

# **HOME AND COMMUNITY-BASED SERVICES FOR OLDER PEOPLE AND YOUNGER PERSONS WITH PHYSICAL DISABILITIES IN WASHINGTON**

## **Final Report**

Prepared for:

**U.S. Department of Health and Human Services  
Health Care Financing Administration**

Prepared by:

**Joshua M. Wiener, Ph.D.  
The Urban Institute**

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**Steven M. Lutzky, Ph.D.  
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**June 5, 2001**

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## **HOME AND COMMUNITY-BASED SERVICES FOR OLDER PEOPLE AND YOUNGER PERSONS WITH DISABILITIES IN WASHINGTON**

Washington is a relatively small northwestern state with 5.8 million people in 1999, about 11.5 percent of whom were age 65 and over.<sup>1</sup> The state is doing well economically and only about 8.9 percent of the population lives in poverty, well below the national average. Washington provides home and community services to a very substantial number of beneficiaries through the Medicaid personal care program, a large Medicaid home and community-based services waiver, and some small and shrinking state-funded programs. Washington has a national reputation as a leader in innovative home and community services and relies heavily on consumer-directed home care and nonmedical residential services, such as assisted living and adult family homes. In fiscal year 1999, almost twice as many people received home and community-based services as received Medicaid-funded nursing home care, making Washington one of the most balanced long-term care delivery systems in the country.

The long-term care policy environment in Washington is shaped by five factors. First, the state is strongly committed to a policy of "aging in place" and to developing an array of home and community-based services (mostly social rather than medical) to meet consumer needs. Second, although the state has a well-organized and politically effective nursing home industry, strong consumer advocates, especially for older people, have provided an effective counterbalance. Consumer advocates have provided much of the political will to redesign the long-term care system and have worked closely with state officials to do so.<sup>2</sup> Third, there has been a consistent vision and stable leadership for over 20 years, with one state government official. His recent retirement and that of another long-time administrator signals a changing of the guard, but not a change in policy. Fourth, the administrative consolidation of aging and disability services at the state and local level has allowed for a degree of administrative and policy coordination that is lacking in other states with more fragmented organizational structures. Fifth, despite the prosperousness of the state and the expansiveness of its home and community-based services, a substantial amount of state policy is driven by two ballot initiatives that sharply

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<sup>1</sup> "State Profiles," <http://www.census.gov>.

<sup>2</sup> Lisa Maria B. Alecxi, Steven Lutzky, and John Corea, *The Efficacy of Using Home and Community-Based Care as an Alternative to Nursing Facility Care in Three States*, (Washington, DC: American Association of Retired Persons, 1996).

limit state spending and revenues. These fiscal constraints have meant that expansion of home and community-based noninstitutional services partly have been financed by a reallocation of resources from nursing home care, creating a direct tradeoff between institutional and noninstitutional services. They have also provided strong pressure to keep costs per recipient low, possibly forcing home and community to be more cost effective than in other states.

This paper analyzes the home and community-based service system for older people and younger adults with physical disabilities in Washington, focusing on the state administrative structure, eligibility and assessment, case management, services covered by Medicaid and other programs, cost containment, and quality assurance. This paper does not address home and community-based services for persons with mental retardation or developmental disabilities or for children. Information was obtained from public documents, state of Washington web sites, and interviews with federal and state officials, provider associations, consumer advocates, and other stakeholders. Interviews were conducted in person in Olympia and Seattle, Washington, during December 1999, and by telephone in June 2000. Questions were asked using an open-ended interview protocol. To encourage candor in their answers, respondents were told that they would not be quoted by name.

## **THE LONG-TERM CARE SYSTEM IN WASHINGTON**

Washington has a lower-than-average supply of nursing home beds and a substantial number of home health agencies. Washington had 27,204 nursing home beds in 285 facilities in 1998—41.7 beds per 1000 elderly people age 65 and over, compared to a national average of 52.5 beds per 1000 elderly people age 65.<sup>3</sup> In recent years, the number of nursing home beds has actually declined in nominal terms and occupancy rates have fallen substantially, partly because of the expansion of alternative services and the growing importance of short-term post-acute care, which makes it harder to maintain high occupancy rates. The state has a very high supply of nonmedical residential facilities, 474 facilities with a total of 21,074 beds in 1998—49.2 beds per 1000 elderly people age 65 and over compared to the national average of 25.5 beds per 1000

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<sup>3</sup> Charlene Harrington, James H. Swan, Valerie Wellin, Wendy Clemena, and Helen M. Carrillo, *1998 State Data Book on Long-Term Care Program and Market Characteristics*, (San Francisco: University of California, San Francisco, 2000).

elderly age 65 and over.<sup>4</sup> (Even this is an understatement of the supply of nonmedical residential facilities because it does not include adult family homes.) In 1998, Washington had 159 licensed home health agencies.

Washington's Medicaid long-term care expenditures (nursing facility, ICF/MR, home and community-based services waivers, home health, and personal care) totaled \$1.104 billion in 1998, 33 percent of which was for home and community-based services, compared to the national average of 26 percent.<sup>5</sup> **Chart 1** summarizes fiscal year 2000 state spending for programs for older people and younger persons with disabilities. Including Medicaid and state-funded programs for nursing home care and home and community-based services for older people and younger adults with disabilities, home and community-based services accounted for 38 percent of long-term care expenditures.

**Chart 1: Washington Public Expenditures for Long-Term Care Services for Older People and Younger Persons with Physical Disabilities, FY 2000**

Service/Program	\$ in Millions	%
Medicaid Nursing Facilities	479.5	61.7
Medicaid Waiver – Community Options Entry System (COPEs)	255.7	32.9
Medicaid Personal Care	39.5	5.1
State-Funded Chore Program	2.8	0.4
State-Funded Residential Care	0.3	<0.1
<b>TOTAL</b>	<b>777.8</b>	<b>100.0*</b>

\*Does not add exactly due to rounding.

**Source:** Aging and Adult Services Administration, Washington Department of Social and Health Services, 2000.

**Chart 2** summarizes the characteristics of Washington's home and community-based services programs. Medicaid is the main source of funding for home and community-based services, which reflects a deliberate strategy over the last 15 years to reduce the role of state-only funded programs. In fiscal year 1984, 97 percent of home and community-based services clients had their services totally financed by state-only programs, while in fiscal year 2000, only two

<sup>4</sup> Ibid.

percent of home and community-based consumers had their services financed by state-only programs.<sup>6</sup>

The two main home and community-based services programs operated by the state are the Medicaid personal care benefit and the Community Options Program Entry System (COPES), which is the Medicaid home and community-based services waiver serving older people and younger adults with disabilities. In May 2000, 6,463 persons received Medicaid personal care benefits, of whom 46 percent were under age 65. During that same period, 23,863 persons received COPES services, of whom 29 percent were under age 65. Thus, while significant numbers of younger people received services under these programs, the bulk of clients are elderly.

