state medians was $8.23. The median hourly wage for a personal care attendant or home care attendant ranged from $6.17 in Louisiana to $10.93 in Alaska, averaging $7.50 nationwide.

Home- and community-based direct-care workers often find it difficult to amass enough hours to earn a living wage. This is especially hard for independent providers who work for only one or two clients, as each client is entitled to only a certain amount of reimbursable care per month. A draft report to the California legislature notes that hourly wages for caregivers in the In-Home Supportive Services Programs range from $6.25 in Sacramento County to $9.70 an hour in San Francisco County (California Department of Social Services 2001). Each worker's earning potential was further limited by the program's monthly cap of $1,627 per consumer (Polivka 2001).

Raymond Glazier (2001) of Abt Associates writes: "The character of the independent provider/personal assistant service (PAS) consumer relationship could, in many such a case, be characterized as mutual exploitation. Both parties to the relationship agree to less than desirable terms because both are at a disadvantage: The independent provider cannot find other employment and values (and often insists upon) cash 'under the table,' while the PAS consumer, consciously or unconsciously, trades more control for lesser quality services, and possibly fewer than his/her authorized hours in order to pay more per hour."

One respondent to a survey of paid family caregivers in Michigan said: "If the state told me they would pay me to care for somebody else for the money I am getting, I would say forget it—for that amount of money for what I'm doing? There has to be love involved because the money certainly wouldn't make somebody go in and do something like [I do]" (Simon-Rusinowitz 1998).

How much higher must wages be to attract and retain more workers? In Wyoming, a study ordered by the Department of Health recommended an increase from $6.92 to $10.23 an hour for direct-support workers in order to improve retention. That figure amounts to 90 percent of the regional average for the lowest paid workers in similar jobs in 12 Western states. It was arrived at after a statewide survey of former direct-care workers who had left the field found that most would have stayed for $10 per hour (with raises for workers with experience).

In addition, the researchers compared direct-care workers' wages to those of workers with equivalent experience in retail and service industries and recommended that the direct-care workers should be paid more, in acknowledgement of the stress and difficulty of the work. In response, the state ruled that $30 million dollars in wage pass-through funds be allocated after July 1, 2002 (State of Wyoming Department of Health 2001). The actual appropriations for the 2003-2004 biennium are $23.4 million for direct-care personnel of the developmentally disabled persons living in home- and community-based settings, and $5.8 million for direct-care workers in Medicaid-certified nursing facilities.

Benefits
Lack of benefits often discourages workers from entering the field or causes them to leave (Close and Estes 1993; Hewitt and Lakin 2001; Feldman 1994; Glazier 2001; Dawson and Surpin 2001; Gaylord 1998; Bratesman 2000; MacAdam 1989). While a number of benefits are generally lacking for direct-care workers, the literature focuses almost exclusively on affordable health insurance.

Lack of company-provided health insurance correlates to high turnover rates, according to a report spanning various industries that was published last year by the Kaiser Family Foundation and Health Research and Educational Trusts. The authors note: "33 percent of all firms that reported 50 percent or more turnover in the last year offer coverage, compared to 68 percent for businesses with lower turnover" (Rowland 2001).

In a survey of state benefits and programs designed for long-term care workers, it was found that only Hawaii and Minnesota currently fund health insurance for direct-support workers, and only Pennsylvania and Texas support other services such as transportation assistance, child care, or bonuses (PHI and NCDHHS 2002The Current Population Survey (March Supplements from 1998, 1999 and 2000) estimated that 35 percent of all home health aides were uninsured, and 12 percent of all direct-care workers receive health care coverage through Medicaid. In Maine, only an estimated 8 percent of home health workers received benefits from their employers.

Health coverage is even lower for workers who are not employed by agencies or facilities. An NCOA survey of administrators found that a lack of health insurance for caregivers ranked as one of the top ethical issues confronting consumer-directed care (Velgouse and Dize 2000).

