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# Personal Care Services: A Comparison of Four States

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The Public Policy Institute, formed in 1985, is part of the Public Affairs Group of the AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of interest to older Americans. This paper represents part of that effort.

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## Foreword

As our society ages, growing numbers of people are finding themselves in need of long-term care services. Most have neither anticipated nor planned for these needs. Many are surprised to discover that Medicare covers very little in the way of long-term care, and only under specific circumstances. Family members provide the bulk of care provided in the home today. But as an individual's disabilities become more severe, there is an increasing need for formal home care services – provided through a home care agency or through a public program.

The primary source of public financing for long-term care is the federal-state Medicaid program – a program designed for people who are poor or whose medical and long-term care expenses deplete their incomes and assets. This critical safety net program is required to provide nursing home care in every state. However, in the US today, people have an increasing preference to receive long-term care services in their own homes and communities. While Medicaid does not *require* states to provide such services, currently every state provides at least some home care services through their Medicaid program.

The type of services that people with disabilities need to maximize and maintain their independence is broad and varied. There is a central core of services, however, that most people consider critical. These services are referred to as "personal care services," and generally include help with basic life activities such as eating, bathing, dressing, using the toilet, and transferring (e.g. from a bed to a chair). Related services such as shopping, meal preparation, bill paying, etc., also may be included as personal care services. Because these services are so important to the maintenance of people in their own homes and communities, AARP decided to study the various ways in which several states provide personal care services through Medicaid.

Every state Medicaid program is different. By examining four states in detail, AARP hoped to provide new insights into the various funding streams and program characteristics that these states use in their attempts to provide personal care to older persons with disabilities. It is our hope that other states will find this report helpful as they attempt to refine and improve their own delivery of personal care services.

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## Executive Summary

### Introduction and Background

Older people with disabilities often require "long-term care," a general term used to describe an array of medical or supportive services that help people perform basic life activities. Within this very broad framework of long-term care, there is a set of services referred to as "personal care." This term generally is used to describe "hands-on" or individualized assistance with basic life activities (sometimes called "activities of daily living" or ADLs) such as eating, bathing, dressing, toileting, and transferring (e.g. to or from a bed or chair). Some programs also define personal care as assistance with "instrumental activities of daily living," or IADLs. These IADLs generally include activities such as shopping, preparing food, managing money, using the telephone, and performing housework. Medical care – whether skilled or unskilled – typically is not considered personal care.

Most long-term care in the U.S. is provided informally by family members and friends, but many people pay out-of-pocket for these services, either through a home care agency, or by independently hiring someone to provide assistance. The primary source of public payment for personal care services is Medicaid. One way that states can provide personal care services through Medicaid is by using home and community-based service (HCBS) "waivers." These waiver programs allow states to provide an array of long-term care services to people who meet the state's nursing home eligibility criteria. The other primary way that Medicaid provides personal care is by incorporating a "Personal Care Option" into the state Medicaid plan. This means that any state choosing this option must provide personal care services to all persons who meet the state's eligibility criteria specified for personal care. The eligibility criteria of the Personal Care Option may differ from the state's nursing home eligibility criteria. States may also develop their own separate state-funded programs to provide personal care.

### Purpose and Methodology

The manner in which a state designs its total mix of personal care services will have an impact on who may eligible to receive services, the type and amount of services they receive, and the cost of these services, both to the state and to the individual. For this reason, AARP commissioned a study of the different ways in which states design and deliver personal care services to older people with disabilities. AARP contracted with the National Academy for State Health Policy (NASHP) to provide detailed information on the delivery of publicly-funded personal care services in four states: Arkansas, Indiana, Massachusetts, and Washington. A survey was designed by NASHP and used to collect program information.

### Findings

#### How the Study States Provide Personal Care Services

Arkansas provides personal care through the Medicaid Personal Care Option. Indiana and Massachusetts provide personal care through a Medicaid waiver and a state-funded program. Washington uses all three approaches to provide personal care: Medicaid waiver, Medicaid Personal Care Option, and a limited state-funded program.