Washington also has a few small state-funded home and community-based services programs. The Chore program provides personal care and the volunteer homemaker and chore program coordinates services for persons with incomes and assets that exceed the eligibility criteria for Medicaid. The chore program served an average of 539 persons per month in fiscal year 2000. In addition, the state provides funding for low-income individuals who reside in adult family homes and boarding homes providing "adult residential care" who do not meet functional or financial criteria of Medicaid personal care or COPES.<sup>7</sup> This program is tiny, serving less than 100 people a month. Neither Medicare nor Medicaid home health plays a major role in providing long-term care in the state, focusing instead on more short-term post-acute care.<sup>8</sup> Indeed, Medicaid home health is administratively separate from long-term care services.

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<sup>5</sup> Urban Institute estimates based on data from HCFA-64 reports, 2000..

<sup>6</sup> Aging and Adult Services, *A Decade of Progress: 1987-1997*, (Olympia, Washington: Washington Department of Social and Health Services, 1998).

<sup>7</sup> Adult Residential Care facilities are licensed boarding homes that provide room and board, help with personal tasks, and may provide help with medications. Residents may have limited supervision.

<sup>8</sup> A sign of the acute care orientation of the home health benefit is that responsibility for Medicaid home health lies with the Medical Assistance Administration rather than the Aging and Adult Services Administration.



**Chart 2: Home and Community Services in Washington**

	<b>Community Options Entry System (COPES)</b>	<b>Medicaid Personal Care</b>	<b>State-funded Chore and Residential Programs</b>
<b>Year Program Started</b>	1983	1989	1970s
<b>Administrative Responsibility</b>	Aging and Adult Services Administration (AASA) of the Department of Social and Health Services (DSHS) has broad overall policy and administrative responsibility for long-term care programs. Initial functional and financial eligibility determinations done by AASA caseworkers in a single-point-of-entry to publicly-funded services. If the client enters residential settings, AASA staff continues case management responsibilities. If client receives in-home services, ongoing case management is transferred to 13 Area Agencies on Aging.	Same as COPES.	Same as COPES.
<b>Functional Eligibility</b>	Individuals must meet nursing facility level of care: individuals must need substantial or total assistance with two or more self-care tasks (eating, toileting, ambulation, self-medication, transfer, positioning, or bathing) or have cognitive supervision needs, or require minimal, substantial or total assistance in three or more ADL tasks.	Requires help with at least one of the following direct personal care tasks—eating, toileting, ambulation, self-medication, transfer, positioning, specialized body care, personal hygiene, bathing or dressing.	Require help with at least one of the following direct personal care tasks—eating, toileting, ambulation, self-medication, transfer, positioning, specialized body care, personal hygiene, bathing or dressing.

**Chart 2: Home and Community Services in Washington, continued**

	<b>Community Options Entry System (COPEs)</b>	<b>Medicaid Personal Care</b>	<b>State-funded Chore and Residential Programs</b>
<b>Financial Eligibility</b>	Up to 300 percent of SSI.	Categorically needy. For a single individual, SSI/SSP level is \$539 a month in 2000. No medically needy coverage.	Low-income, but ineligible for COPEs or Medicaid personal care. Less than \$10,000 in assets for one person; \$15,000 in assets for two persons. Sliding fee schedule for services.
<b>Number of Beneficiaries</b>	Average monthly caseload in 2000: 22,213 clients. Total unduplicated clients 4/1/99-3/31/00: 28,902.	FY 2000 average monthly caseload: 6,514.	FY 2000 average monthly caseload: Chore: 539; State-funded adult family homes and adult residential care: 56.
<b>Funding Source</b>	Medicaid	Medicaid	State funds.
<b>Expenditures</b>	\$255.7 million in FY 2000	\$39.5 million in FY 2000	\$2.8 million for Chore program; \$0.3 million for residential care program.
<b>Covered Services</b>	Assistance with personal care and household tasks in the home, adult day care, environmental modifications, home delivered meals (limited to one per day), home health aide services (beyond the amount duration and scope of regular Medicaid home health), personal emergency response systems, skilled nursing (beyond the amount, duration, and scope of regular home health), specialized medical equipment and supplies, training to meet a therapeutic goal, and transportation services to meet a therapeutic goal and beyond regular Medicaid transportation, and services in adult family homes and assisted living facilities. Services are to be provided in the home and are not designed to be provided at the workplace or other settings in the community.	Personal care, including help with household tasks.	Personal care, chore services, adult family homes, and adult residential care. Volunteers receive supervision and transportation to provide chore services.

**Chart 2: Home and Community Services in Washington, continued**

	<b>Community Options Entry System (COPEs)</b>	<b>Medicaid Personal Care</b>	<b>State-funded Chore and Residential Programs</b>
<b>Consumer Direction</b>	Used by majority of persons receiving in-home services. Required of all clients needing more than 112 hours of service a month.	Same as COPEs.	Same as COPEs.
<b>Cost Containment Mechanisms</b>	Aggressive effort to limit and reduce nursing home use in order to reallocate resources to home and community services. Individual expenditures must be below 90 percent of average cost of nursing home care. Heavy use of low-cost independent providers. Payment rates considered low by many stakeholders. No waiting list.	Same as COPEs.	Same as COPEs.
<b>Quality Assurance Mechanisms</b>	Agency-directed and independent provider home care workers must have 22 hours of training and pass a written and hands-on test and receive 10 hours of continuing education annually. Workers must pass a criminal background check that is limited to Washington crimes. Home care agencies are licensed and supervisors must visit client twice a year. Case managers must conduct annual face-to-face assessment with clients. Adult family homes and assisted living facilities are licensed and surveyed annually. Medicaid standards exceed licensure standards.	Same as COPEs.	Same as COPEs.

## ADMINISTRATIVE STRUCTURE

Unlike most other states, Washington has consolidated administrative and policy responsibility for long-term care for older people and younger persons with disabilities at the state level within the Aging and Adult Services Administration (AASA) of the Department of Social and Health Services (DSHS) and at the local level within 13 area agencies on aging (AAAs). AASA is responsible for virtually all financing, regulation, quality assurance, and policy for nursing homes and home and community-based services for both Medicaid and state-funded programs. The DSHS, which is the single state agency for Medicaid, has assigned these tasks to AASA for Medicaid long-term care services.

There is a single point-of-entry for all state-supported long-term care services. AASA regional staff initially assess all applicants and authorize services. AASA provides case management for people in nursing facilities and nonmedical residential facilities, including adult family homes, adult residential care, and assisted living. AAAs provide ongoing case management and reauthorization of services for all clients age eighteen or older who remain in their own homes. AAAs make payments to agency providers (but not independent providers who are paid directly by the state) and then are reimbursed by DSHS. Stakeholders generally describe the relationship between the state and the AAAs as good.