Findings from a Los Angeles County In-Home Supportive Services Providers survey indicate that close to half (45 percent) of IHSS's caregivers (32,000) are uninsured (Cousineau 2000). The same study revealed that 23 percent of the uninsured home care workers had postponed filling a needed prescription or left it unfilled within the past year, 40 percent of those who were uninsured delayed or did not seek medical treatment, and about 5 percent delayed needed surgery due to its cost. A third (33 percent) of the uninsured female workers between the ages of 18 and 64 had not received a Pap test in the previous two years, compared with 13 percent of those with private insurance, and 35 percent of the uninsured women over 50 had not received a mammogram in the previous two years, compared with 9 percent of those with private insurance (Cousineau 2000).

In a report written by Health Care For All in Massachusetts, a survey of 196 direct-care workers revealed that 25 percent were uninsured, and that direct-care workers were three times more likely to be uninsured than other adults in Massachusetts. The researchers also found that individuals working within this sector were more likely to avoid seeking medical care because of cost, and less likely to have a regular health care provider than the general Massachusetts population. The report also states that all of the employers of these direct-care workers offered health insurance, but premium rates prevented the workers from purchasing it. Further, the report suggests that since more than 75 percent of the clients being cared for by the surveyed workers receive publicly funded care, payment rates for these home-, community-, and nursing facility-based services "significantly affect workers' wages and access to employment-based health insurance benefits" (Hams et al. 2002).

After the California studies were completed, several of the state's public authorities began providing low-cost health insurance to direct-care workers. In San Francisco County, for instance, a program created in 1999 provides coverage for $3 a month. Independent providers (the public authority's title for the workers providing consumer-directed care and services) who have worked at least 25 hours in each of the previous two months are eligible for coverage.

Training
The amount and type of formal training that a caregiver receives—if any—depends on many factors, including his or her job title, the requirements of the state where he or she works, and the preferences of the organization or individual that employs him or her. Furthermore, the question of whether

caregivers should be trained at all, and if so how, is a topic of debate among disability advocates and other long-term care stakeholders.

The Centers for Medicare and Medicaid Services (CMS) require home health aides who provide services under the auspice of Medicare to receive a minimum of 75 hours of training, including at least 16 hours of supervised practical training. In addition, they must receive at least 12 hours of continuing education per year (Code of Federal Regulations; Title 42, Volume 3, Parts 430 to the end; r. 2000).

Beyond that regulation, there are no federal training standards for direct-care workers in home- and community-based settings. While some states require as much as 40 hours of training for home care or personal care assistants, others require none at all (Hewitt and O'Nell 1998). "Despite the depth and demands of this role, (the long term care) field has done little beyond basic training to prepare and sustain the direct-support practitioners in their jobs and help them grow in a meaningful career path" (Taylor 1998). Further, state-by-state and local training certifications are rarely portable in formal caregiving systems, meaning experience is not considered when a worker leaves a position in a nursing home to work in a community-based setting. State and local training, no matter the cost or appropriateness to the employer or worker, must be repeated when crossing state lines (Larson et al. 2001).

Typically, the employer decides how much and what kind of training workers need. One 1992 study found that 90 percent of all residential service providers "require and provide some form of classroom in-service and 80 percent require on-the-job training for direct service employees" (Gaylord 1998). Agencies and other entities that train workers vary widely in what they teach, but certain key elements, such as infection control, the patient's bill of rights, emergency procedures, and first aid, are nearly universal. These elements tend to be based on practices used in institutions and on training requirements for certified nursing assistants (Hewitt and Lakin 2001).

Training is often provided in the form of orientation and a series of in-services. According to Sandy Henry and her colleagues at Dungarvin Inc. (a long-term care provider), such training often satisfies state regulations but fails to meet the needs of the workers or the people they support (Gaylord 1998). Another example of basic training is the program offered by the Northwestern Illinois Center for Independent Living. Its two-day training for personal assistants covers bowel and bladder care and certain specific disabilities (Kekstadt 2000).

Many experts believe that the skills needed to be a successful direct-care worker in home- and community-based settings should be developed more systematically. Ford and Honnor (2000) believe these workers need more knowledge and skills than those who work in institutional settings, as they often perform a wider range of tasks. Dawson and Surpin (2001) say entry-level training should be "upgraded and expanded to reflect current care needs, clinical realities, and adult life-long learning techniques—particularly to cultivate problem-solving, interpersonal, and communication skills and specific skills related to caring for clients with Alzheimer's disease, physical disabilities, and depression."