Definition of Personal Care

States have wide latitude in defining personal care: it may be limited to activities of daily living (ADLs) or expanded to cover instrumental activities of daily living (IADLs). Definitions of personal care are quite broad in three states (Arkansas, Indiana, and Massachusetts) and focused primarily on "hands-on" activity of daily living tasks in the fourth state (Washington).

Eligibility Criteria

States may decide to offer services broadly or to target services to a particular group of beneficiaries. States vary in the type of functional eligibility criteria they use for providing personal care services, yet all states have at least one program that provides personal care based strictly on ADL needs. For example, Indiana's waiver and state-funded programs both use medical or ADL criteria as the basis for eligibility. Programs in Arkansas, Massachusetts, and Washington use ADL criteria. However, the Massachusetts waiver program requires beneficiaries to also need a skilled service.

Eligibility and Cognition

Often people with cognitive impairments are physically capable of performing ADLs and IADLs but, because of their impairment, need supervision and reminding to complete a task. Unless functional eligibility requirements allow for this level of assistance and the assessment process measures this need, people with cognitive impairments will not be eligible for personal care services. Eligibility criteria in Indiana, Massachusetts and Washington's waiver programs allow people with dementia to qualify for services due to the need for supervision. In Arkansas, the need for supervision due to dementia alone is not considered a basis for an impairment. Dementia does not qualify an applicant for personal care under the Personal Care Option or the state-funded Chore Services Program in Washington.

Personal Care in Residential Settings

All four states provide support for beneficiaries living in residential settings; however, the approaches vary across states. The policies are more explicit in Arkansas and Washington which reimburse for services in residential care facilities (Arkansas) and licensed boarding homes that meet requirements that exceed the licensing rules (Washington). The Massachusetts Medicaid program covers services in subsidized elderly housing and in facilities that could be registered as assisted living residences using a special option under the state plan. Beneficiaries in Indiana may be served in residential settings under the waiver only to the extent they are not licensed, yet are marketed as "assisted living."

Authorization Process

Once a person is found to be eligible to receive services, there is a separate process for authorizing the actual services to be received. Personal care services are authorized by physicians in Arkansas and by single entry point agencies in Indiana, Massachusetts and Washington.

Family Members, Independent Providers, and Other Supports

Historically, home care services are provided by staff that are hired, trained and supervised by home care agencies. However, several states allow beneficiaries to receive services from family members or other individuals who are not employed or supervised by an agency. Arkansas allows reimbursement for adult children of the client or other family members who are not a spouse or guardian. Under waiver and state-funded programs, Indiana and Washington reimburse family members (except a spouse or a parent of minor child) to provide personal care services. In Washington, about 7,000 individuals have received training to provide care and about 50 percent of these providers are family members.

**Conclusions**

Personal care is an essential service that enables people with functional impairments to live in the community. The scope and nature of personal care programs depend, to some extent, on their source. States facing financial pressures are more likely to expand personal care through Medicaid waiver programs than through the Personal Care Option or state-funded programs. Waiver programs give states greater ability to control spending and target services to people who meet the nursing facility level of care criteria. States seeking to find the balance between expanding services and controlling costs may also use the Personal Care Option and set limits on the number of hours of service that can be delivered or use other requirements to target services, such as setting a minimum threshold of need.

State differences among programs covering personal care may be artificial and misleading when focusing on a single service. Each service has to be seen in the context of the state's total long-term care system. Services that may seem narrow and limited when viewed on their own are likely to be part of system that, seen in its totality, covers the same scope of care as a system that adopts a broad personal care service.

That said, the adequacy of the overall system may still leave gaps in coverage from the perspective of a person with disabilities. While the full range of personal care services may be available through the various programs offered in a state, an individual may not be eligible for all the different programs. For example, an individual may meet the *financial* eligibility criteria for waiver services, but not for the Personal Care Option. If this person meets the *functional* eligibility criteria for the Personal Care Option, but not for the waiver program, he or she may be ineligible for services under Medicaid. States should examine the extent to which both their overall systems and individual programs provide adequate personal care services to people with disabilities.