According to stakeholders, the unification of aging and disability services at both the state and local level contributes to increased efficiency in the funding and delivery of long-term care services.<sup>9</sup> Bringing together all of the administrative and policy components into one agency helps to resolve policy conflicts and allows for easier transfer of funds from one service to another by averting turf wars between the agencies responsible for handling these services. Having both state and local levels centralized has also facilitated communications between the state and the local agencies because each side only has to communicate with one agency. Similarly, from the consumer perspective, the single point-of-entry to the system helps ensure that clients will obtain the services that people with disabilities need because the caseworker can authorize services from a number of programs.

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<sup>9</sup> Alecxih, Lutzky, and Corea, op. cit.

Relying on AAAs for ongoing case management also allows the state to draw on local norms and values and on their knowledge of the availability of services in relatively small geographic areas. In addition, according to some state officials, the use of local rather than state agencies makes the legislature more likely to increase funding for administrative activities because doing so does not mean more state employees, which is politically unpopular.

### **ELIGIBILITY CRITERIA AND ASSESSMENT**

Functional and financial eligibility requirements vary by program, but are relatively broad and are designed to cast a fairly wide net in terms of covering the population with disabilities. In terms of functional eligibility, for the COPES Medicaid waiver, individuals must be eligible for nursing facility care and likely to require nursing facility care within the next 30 days or already be in a nursing facility. Regulations require that individuals need substantial or total assistance with two or more self-care tasks (eating, toileting, ambulation, self-medication, transfer, positioning, or bathing) or have cognitive supervision needs, or require minimal, substantial or total assistance in three or more ADL tasks.

The functional criteria for the Medicaid personal care benefit and the state-funded Chore program require help with at least one of the following direct personal care tasks—eating, toileting, ambulation, self-medication, transfer, positioning, specialized body care, personal hygiene, bathing or dressing. In addition, individuals receiving Chore program services must be judged to be at risk of placement in a long-term care facility.

In line with the state's consolidation of administrative responsibilities, AASA local offices determine financial eligibility for Medicaid and state-funded programs. In order to be eligible for COPES, individuals must have incomes below 300 percent of the federal Supplemental Security Income (SSI) benefit level, but there is no medically needy coverage. As a result, some state officials said that "some people fall between the cracks." To solve that problem, DSHS is proposing in its 2001-2003 budget to develop a waiver to include the medically needy for persons in residential care settings (but not in in-home care).

In order to be eligible for Medicaid personal care, individuals must meet categorically needy Medicaid eligibility (generally SSI) income and resource standards. Washington provides a state supplemental payment to SSI, which made single persons with incomes up to \$539 a

month in 2000, eligible for Medicaid.<sup>10</sup> Medically needy individuals are not eligible for Medicaid personal care.

The financial eligibility standards for the state-funded programs are designed to reach persons with higher incomes and assets than Medicaid, but these programs are playing a sharply decreasing role in the state's long-term care system. In order to be eligible for the Chore program, individuals must be age 18 or older and not eligible for other programs (including Medicaid) and not have assets that exceed \$10,000 for one person and \$15,000 for two persons. Services are offered on a sliding fee scale.

Although quite liberal in its financial eligibility standards, the state is fairly aggressive in its recovery of the costs of Medicaid and state-funded long-term care services from the estates of deceased beneficiaries. In addition, to prevent individuals from divesting themselves of assets to become eligible to Medicaid, state law contains penalties for persons who receive resources that are transferred for less than adequate compensation, although individuals are permitted to receive fairly substantial sums with no penalty.

## **CASE MANAGEMENT**

Case management is a critical component of the service system in Washington, with responsibilities allocated by stage in the care process and by setting. Initial requests for services are the responsibility of regional AASA staff, who are mostly social workers. These staff visit the applicant in their current living setting, conduct a comprehensive assessment of need, assist with Medicaid applications, if necessary, and develop a plan of care. Ongoing responsibility for individuals who remain in their homes is transferred to the local AAA once eligibility has been established, a plan of care written and services authorized. In contrast, ongoing case management for persons in nursing homes, adult family homes, and boarding homes (including assisted living) remains the responsibility of the regional AASA case manager. Face-to-face reassessments are done annually.

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<sup>10</sup> Brian K. Bruen, Joshua M. Wiener, Johnny Kim, and Ossai Miazad, "State Usage of Medicaid Coverage Options for Aged, Blind, and Disabled People," *Assessing the New Federalism* Discussion Paper #99-09, (Washington, DC: The Urban Institute, 1999).

In the last few years, there has been growing concern that case manager caseloads are too high to allow for adequate contact and to monitor quality of care. The average caseloads had increased sharply in 1995 when responsibility for younger persons with disabilities were transferred to the AAAs under a staffing model that assumed a minimal amount of time would be required to manage these younger clients. During the late 1990s, each AAA case manager had about 100 clients, which recently has been reduced to 85 clients, and the DSHS budget for 2001-2003 proposes to further reduce the average caseload to 75 clients. Nonetheless, some stakeholders believe that even this ratio is too high and that case managers should not have more than about 50 clients. In contrast, disability advocates report that many younger people with disabilities want "to be left alone" and do not need active case management. They argue that the same applies to persons who have a lot of family or who are cognitively intact. According to one observer, the AAAs pay more attention to overall average costs than to the expenditure levels of particular individuals.

The state treats case management as an administrative expense rather than a service. Thus, payment to the AAAs for case management is a fixed amount for each fiscal year which does not increase if caseloads rise until the payment level is changed in the subsequent year. State payments to the AAAs for administrative costs are adjusted annually based on expected caseload. Since it is not a per case payment, this may act as a disincentive for AAAs to conduct outreach.

## **SERVICES**

Washington's home and community-based services programs cover a very broad range of services, including a choice of agency or consumer-directed home care and nonmedical residential care. Although some observers thought that staffing shortages and provider reimbursement levels limited beneficiary access to some services, stakeholders were generally satisfied with the set of services covered. COPES covers assistance with personal care and household tasks in the home, adult day care, environmental modifications, home delivered meals (limited to one per day), home health aide services (beyond the amount duration and scope of regular Medicaid home health), personal emergency response systems, skilled nursing (beyond the amount, duration, and scope of regular home health), specialized medical equipment and supplies, training to meet a therapeutic goal, transportation services to meet a therapeutic goal,

and services in adult family homes, adult residential care, and assisted living facilities. A limitation of COPES services is that they are only available in the home and are not allowed to be provided at the workplace or other settings in the community. The state intends to amend their waiver after the renewal is approved to allow services outside of the home.

The Chore program and Medicaid personal care provide help with the activities of daily living and household tasks. Under the Medicaid personal care benefit, household help may not exceed 30 percent of the hours provided. Medicaid personal care services are provided in "adult residential care" and "adult family homes," as well as, in individual's homes. Medicaid personal care may not be provided in assisted living facilities. The Volunteer Chore program pays the administrative and transportation costs for volunteers to get to the homes of elderly persons with impairments.