The Community Support Skills Standards is a group of 12 skills and supports for direct-support professionals that disability advocates determined to be core competencies or needs. They include "education, training and self-development" and "vocational, educational and career support" (Gaylord et al. 1998). The Direct Support College, developed by Hewitt and Lakin, is another attempt to create national standards for direct-support workers. Five core curricula are available on-line through this Internet-based "college," with plans for a dozen in all. Hewitt and Larson (1994) argue that direct-support professionals need structured training in order to develop the necessary "knowledge, skills, and attitudes" to do their job effectively.

The World Institute on Disability recommends that the following competencies be included in a federal definition of a personal attendant:
- Personal maintenance and hygiene activities
- Mobility tasks
- Household maintenance tasks
- Cognitive and life management activities such as money management, planning, and decision-making
- Security-related services such as interpreting for people with hearing or speech difficulties (Glazier 2001).

Training standards are more limited for informal caregivers than they are for workers whose services are reimbursed by the government. One survey revealed that of 41 responding states, only four (New York, Washington, South Carolina, and Utah) required any training for paid informal caregivers (Niesz 2001). "Informal caregivers are seldom adequately trained and almost never offered appropriate follow-up services," writes researcher Peter Arno and colleagues.

"They are left to negotiate an increasingly complex and fragmented system and to find whatever help they can by whatever means they can" (Arno et al. 1999).

That is as it should be, according to some: Certain disability advocates and other long-term care stakeholders strongly oppose formal training and standards for direct-care workers. Such training, they believe, reinforces the medical model of equating disability to illness, contributes to a hierarchy in which the worker dominates the consumer, and gives the individual receiving care less control in directing his or her care (Glazier 2001; ADAPT; Moseley 1999). The Center for an Accessible Society (n.d.) believes that state training requirements often do not meet any long-term care consumer needs because of the diversity of the population—citing that the consumer of the services is best fit to determine his/her own needs in terms of training. Further, the Center believes that these requirements and training packages only increase program costs.

Yet others argue that consumer-directed care calls for more training, not less—or at a minimum, a whole new kind of training. Polivka (2001) believes states should educate consumers and caregivers about each other's role in consumer-directed care and the risks and responsibilities involved. Similarly, Charles Moseley (1999) of the National Program Office on Self-Determination asserts that educating family caregivers and consumers on how to work with caregivers is essential to fulfilling the promise of consumer-directed care.

ADAPT (n.d.) recommends combining the two existing models for home care workers into one, creating a class of worker somewhere between the minimally trained personal care attendant and the medically oriented home health aide. The organization believes workers should provide both health care and personal assistance services, regardless of whether they provide agency-based or consumer-directed care.

Even if there were general agreement on what training was needed, however, it would take time to build up the systems needed to provide it. In reports about direct-support professionals, Hewitt and her colleagues could have been writing about direct-care workers in virtually all forms of home- and community-based care when they discussed barriers to training. Decentralization of services and lack of qualified trainers make it difficult to train direct-support professionals, note Hewitt and Larson (1994). A final obstacle is the shortage of money allotted for training (Hewitt and Lakin 2001).

Conclusion

The literature documents the challenge of finding people to provide personal assistance to the growing number of Americans with disabilities and long-term illnesses.

Changes in public policy and consumer preferences are increasingly shifting services from institutions to homes and other community settings. In some cases, consumers are taking charge of directing their own services. In others, family members and friends are being paid for the services they provide. The research correlates these changes with higher levels of consumer satisfaction.

However, the move away from facility-based care will create a need for more personal assistance workers, and employers are already finding it difficult to meet current demands. Studies highlight the factors that make it difficult to retain workers in these positions or recruit new workers to the field, which include the following:

- Low wages
- Lack of affordable health insurance and other benefits
- Insufficient training
- Inadequate supervision and support
- Limited opportunities for advancement

Research has examined interventions aimed at removing roadblocks in these areas, but the scale of these evaluations has been limited and the results are primarily anecdotal or perceptual. More comprehensive research could better illuminate how these factors affect the workforce and what can be done to improve recruitment and retention rates.