A common theme emerged from each program area in the states reviewed. Policy decisions involve balancing meeting people's needs and allocating resources. The balance involves multiple factors that affect a program: financial and functional eligibility, services, service limits, and the authorization process. Each area can be examined along a continuum from cost control to maximum access. Decisions in one area can be balanced in another. For example, eligibility decisions may be drawn tightly so as to limit the number of people potentially eligible for a service or program. The service package can be designed quite broadly to allow the target population to receive the most flexible and appropriate service to meet their assessed need.

States are very individualized in the scope, structure, organization, and funding of community-based long-term care programs. However, as they examine, refine, and expand delivery systems, states look to one another for best practices and experience. Further efforts are needed to help states report on and disseminate their experience with initiatives that expand the availability of long-term care services. States also need assistance building data systems that will support more detailed research on the impact of these initiatives.

## Introduction

Older people with disabilities often require "long-term care," a general term used to describe an array of services that help people perform basic life activities. The need for long-term care may result from chronic illness, disability, or functional impairment. Within this very broad framework of long-term care, there is a set of services generically referred to as "personal care." While definitions of personal care vary, the term generally is used to describe "hands-on" or individualized assistance with basic life activities (sometimes called "activities of daily living" or ADLs) such as eating, bathing, dressing, toileting, and transferring (e.g. to or from a bed or chair). Some programs also define personal care as assistance with "instrumental activities of daily living," or IADLs. These IADLs generally include activities such as shopping, preparing food, managing money, using the telephone, and performing housework. Medical care – whether skilled or unskilled – typically is not considered personal care. Neither are other long-term care services such as case management, social services, transportation, or home modifications/repairs.

While any long-term care service plan must be designed to meet the specific needs of the individual, many consider personal care services to be the critical centerpiece of an effective system. If a person needs help with basic life activities and does not have access to assistance, it is difficult to remain living at home. Given the premium that most Americans place on maintaining independence and avoiding institutionalization, it is critical that public policies address the need for personal care services for people with disabilities.

## Background

Most long-term care in the U.S. is provided informally by family members and friends. But as one's disability level becomes more severe, families often must turn to formal, or paid, sources of home care. Some 2.3 million adults of all ages live in home and community-based settings and require help with two or more self-care activities (GAO 1999). Some people pay out-of-pocket for these services, either through a home care agency, or by independently hiring someone to provide assistance. Other people turn to public programs for help with personal care. While Medicare provides some personal care services under its home health benefit, it was not designed as a long-term care program. To ensure that Medicare does not *become* a long-term care system, it places restrictions on who can receive home care services and under what conditions. Medicare will provide personal care only to home health beneficiaries who also have a need for skilled care. For persons with very low assets and limited incomes, personal care services may also be provided by state Medicaid programs. In addition, some states use their own funding to provide personal care for people with disabilities.

There are two primary ways that state Medicaid programs provide personal care. It should be noted that both alternatives are optional for states. Medicaid does not require states to provide personal care services. One way that states can provide personal care services through Medicaid is by using home and community-based service (HCBS) "waivers." These waiver programs, authorized under Section 1915(c) of the Social Security Act, allow states to provide an array of long-term care services to people who meet the state's nursing home eligibility criteria. Today, every state uses at least one such waiver program to provide long-term care services to older

people with disabilities.[1] Most of these programs include personal care as a covered service under the waiver. One reason that states use waiver programs is that these programs limit the number of people served and, therefore, the state's expenditures. People who meet waiver eligibility criteria are not automatically entitled to receive these services. In fact, many waiver programs have lengthy waiting lists.

The other primary way that Medicaid provides personal care is by incorporating a "Personal Care Option" into the state Medicaid plan. [See 42 C.F.R. 440.170(f).] This means that any state choosing this option *must* provide personal care services to all persons who meet the eligibility criteria specified for personal care. While Federal law does not *require* states to restrict their spending on the Personal Care Option, states may contain their financial exposure by setting limits on the number of hours of service they will provide. The Personal Care Option's eligibility criteria may differ from the state's nursing home eligibility criteria. This important distinction allows some states to provide personal care services to people who do not meet the state's nursing home eligibility criteria, which often include medical needs as well as functional disabilities. While the functional eligibility criteria of the Personal Care Option may be less restrictive than those of the wavier programs, their financial eligibility criteria may be more restrictive.