The DSHS 2001-2003 budget is proposing three changes that would further broaden the range of services available to people with disabilities. First, in order to better meet the needs of clients with medical needs, the skilled nursing component of COPES would be strengthened by removing the present 12 visits per six-month utilization limit. Second, in order to better integrate younger people with disabilities into the community, transportation and medically necessary personal care services would be provided to enable Medicaid beneficiaries to travel to work sites. Third, in order to encourage new approaches to care, a Long-Term Care Community Options Grant Program would be established to fund innovative pilot projects.

### **NONMEDICAL RESIDENTIAL CARE**

Nonmedical residential facilities, including adult family homes, assisted living facilities, and adult residential care are major providers of long-term care in Washington *Chart 3* describes the categories of residential care in the state. Fully 95 percent of publicly-funded persons receiving services in these settings are financed by COPES, about 4 percent of people in these facilities receive Medicaid personal care, and less than one percent of people are funded through a state-only program.<sup>11</sup> Average monthly publicly-financed caseload for all sources of payment totaled 7,390 in fiscal year 2000, with 3,150 residents in adult family homes, 1,285

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<sup>11</sup> Aging and Adult Services Administration, Department of Social and Health Services, unpublished data, 2000.



residents in adult residential care, 2,827 residents in assisted living facilities, and 128 residents in other settings.

**Chart 3: Types of Nonmedical Residential Care in Washington**

<b>Adult Family Homes (licensed as adult family homes)</b>	Adult family homes are residential homes licensed to care for up to six residents. They provide room, board, laundry, necessary supervision, assistance with activities of daily living, personal care, and social services, if necessary.
<b>Assisted Living (licensed as boarding homes)</b>	Assisted Living offers private apartments; this service emphasizes privacy, independence, and personal choice. Supervision includes meals, personal care, help with medication, limited supervision, organized activities, and limited nursing services. Assisted Living is staffed 24 hours a day, and help is available around the clock.
<b>Adult Residential Care (licensed as boarding homes)</b>	Adult Residential Care facilities are licensed boarding homes. They provide room and board, help with personal care tasks, and may provide help with medications. Residents may have limited supervision.
<b>Enhanced Adult Residential Care (licensed as boarding homes)</b>	Enhanced Adult Residential Care provides all of the same services as Adult Residential Care. In addition, limited nursing care may be provided and no more than two people will share a room.

**Source:** Aging and Adult Services Administration, *Options: You Have a Choice*, (Olympia, WA: Washington Department of Social and Health Services, 1998).

State Medicaid policy on assisted living facilities emphasizes the philosophy of "aging in place," the use of "negotiated service agreements," and "managed risk." Structural requirements for Medicaid participation exceed the licensing requirements for assisted living facilities. Under Medicaid, newly constructed assisted living facility units must include individual apartments with a full private bathroom, a locking door, a mini-kitchen, and 220 square feet.<sup>12</sup> Limited nursing services are provided. Adult family homes are residential settings caring for up to six residents providing room, board, laundry, supervision, assistance with personal care, and social services, if necessary. Nurse delegation is permitted for boarding homes, adult family homes

<sup>12</sup> The negotiated service agreement is a written plan of services that includes input from the resident to the maximum extent possible. Managing risk means balancing the resident's choice for independence against the safety of the resident and other persons in the facility. Existing facilities built before 1996 must provide a minimum of 180 square feet. Each unit includes a mini-kitchen, including a refrigerator and a stove-top or microwave. Some residents may choose or may not be appropriate for a kitchen.

and assisted living facilities. In its 2001-2003 budget, DSHS is proposing to expand a pilot project that provides specialized dementia care in boarding homes.

During the 1990s, there was a boom in adult family homes and assisted living facilities, but the supply has leveled off and some stakeholders now believe that there is overcapacity. Many of the assisted living facilities in the state are owned and operated by national, for-profit chains. Although there was a moratorium on additional adult family homes for a brief period, construction and expansion of assisted living facilities and adult family homes is not controlled through the certificate of need program.

Importantly, most residents of adult family homes and assisted living facilities are private pay, rather than dependent on Medicaid, making them a mainstream service option and not just a service for the lower-income population. Assisted living facilities and adult family homes have the option of fully participating in Medicaid or of limiting the number of publicly-supported residents that they admit.

### **CONSUMER DIRECTION**

Clients in both the Medicaid personal care program and COPES have a choice of using licensed home care agencies or independent providers. Under the independent provider option, the worker is a direct employee of the client, with the state assuming responsibility for payment and paying taxes. With assistance from the AAA case manager, the client is responsible for hiring, supervising, and finding replacements for the caregiver. Clients using independent providers, therefore, have more supervisory responsibilities than do agency clients. The proportion of in-home care clients using independent providers has been growing steadily and is now a clear majority of home care clients.<sup>13</sup> In 1999, 12,000 clients used independent providers, while 9,000 clients used agencies.<sup>14</sup>

In general, independent providers help with activities of daily living and household tasks. In 1999, the state enacted legislation allowing disabled, but cognitively intact individuals residing in their own homes to direct workers who perform health-care tasks (e.g., opening a

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<sup>13</sup> Joint Legislative Audit and Review Committee (JLARC), Quality Assurance of In-Home Care Services, Report 99-2 (Olympia, WA: State of Washington Joint Legislative Audit and Review Committee, 1999).

bottle of medication and taking it, monitoring blood sugar, bladder catheterization, or wound care). The legislation only allows "paid personal aides" or independent providers to perform these tasks; a home care agency aide cannot do these activities. According to most observers, this distinction was not based on a policy rationale but was because the disability community was very organized and lobbied hard for delegation for consumer-directed care, while the home health and home care agencies were not focused on the issue. Disability advocates argue that nursing delegation is hotly contested by physicians and registered nurses "because it cuts into their business and potentially results in their assuming legal liability."

Independent providers must be at least 18 years of age and not the spouse or parent of the client. Other family members are permitted to be providers. They must complete a state-designed training course (see the section on quality of care below). Payment level is \$7.18 per hour as of July 2000. DSHS withholds FICA and Medicare taxes and pays the employer share of these taxes (see the section on cost containment). The state also pays federal and state unemployment taxes, but will not withhold federal income taxes, leaving it to workers to make estimated payments. In addition, independent providers are not eligible for workers compensation because they are considered "domestic servants," who are exempted from coverage in Washington.

Some stakeholders noted that efforts to monitor the number of hours that independent providers actually work are weak. The only person to sign off on the official invoice to DSHS is the independent provider; neither the client nor the case manager is involved. Attendance is verified for independent providers on a sample basis by the AAA case manager.