RESOURCE LIST

FOR CONSUMERS

ADAPT promotes home- and community-based services for people with disabilities. www.adapt.org

Alzheimer's Association has made family and formal caregiving a priority. To read about its resources and tips for family caregivers, go to www.alz.org/FamCare/overview.asp

The Campaign for Quality Homecare is a grassroots movement in California to improve the situation for workers and recipients of services participating in the state's In-Home Supportive Services program. www.calhomecare.org/

National Program Office on Self-Determination provides links, articles, and message boards on self-determination, as well as articles on personal care assistants.
www.self-determination.org/index.htm

The **World Institute on Disability** (WID) is a nonprofit, national public policy center dedicated to promoting independence and full societal inclusion for people with disabilities. www.wid.org

FOR FAMILY CAREGIVERS

Caregiver Jobs Clearinghouse provides displaced workers with caregiving career opportunities in long-term care. www.carecareers.net/

Center for Family Caregivers provides emotional support to family caregivers. www.familycaregivers.org/index.html

Empowering Caregivers™ is a site devoted to caregiving, offering information on caregiving practices and resources, message boards, and newsletters. www.care-givers.com/pages/main.html#Anchor

Family Caregiver Alliance works to address the needs of families and friends providing long-term care by developing services, advocating for public and private support, conducting research, and educating the public. Core services include consultation on long-term care planning, service linkage, legal and

financial consultation, respite services, counseling, and education.
www.caregiver.org

International Center for Disability Resources on the Internet (Caregiver Section) helps caregivers find resources and support worldwide.
www.icdri.org/caregiver/caregiving_resource_page.htm

National Alliance for Caregiving is a national organization that disseminates research and information for family caregivers and the professionals who support them. www.caregiving.org

National Family Caregivers Association (NFCA). NFCA is a grassroots organization created to educate, support, empower, and speak for the family caregivers. www.nfcacares.org/

Well Spouse Foundation is a national, not-for-profit membership organization that supports wives, husbands, and partners of the chronically ill and/or disabled. www.wellspouse.org/

FOR PAID CAREGIVERS AND PERSONAL ASSISTANTS

Connecticut Association of Personal Assistants promotes professional growth for personal assistants through support, advocacy, outreach, and public education. www.ctapa.org

Direct Care Alliance is a coalition of long-term care consumers, workers, and providers working for reforms in both public policy and workforce practices to ensure a stable, valued, and well-trained direct-care workforce.
www.directcarealliance.org

Iowa Caregiver's Association is a statewide professional association for Certified Nurse Assistants, Home Care Aides, Patient Care Technicians, and other direct-care/support workers. www.iowacaregivers.org/

The National Alliance of Direct Support Professionals is a coalition of organizations and individuals committed to strengthening the direct-support workforce. www.nadsp.org/

National Network of Career Nursing Assistants is a nonprofit, educational organization promoting recognition, education, research, advocacy, and peer

support development for nursing assistants in nursing homes and other long-term care settings.
www.dbmmgt.com/websuite_Career_Nursing_Assistants/pages/home.htm

The Quality Mall houses the "Staffing Store" that provides the browser with easily accessible information on people who provide direct support and other services to people with developmental disabilities. www.qualitymall.org/main/

Wisconsin Council on Developmental Disabilities is addressing direct-support workforce issues in the state. www.wcdd.org/

FOR PROVIDERS

ANCOR (American Network of Community Options and Resources) is a nonprofit trade association representing private providers who provide supports and services to people with disabilities. www.ancor.org/dev/

Association of Developmental Disabilities Providers offers proactive, statewide leadership to improve the social, political, and economic well-being of community organizations that provide services and support to people with developmental disabilities and their families. www.addp.org/

National Association for Area Agencies on Aging (N4A) is the umbrella organization for the 655 area agencies on aging (AAAs) and more than 230 Title VI Native American aging programs in the US. Through its presence in Washington, DC, N4A advocates on behalf of the local aging agencies to ensure that needed resources and support services are available to older Americans. www.n4a.org/

National Association for Home Care and Hospice is a national organization representing home care agencies, hospices, home care aide organizations, and medical equipment suppliers. It sponsors a national certification program for home care aides through its Home Care University (www.nahc.org/HCU/credent.html).