In qualifying for Medicaid, most states require individuals to have very few assets (generally no more than $2,000). Individuals also must generally be poor or impoverish themselves as a direct result of their medical and/or long-term care expenses. These very restrictive financial eligibility criteria apply to people who receive personal care services under a state's Medicaid plan. States are allowed (but not required) to permit people with somewhat higher incomes to receive waiver services. These higher income eligibility criteria are consistent with those allowed for nursing home residents. Many states (35) use a "special income rule" that allows waiver beneficiaries to have incomes as high as 300 percent of the Federal Supplemental Security Income (SSI) payment level (Kassner and Shirey 2000). Three hundred percent of SSI is $1,536 in 2000. States may not apply this income standard to beneficiaries who receive personal care benefits under the Personal Care Option.[2]

Another way that Medicaid waiver services may differ from personal care services offered under the Personal Care Option is in terms of "comparability." This term means that any services offered under the Personal Care Option must be available statewide. Such services also must be made available in the same amount, scope, and duration to all beneficiaries who meet eligibility criteria. Waiver services cannot duplicate services already available under the state plan; however, states that limit a state plan service (such as personal care) may cover the same service under a waiver without limits or with different limits. States may also define a service differently under a waiver in a way that supplements what is available under the state plan. In order to control spending, some states limit the number of hours of personal care that may be provided under the Personal Care Option or require beneficiaries to need more than a specified number of hours of care. States that restrict personal care services in their Personal Care Option

[1] Arizona does not use the Section 1915(c) HCBS waiver program used in other states, however, it provides comparable services using a Medicaid 1115 managed care waiver.

[2] For a more detailed discussion of Medicaid financial eligibility, see Kassner, E. & Shirey, L. *Medicaid Financial Eligibility for Older People: State Variations in Access to Home and Community-Based Waiver and Nursing Home Services*, AARP, 2000.

can cover them under an HCBS waiver without limits. Table 1 highlights the different options that states face when deciding whether to provide personal care as a Medicaid state plan service or through a waiver.[3]

**Table 1: Differences Between Personal Care Option and Waiver Programs**

| Issue | Personal Care Option | HCBS Waivers |
|---|---|---|
| Entitlement | Yes; states must provide services to all beneficiaries who qualify for Medicaid | No; states limit spending for waiver services |
| Scope | Must be available in the same amount, scope, and duration to all beneficiaries across the state | May be limited to specific areas or groups of beneficiaries |
| Duplication | Provided in accordance with the state plan | May not duplicate services available in the plan but may contain different limits, definitions, or providers than the state plan |
| Functional criteria | Beneficiaries must meet the requirements to receive the service covered | Must meet the state's nursing home level of care criteria |
| Income | Must be SSI or otherwise eligible for Medicaid | State may set eligibility up to 300% ($1,536) of the Federal SSI payment standard ($512) |

Finally, states may develop their own rules by designing personal care services and funding them entirely with state dollars. States may choose this alternative for a number of reasons. First, they can provide only personal care services, without having to provide (and pay for) other Medicaid services. This factor is significant because, once an individual is found to be eligible for Medicaid (either through the Personal Care Option or through a waiver), the state must also provide an array of services such as doctor visits and hospital care. Second, states may want to design functional and/or financial eligibility criteria that are more generous than those allowed by Medicaid. For example, some state-funded programs serve people who have incomes that exceed 300 percent of SSI. In these cases, the beneficiary generally must pay for a share of the cost of services received. Many state-funded programs avoid linking eligibility for personal care services with nursing home eligibility criteria, as the HCBS waivers require. States also may want to provide different amounts of service – either by providing a more generous service package, or by more strictly limiting services.[4]

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[3] A limited amount of personal care services may be offered under the Medicaid home health benefit, but these services are not addressed in this paper.

[4] For more information on state-funded programs, see Kassner, E. and Williams, L. *Taking Care of Their Own: State-funded Home and Community Based Care Programs for Older Persons*, AARP, 1997.

## Purpose and Methodology

The manner in which a state designs its total mix of personal care services will have an impact on who may be served, the type and amount of services they receive, and the cost of these services, both to the state and to the individual. For this reason, AARP commissioned a study of the different ways in which states design and deliver personal care services to older people with disabilities.