Independent providers automatically qualify for the Washington Basic Health Plan, the state-sponsored health insurance plan for low-income persons who do not qualify for Medicaid, at a cost of \$10 per month as long as the worker earns at least \$500 a month as an independent provider and has family income below 200 percent of the federal poverty level. Agency workers who provide services to children, older people, and individuals with developmental disabilities are also eligible regardless of family income. In January 2000, home care agencies were given

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<sup>14</sup> Lyle Quasim, "Home Care Quality Improvement: Proposals for Governor Gary Locke," (Olympia, WA: Washington Department of Social and Health Services, 1999).

the option to use state funds to obtain health coverage through alternative plans with benefits that are substantially equivalent to the Basic Health Plan.

Most clients have a choice between agency-directed and consumer-directed care, and the driving force in the expansion of the use of independent providers has been the offering of clients' options. However, a factor shaping consumer-directed home care in Washington is that state policy requires clients who need more than 112 hours of service a month to use an independent provider rather than an agency, except in relatively rare exceptions. While agency hours are capped at 112 hours per month, independent provider services are currently capped at 184 hours a month. Devised principally as a cost containment mechanism, the combination of limits on hours and low hourly payment rates is intended to keep in-home per person expenditures below 90 percent of the average cost of nursing facility care. When the 112 hour limit was first established, less than 100 clients were receiving enough service hours to be affected by the requirement. But, by 1999, over 7,000 clients (about 36 percent of all COPES clients) were authorized for more than 112 hours of service a month. Among clients needing fewer than 112 hours of care a month and having a choice of type of caregiver, about 30 percent chose independent providers in 1998, indicating a substantial amount of consumer willingness to use independent providers.<sup>15</sup>

One consequence of these incentives and policies is that independent provider clients are substantially more disabled and "vulnerable" than agency-directed consumers.<sup>16</sup> In an analysis of state assessment data for 1998, the State of Washington Joint Legislative and Audit Review Committee found that, compared to agency clients, independent provider clients need more hours of help performing activities of daily living, require more hours of cognitive support help, have more authorized service hours, are less likely to self-administer medications, and have a substantial but lower percent of substitute decisionmakers than agency clients. There was also a major difference in living arrangement, with only 26 percent of independent provider clients living alone compared to 66 percent of agency clients. Their analysis found that 20 percent of independent provider clients live alone and are judged "unable to supervise their caregiver" by the case manager. In contrast, state officials estimated that only eight percent of independent

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<sup>15</sup> JLARC, op. cit.

<sup>16</sup> JLARC, op. cit.

provider clients have significant cognitive impairment and no informal support. These clients reportedly receive much more case management as a way of compensating for the lack of informal caregivers.

Although the theory of consumer-direction often emphasizes clients going into the marketplace to find workers, family members play a major role as independent providers in Washington. Originally, the state's rules only allowed non-spousal family members to be independent providers if they met certain low-income and employment guidelines. These restrictions were eliminated in 1995, allowing any non-spousal family member to be an independent provider. A recent AASA survey of all clients assessed during 1998 found that 52 percent of independent providers were family members.<sup>17</sup> Despite the heavy prominence of family caregivers, one stakeholder reported that many younger people with disabilities do not want their informal caregivers to be their paid providers because they want to have more of a business relationship with the worker.

Views of consumer-directed services varied, but this approach to care is firmly entrenched in the Washington system of home and community services. State officials characterized their general philosophy for self-directed care as one of delegation. That is, the aide should be able to do anything the individual would be allowed to do themselves. Advocates for younger people with disabilities see independent providers as "doing the same things that those without disability do—e.g., taking medication, performing bowel care, and feeding oneself." In their view, people with disabilities should be in charge of their own care. Advocates further argued that there should not be an assumption that persons with cognitive impairment cannot direct their own care since they can rely on surrogate decisionmakers.

While disability advocates were strongly supportive of the existing use of consumer direction, there were aspects of the current system that they would change. First, they want services to be available outside of the house to help them work and participate more broadly in the community. Second, some consumers were interested in finding some way of ensuring backup when workers are sick or do not show up.<sup>18</sup> Third, some consumer representatives also supported voluntary consumer training to aid them in their managerial responsibilities. Finally,

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<sup>17</sup> JLARC, op. cit..

another proposed change would be to allow workers to help people with disabilities in parenting their child. Currently, providers are not allowed to do any task that assists the child, including tasks such as cooking or laundry, even when including the child involves roughly the same amount of work.

Home care agency representatives saw some problems with consumer-directed care. While granting that independent providers offer more flexibility, they argued that agencies have become more responsive in the provision of services on holidays and weekends. The problem, they insist, is not in agency policies, but in finding people who are willing to work those times and days. Moreover, in their view, younger people with disabilities are more able to cope with consumer direction; older people are "more tired, more trusting of agencies, and more dependent on families to make decisions." Older people are also more likely to have serious cognitive impairment, which can limit their ability to take on these tasks. A persistent concern of home care agencies, along with other stakeholders, is that COPES clients have a nursing home level of care, but there is very little medical expertise available either on the part of independent providers or case managers.

## **COST CONTAINMENT**

Cost containment is a major concern of the state, and officials believe that they have developed a significantly more cost-effective system of care than exists in most other states. In a study of Washington's long-term care system that compared actual expenditures to an estimate of what they would have been had the state not shifted to home and community-based services, Alecxih, Lutzky, and Corea concluded that the 1994 system cost the state 17 percent less than if the previous, more nursing-home oriented, system was maintained in place.<sup>19</sup> A 1994 General Accounting Office report also identified Washington State as having a cost-effective system of long-term care.<sup>20</sup> The state has shifted much more in the direction of home and community services since these studies were done.

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<sup>18</sup> Project PAS-Port for Change, *We Choose Independence*, (Olympia, WA: PAS-Port for Change, 1999).

<sup>19</sup> Alecxih, Lutzky, and Corea. *op. cit.*

<sup>20</sup> U.S. General Accounting Office, *Medicaid and Long-Term Care: Successful State Efforts to Expand Home Services While Limiting Costs*, (Washington, DC: U.S. Government Printing Office, 1994).

The emphasis on cost containment is, in large part, due to spending and revenue restrictions resulting from ballot initiatives in 1994 and 1999. Passed in 1994, Initiative 601 limits the rate of growth in state expenditures financed from the general fund to the sum of the percentage change in inflation and population growth, roughly about 4.8 percent in 1995-1997 and 4.1 percent in 1997-1999.<sup>21</sup> However, with reduced inflation, the growth rates for 1999-2001 are only a little over three percent. Adding to these constraints, Initiative 695, which passed in 1999, eliminated the state's relatively high motor vehicle excise tax and replaced it with a \$30 yearly fee, reducing state revenues by hundreds of millions of dollars. The ballot initiative also required the state and localities to hold a referendum on any proposed fee or tax increases. While the initiative has been legally challenged and held unconstitutional, state officials have agreed to live within the budgetary restraints that it imposed.