GOVERNMENT AGENCIES AND RESOURCES

Centers for Medicare and Medicaid Services is the federal agency within the US Department of Health and Human Services that houses the Medicare and Medicaid programs. These programs benefit about 75 million Americans. The

CMS web site has resources and information for consumers about disability and aging issues. cms.hhs.gov/medicaid/consumerag.asp

DisabilityInfo.gov is the online resources for President George W. Bush's *New Freedom Initiative*. It is a comprehensive online resource specifically designed to provide people with disabilities with the information they need to know quickly. The site provides access to disability-related information and programs available across the government on numerous subjects, including civil rights, education, employment, housing, health, income support, technology, transportation, and community life. www.disabilityinfo.gov/

National Institute on Disability and Rehabilitation Research's goal is to generate, disseminate, and promote new knowledge to improve the options available to disabled persons. www.ed.gov/offices/OSERS/NIDRR/About/

Office of the Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of the US Department of Health and Human Services on policy development, and is responsible for major activities in the areas of policy coordination, legislation development, strategic planning, policy research and evaluation, and economic analysis. Personal Assistant Services are a key area their work and can be found at: aspe.os.dhhs.gov/daltcp/index-p.htm#personal

POLICY AND RESEARCH ORGANIZATIONS

Center for an Accessible Society is a national organization designed to focus public attention on disability and independent living issues by disseminating information developed through NIDRR-funded research to promote independent living. www.accessiblesociety.org/about.htm

Center for Health Care Strategies (CHCS), Inc.; Community Integration Initiative. The Center for Health Care Strategies (CHCS), in a major initiative tied to the US Supreme Court's decision in the 1999 *Olmstead v L.C.* case, awarded planning grants to seven states to improve their community-based long-term care services. The site includes several papers and resources on the community based workforce. www.chcs.org/ConsumerAction/communityintegration.html

Home and Community Based Services Resource Network is a partnership between the Assistant Secretary for Planning and Evaluation (ASPE), CMS - Centers for Medicare & Medicaid Services, state agencies that purchase and

manage HCBS services, and consumers. The mission of the Resource Network is to work with states, the disability and aging communities, and others who are committed to high-quality consumer-directed services in integrated settings through cost-effective delivery models. www.hcbs.org/

Human Services Research Institute is active in its efforts to build the capacity of the direct-care workforce and shape a competent direct-service workforce with the skills, knowledge, and values that will help people lead self-determined lives. Toward this end, HSRI staff are engaged in a variety of demonstration, research, and technical activities to help government and human service employers ensure a robust workforce. www.hsri.org/ddworkforce/about.html

Independent Living Research Utilization is a national center for information, training, research, and technical assistance in independent living. Since ILRU was established in 1977, it has developed a variety of strategies for collecting, synthesizing, and disseminating information related to the field of independent living. www.ilru.org/index.htm

Institute for the Future of Aging Services is a policy research center housed within the American Association of Homes and Services for the Aging whose aim is to help ensure that the needs of older people are met. www.futureofaging.org/#

National Clearinghouse on the Direct Care Workforce is a resource center supporting efforts to improve the quality of jobs for frontline workers across the long-term care spectrum. The Clearinghouse collects and analyzes a wide range of information related to public policy, workplace practices, and other issues that affect direct-care workers and their clients, and disseminates this information to providers, workers, consumers, advocates, policymakers, and researchers. www.directcareclearinghouse.org

PHI focuses on strengthening the direct-care workforce within our nation's long-term care system through developing innovative approaches to recruitment, training, and supervision; client-centered caregiving practices; and effective public policy. www.PHInational.org

Research and Training Center on Community Living (RTC) is part of the Institute on Community Integration, a University Center for Excellence in

Developmental Disabilities in the College of Education and Human Development at the University of Minnesota in Minneapolis. The RTC works with community support systems for people with developmental disabilities and their families, providing research, evaluation, training, and technical assistance. Among other things, it sponsors several websites, publishes a quarterly magazine, and provides organizational support to NADSP (see For Paid Caregivers). The RTC also helped to develop and maintains the Internet-based College of Direct Support (www.collegeofdirectsupport.com/), where workers can advance through several professional stages while earning first an associate's and then a bachelor's degree. www.rtc.umn.edu

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