These restrictions, especially Initiative 601, have placed substantial pressure on the state to moderate the overall rate of growth in expenditures. For long-term care, this has meant that expansions of home and community-based services have been financed to a significant extent by constraining nursing home expenditures through limiting bed supply, reducing utilization, and controlling payment rates. In what was viewed as the beginning of a fundamental change in the long-term care system, the legislature and Governor Lowry enacted SHB 2098 in 1993 which promoted expansion of home and community care financed largely by relocating 750 nursing home clients over the 1993-95 biennium. In 1995, the legislature enacted E2SHB 1908, which authorized AASA to limit unnecessary nursing home utilization by systematic diversion and voluntary relocation of clients to home and community settings. The budget was based on reducing Medicaid nursing home residents by 1,600 clients over the 1995-1997 biennium. Prior to these two laws, the nursing home industry was viewed as the dominant force in long-term care in Washington, with very strong links to the legislature.

Medicaid nursing home utilization has dropped in nominal terms from a peak of 17,448 residents in fiscal year 1993 to about 13,789 in fiscal year 2000, despite an increase in the number of older people in the state. In 1995, Washington began an intensive program of case management, which aggressively seeks to relocate nursing facility residents back to their homes.

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<sup>21</sup> Len Nichols, Leighton Ku, Stephen Norton, and Susan Wall, Health Policy for Low-Income People in Washington, *Assessing the New Federalism* (Washington, DC: The Urban Institute, 1997).

As part of that effort, Washington provides a one time "discharge allowance" to help nursing facility residents to find a place to live and set up housekeeping after a stay in a nursing home. Whether the state will be able to continue to reduce nursing home use is very controversial. According to one observer, the option of moving people out of nursing homes is "played out." In the view of this stakeholder, "hospitals already push out lighter care people so that the nursing home residents are more disabled and medically complex. COPES has taken or diverted a lot of lighter care people away from nursing homes. Nursing home use has dropped and they are less likely to have light care people."

For nursing homes, rates of increase in Medicaid payment rates have fallen sharply in recent years. The nursing home industry believes that repeal of the Boren Amendment, which established minimum federal standards for Medicaid nursing home reimbursement rate, was very important because it deprived the industry of the leverage needed to "make the state pay reasonable rates that increase with inflation." According to Washington Health Care Association figures, average increases in Medicaid nursing home rates between 1998 and 2001 have been less than 2.0 percent a year, levels that are below the allowed Initiative 601 expenditure growth rates.<sup>22</sup> Despite complaints about reimbursement levels, average daily Medicaid nursing home payment rates were \$116 in 1998, compared to average national rates of \$96.<sup>23</sup> Repeal of the Boren amendment has resulted in the industry opposing more nursing home beds, since they want to make sure that there are funds to adequately reimburse existing providers before adding additional supply.

In contrast, state officials do not believe that repeal of the Boren amendment has had much of a direct effect on payment rates because of the political power of the industry with the legislature. Payment rates and methods are written in detail into statute by the legislature, so there is little administrative discretion. The 2001-2003 DSHS budget proposes to reduce nursing home rates for non-resident care costs and to provide some increases for expenses more directly related to client needs. The net result of these two changes would be net savings of 1.27 percent on Medicaid nursing home expenditures.

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<sup>22</sup> Washington Health Care Association, "History of Percentage Change of Total Medicaid Weighted Rate Compared to 601 Fiscal Growth Factor," (Olympia, WA: Washington Health Care Association, 1999).

<sup>23</sup> Harrington et al, op. cit.



The Washington certificate of need program has innovative controls on the nursing home supply.<sup>24</sup> For example, Washington includes utilization of home and community-based services in its calculation of whether there is unmet need for nursing home beds. The current bed/population ratio target used for certificate of need decisions is below the existing supply, and in 1999 the legislature set the planning target at 40 beds per 1000 elderly persons. In addition, Washington has a "bed banking" policy that encourages withdrawal of unused beds and also conversion to assisted living. The state maintains a program that allows facilities to bank beds through two mechanisms—one for facilities that are closing and would like to retain or sell the rights to these beds, and one for facilities that would like to bank beds for alternative use (e.g., to convert nursing home beds into assisted living beds). As of 1998, more than seven percent of the state's total nursing home bed complement were "banked," and these beds are counted as available beds in the state's calculation of unmet need.

According to state officials, the legislature has directed DSHS to stay within budget by "any means necessary." Despite the interest in cost containment, this has not resulted in constraints on the number of people served. Unlike many other states, Washington does not have a waiting list for its Medicaid waiver services. Expenditures for home and community-based services are controlled by a variety of mechanisms.

First, the state slightly limits the cost per person in COPES, but concentrates on monitoring overall expenditures. Theoretically, individuals in COPES can receive services that cost up to 90 percent of nursing home costs, but state officials say that they budget at about 40 percent of nursing home costs. Thus, most people receive services that are much less costly. In fiscal year 2000, the average monthly cost of persons receiving COPES home and community services was \$959 compared to about \$2,898 for nursing home care. According to one stakeholder, the dollar cap on the cost of services strongly encourages the use of independent providers because clients can obtain almost twice as many hours for the same expenditure level as they can if they use agencies.

Second, as noted above in the discussion of consumer direction, Washington has attempted to keep down costs and make alternative residential facilities to nursing homes more

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<sup>24</sup> Joshua M. Wiener, David G. Stevenson, and Susan M. Goldenson, "Controlling the Supply of Long-Term Care Providers in Thirteen States," *Journal of Aging and Social Policy*, vol. 10, no. 4, 51-72, 1999.

affordable through use of nurse delegation, which can save money by allowing people who provide personal care or homemaker services to perform certain nursing functions, such as, injecting medication or changing dressings on wounds. Nurse delegation reduces the need for higher-paid skilled nursing staff. State officials are interested in expanding nurse delegation.

Third, also as discussed above, Washington makes very heavy use of low-cost independent providers rather than agencies. Fully 55 percent of COPES clients use independent providers rather than agencies, which cost almost twice as much as do independent providers. Moreover, as noted above, regulations require that clients who need more than 112 hours of service a month must use independent providers rather than agencies. Home care agencies insist that the cost comparisons between the two types of care must be done cautiously because independent providers require a great deal more time and attention by case managers. For independent providers, they argue, the administrative costs are borne by the area agencies on aging.

Finally, Medicaid payment rates were characterized by most stakeholders as low, especially for independent providers. After vigorous lobbying by advocacy groups, the legislature agreed to raise payment rates by \$1.00 per hour in two steps, raising reimbursement levels to \$7.18 an hour as of July 2000. By comparison, home care agencies receive \$12.62 an hour. According to a DSHS report, this increase for independent providers still leaves the payment rate well below the level in Oregon, which was \$7.99 to \$8.21 an hour.<sup>25</sup> Reportedly, individuals can make \$7.50 an hour working in fast food restaurants or \$9.00 an hour plus tips driving vans for parking lots.

Adult family homes, adult residential care and assisted living facilities are reimbursed on a system that varies by geographic area and level of disability. There are three geographic areas—King County (i.e., Seattle), metropolitan counties, and nonmetropolitan counties. Adult family homes have four levels of disability and assisted living facilities have three levels of disability. Adult family home rates in King County vary from \$41.19 to \$72.90 per day, as of July 2000. Assisted living facility rates in King County vary from \$62.74 to \$76.96 per day, as

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<sup>25</sup> Quasim, op. cit.

of July 2000. The goal of tying reimbursement to disability level is to reduce the large number of facilities that receive rates that are calculated as an exception to standard policy.

### QUALITY ASSURANCE

Compared to many other states, Washington has an extensive quality assurance system for home and community-based services, but it also makes much heavier use of independent providers and nonmedical residential services where quality assurance mechanisms are less developed. Quality assurance for home and community-based services is high on the political and policy agenda in Washington, in part because of an extensive series of articles in the *Seattle Times* during December 1999 which alleged extensive abuse of persons with disabilities by long-term care providers.<sup>26</sup> A major theme of the articles was that the existing system does not successfully "weed out" abusive employees and that state officials do not aggressively follow up when problems are uncovered. These allegations of poor quality care have been highlighted by court cases, which resulted in multi-million dollar damage awards against the state.<sup>27</sup> Responding to these articles, the state long-term care ombudsman proposed an "immediate, systemwide 'stop placement' on admissions to boarding homes and adult family homes."

While state officials acknowledged problems with some providers, they generally believe that quality of care is good and that the reported cases are isolated incidents. Moreover, they characterized the *Seattle Times* articles as "old news," dealing with cases that took place before reforms were instituted.<sup>28</sup> They further noted that in 1999 Governor Locke ordered a face-to-

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<sup>26</sup> Eric Nalder, "Suffocation Looked Like Foul Play, But It Took a Month to Tell Policy," *Seattle Times*, December 12, 1999; Kim Barker, "Disabled Women Suffered and Died From Negligence, But It Wasn't a Crime," *Seattle Times*, December 13, 1999; Eric Nalder, "Law Fails to Protect and Fails to Provide Justice for Elderly and Inform," *Seattle Times*, December 14, 1999; Kim Barker, "Felon's Dream Job: Scant Screening, Lots of Easy Marks," *Seattle Times*, December 15, 1999. "Some Who Slipped Through the Cracks," *Seattle Times*, December 15, 1999; Eric Nadler and Kim Barker, "Here's What Needs to be Done so That Abusers Get Caught, Pay for Crimes," *Seattle Times*, December 16, 1999; Eric Nadler, "Niece Played Detective; Got Results," *Seattle Times*, December 16, 1999; Michael R. Fancher, "Quick Action, Doubts Both Follow Times Series on 'Throwaway People,'" *Seattle Times*, December 19, 1999.

<sup>27</sup> In one case, the state agreed to pay \$8.8 million in damages to a disabled woman, Linda David, who was abused by her husband, who was a paid caregiver in the state's Chore program. County prosecutors have charged her husband with a variety of criminal charges, including assaulting his wife. In the Beckman case, a jury awarded \$17.8 million in damages to three disabled men who were molested in a state-licensed boarding home. Because the molester has no financial resources, the state will have to pay virtually all of the damages itself.

<sup>28</sup> See, for example, Kathy Leitch, "Media Statement: Beckman vs. DSHS," Olympia, Washington, March 23, 2000, <http://www.wa.gov/dshs/mediareleases/pr00051.htm>, accessed August 2000.

face review of all high-risk home care situations to ensure that citizens were not at risk, which uncovered only a small number of problems.

Although there is no requirement for training before they start work, all residential facility employees and agency and independent provider home care workers are required to attend a 22 hour training program, pass a written and a hands-on competency test, and participate in 10 hours of continuing education annually. If the worker has already taken the introductory course, then he or she must take a more advanced course. Workers can view videotapes in lieu of actually attending a class, but they must still pass the competency test. In many AAAs, case managers are responsible for seeing that home care workers comply with the state training requirements, and most, but not all, AAAs have some sort of tracking system to ensure worker training.

While agreeing to some required training, consumer advocates reported that "younger people with disabilities feel that the training that is given is often 'wrong' or not the way they want things done. There is a 'one size fits all' approach to training. Training needs to be more flexible and individualized and it needs to involve consumers more." Other advocates argued that people with disabilities worry that formal training can lead to loss of influence and control by the consumer. They contended that training of providers should be designed and conducted by people who use the services and that a problem with the current system is that people with disabilities have not had input into the training program.<sup>29</sup> In addition, they believe that there is too much emphasis on the technical aspects of care rather than on promoting quality of life. One stakeholder said that younger people with disabilities are galled that they have to give up their workers while this training is being done because Medicaid does not pay for training before work actually begins. Reportedly, home care agencies fear that they are training workers who will go to work for higher paying nursing homes.

In addition to receiving training, all long-term care providers, including home care agency and independent provider workers must submit to a criminal background check. However, the investigation is limited to crimes committed in Washington State, except for home care workers. Governor Locke proposed and legislation passed in 2000 that required Federal

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<sup>29</sup> PAS-Port, op. cit.

Bureau of Investigation interstate criminal background checks be conducted on persons who have not lived in the state for three years. A 1999 law requires the establishment of a registry of personal aides who have abused, neglected or exploited persons self-directing their care, and a 2000 law makes specified drug crimes a permanent disqualifier for home care workers. In 1999, the state legislature passed legislation requiring DSHS to conduct a feasibility study of developing and maintaining a registry related to incidents of abuse, neglect, abandonment, and financial exploitation of vulnerable adults in all home and community-based settings.

In 1998, responsibility for licensing of boarding homes—adult residential care homes and assisted living facilities was transferred to DSHS. The system is centrally managed for consistency in regulatory activities. The staff initially emphasizes consultation and technical assistance to prevent care problems, but have available an array of sanctions to ensure compliance. Monitoring visits are unannounced, structured, resident focused, and always include a resident rights interview. There is also a complaint resolution system. The state long-term care ombudsman has characterized training standards for workers in boarding homes that do not have a Medicaid contract as "incredibly weak," requiring only training in CPR and first aid. Current law does not give DSHS authority to deny an adult family home license based on the applicant's lack of ability or expertise to provide care to vulnerable adults. In their 2001-2003 legislative submission, DSHS proposes to require that adult family home providers have successful caregiving experience before obtaining a license or being responsible for providing care through qualified staff. Fire safety has been a concern in some facilities, but each county has its own fire code and enforcement varies by county, making it difficult for the state to impose uniform requirements.

Responsibility for quality assurance of home care services is the responsibility of AASA and the AAAs. In general, AASA monitors the AAAs and the AAAs monitor the direct care providers. In a report on quality assurance in home care, the State of Washington Joint Legislative Audit and Review Committee found that many of the quality assurance activities emphasized administrative requirements, and they called for more "performance and program results monitoring."<sup>30</sup>

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<sup>30</sup> JLARC, op. cit.

AASA conducts annual monitoring of AAAs for administrative and fiscal requirements, develops standardized client assessment tools, conducts the initial assessments and service authorization, designs the mandatory training program, sets the requirement for a criminal background check, establishes client home visit standards for case managers, operates a system for complaints and investigations (including adult protective services), and establishes some program standards for AAAs and their subcontractors.

Examples of quality assurance activities in which AAAs are involved include setting standards for management of client cases files and supervisor reviews of case files, providing nurse oversight and consultation services, performing annual home visits, verifying caregiver training, and helping clients where care needs change, and assisting with worker problems. In addition, they do some client monitoring, review home care agency contracts, and set home visit standards for agency supervisors. Administratively, time sheets are required for all agency workers and independent providers; performance evaluations are required for agency workers; and reviews are conducted matching the client service plan with services received.

All home care agencies are initially licensed by the Washington Department of Health, but annual monitoring is conducted by the AAAs and the results sent to the Department of Health. Licensure requirements are structurally oriented, but, according to home care providers, are less paperwork oriented than in the past. As part of their contracts, requirements set by the AAAs for the home care agencies include standards for how client case file information is maintained, procedures for how billing is handled, a twice-yearly minimum requirement for home care agency supervisor visits to the client, rules regarding timesheet completion by caregivers, and requirements for annual performance evaluation of caregivers. While home care providers report a conscious effort to move to monitoring outcomes, consumer satisfaction surveys are not a routine part of the quality assurance system. The contract for the provision of personal care is a major tool in monitoring and assuring quality of care.

In comparison, the independent provider program has far more limited external oversight and accountability controls, most of which pertain to when an independent provider is initially hired. AASA's policy is that quality oversight is the initial responsibility of the client. Case management and adult protective services are the additional components of quality assurance in the program. As with agency caregivers, independent providers are required to pass a criminal

background check and complete the standard caregiver training. The AAA case manager is responsible for ensuring that these basic quality assurance requirements are met, and for serving as an on-going resource for independent provider clients should they need any assistance with their caregiver. While agency clients receive at least three home visits per year by someone other than the direct provider, independent provider clients are required to receive only one visit for reassessment. According to state officials, however, clients received an average of three visits a year. While noting that some independent provider clients are very capable of supervising and directing their care, the Joint Legislative Audit and Review Committee stated that, "Depending on their needs and level of independence, many clients in this category (needing more than 112 hours of care per month) may be able to adequately supervise their caregiver and self-direct their care. However, this policy may also place other, more vulnerable clients into a care environment with fewer quality controls." In defense of the existing system, advocates for younger people with disabilities argued that there are not any good data on the relationship between additional layers of oversight and quality of care, dismissing much of it as useless paperwork.

A major shortage of long-term care workers, which is linked to the problem of low wages, may affect quality of care. The state's economy is strong and unemployment was 4.8 percent in July 2000, which, while low, was above the national average.<sup>31</sup> As a result of low wages and benefits, recruitment of independent workers is difficult, especially in the Seattle area. Stakeholders in Washington characterized labor shortages for registered nurses, licensed practical nurses, and aides as "very difficult," a "crisis," and "a huge problem," with providers "pulling their hair out" and operating at a "very high level of frustration" because they are "starved for resources." Although defending the system, disability advocates noted that "if clients cannot get a replacement worker, they will put up with a lot."

A key concern of home care agencies and some state officials is that low-paid, unskilled, independent providers, adult family homes, adult residential care, and assisted living facilities are serving extremely disabled clients. In the view of these stakeholders, these providers need access to nurses and others with clinical expertise, which they are not receiving and some do not

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<sup>31</sup> Bureau of Labor Statistics, "News: Regional and State Employment and Unemployment: July 2000," (Washington, DC: U.S. Department of Labor, August 2000).

know enough to know that they should ask for medical help. According to one stakeholder, the state has over emphasized personal care and neglected the medical problems of its clients. He argued that the medical problems of the clients meant that "we are in the health care business and not the social services business. We are serving a vulnerable population with a care plan that is too thin."

## **CHALLENGES FOR THE FUTURE**

Washington has a highly developed system of home and community-based services that provides care to a substantial number of people. It is among the nation's leaders in using consumer-directed care and nonmedical residential services, such as adult family homes and assisted living. Although it used to have significant state-only funded programs, it now relies almost entirely on Medicaid personal care and home and community-based service waivers as the source of financing for its noninstitutional services.

As Washington looks to the future, it faces at least three major issues. First, although the state's economy is in very good financial shape, expenditure limits established by Initiative 601 and revenue limits established by Initiative 695 sharply constrain the state's ability to increase funding for all public services, including home and community-based care. Since 1993, the state has been able to free up funds for noninstitutional services by actually reducing the number of Medicaid nursing home residents in nominal terms and shifting funding to home and community-based services. Indeed, Medicaid nursing home use has fallen even faster than projected in state budget assumptions. However, starting in mid-1999, Medicaid nursing home use began to stabilize and is now running above the level projected in the state budget. In addition, raising the wages of long-term care workers, for which there is considerable political pressure, will raise costs and could ultimately affect the number of people served. Thus, a key question is whether funding for home and community-based services will continue to rise or will it plateau. The impact of the *Olmstead* decision is unclear, although state officials believe that the impact may be principally on services for people with mental retardation or developmental disabilities because home and community services are less well developed for that population.

Second, Washington initially promoted a very strongly social service model of home and community-based services, with a major emphasis on aging in place. As the state's home and community-based services waiver has become the dominant source of financing, publicly-funded



clients increasingly must meet the nursing home level of care, which means that they must be very disabled. This high level of disability may be associated with substantial medical and nursing needs, which may not be adequately addressed in the existing system. Indeed, the state is developing a number of strategies to strengthen the medical component of its system, including allowing more nursing visits and increasing reimbursement for them, changing the comprehensive assessment to identify more nursing needs, having AAAs use nursing staff more flexibly, and exploring various ways of integrating acute and long-term care services. A critical issue for the future will be the balance between medical and social services and how they interact.

Third, the combination of heavy reliance on consumer directed-services and nonmedical residential services with the increasing disability of the client population has raised a number of issues relating to quality of care. Although Washington is one of the few states requiring independent providers to undergo any training and criminal background checks, there is substantial political pressure to increase the quality of care oversight for these and other providers. The tight labor market, especially in the Seattle area, may add to the problems by making a range of long-term care providers and independent provider clients less willing to dismiss unsatisfactory workers because they are uncertain about how quickly they can obtain replacements and whether the new workers will be any better. Disability advocates resist this additional oversight because they fear losing control over their workers and doubt that additional oversight will improve quality of care. The impact of additional quality of care requirements on the large proportion of independent workers who are family members is also unclear. Nonetheless, intensity of press scrutiny and the highly visible involvement of the governor in quality of care issues would seem to guarantee that quality of care will be high on the policy and political agenda.