AARP contracted with the National Academy for State Health Policy (NASHP) to provide detailed information on the delivery of personal care services in four states: Arkansas, Indiana, Massachusetts, and Washington. These states were selected because they represented diversity on a number of factors: use of a Medicaid waiver providing personal care; use of the Medicaid Personal Care Option under the state plan; use of state funds to provide personal care; and use of consumer-direction in the delivery of personal care services. These states also provided geographic diversity.

A survey was designed by NASHP and used to collect information on program expenditures, clients served, program regulations, and assessment tools. Telephone calls were made to key contacts in each state to obtain background information and to clarify information. Prior to publication, state contacts were given the opportunity to review the report.

## Findings

This paper presents descriptive information comparing the four study states on a number of variables: definition of personal care; eligibility criteria; coverage of people with cognitive impairments; benefit limits; provision of other supports; provision of personal care in residential settings; the service authorization process; payment of family members and independent providers; and provider qualifications. Policies in each of the four states are described in each section followed by a brief analytic comparison. The terms Personal Care Option or personal care program are used to describe personal care services funded under the Medicaid state plan. Other personal care services discussed in this paper are provided either under a Medicaid HCBS waiver or by a state-funded program.

### How the Study States Provide Personal Care Services

Table 2 illustrates the various ways that the study states offer personal care services. It provides data on expenditures and people served. Arkansas provides personal care through the Medicaid state plan using the Personal Care Option.[5] Indiana and Massachusetts provide personal care through a Medicaid waiver and a state-funded program. Washington uses all three approaches to provide personal care: Medicaid waiver, Personal Care Option, and a limited state-funded program.

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[5] Arkansas also has a very limited state-funded personal care program, but details about the program were not obtained for this paper.

| Table 2: Summary of State Home Care Programs | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Home Care Expenditures** (in millions) | | | | | | | | | |
| | **Arkansas** | **Indiana** | | **Massachusetts** | | | **Washington** | | |
| | **Personal Care Option** | **HCBS waiver** | **State funds** | **Personal Care Option*** | **HCBS waiver** | **State funds** | **Personal Care Option** | **HCBS waiver** | **State funds** |
| 1998 | $59.6 | $12.3 | $31.7 | $6.3 | $5.5 | $134.2 | $64.0 | $92.4 | $7.0 |
| 1999 | $58.6 | NA | NA | $8.6 | NA | $139.9 | $47.0 | $123.8 | $3.7 |
| **Clients Served** | | | | | | | | | |
| | **Arkansas** | **Indiana** | | **Massachusetts** | | | **Washington** | | |
| 1998 | 19,166 | 2,476 | 9,948 | 710 | 3,500 | 38,285 | 8,697 | 9,937 | 1,148 |
| 1999 | 18,800 | NA | NA | 760 | NA | 39,524 | 7,233 | 12,843 | 787 |

* References to the Personal Care Option in Massachusetts do not appear elsewhere in this report. Information about this program's services to people age 65 and older came to our attention only after the paper's initial publication. Table 2 now reflects the number of older clients served and the expenditures for this population.

Definition of Personal Care

States have wide latitude in defining personal care under both state-funded and Medicaid programs. Personal care may be limited to activities of daily living (ADLs) or expanded to cover instrumental activities of daily living (IADLs).

In ***Arkansas'*** personal care program, the definition of personal care focuses on "hands-on" tasks but also covers IADL related activities when they are considered incidental to the hands-on care. The state definition provides that "Personal care aide services involve primarily 'hands-on' assistance, by a personal care aide, with a client's physical dependency needs – eating (including meal preparation), bathing, dressing, personal hygiene, taking medications, laundry, incidental housekeeping and shopping for personal maintenance items. The tasks the aide performs are similar to those that a nurse's aide would normally perform in a hospital or nursing facility." Care plans are individually designed to assist with a client's physical dependency needs related to routines of daily living. The rules also describe other "activities of daily living" that may be covered in limited circumstances – laundry, incidental housekeeping, and shopping for items needed for personal maintenance. Incidental housekeeping covers cleaning the floor and furniture "only in the area of service delivery." Workers are allowed to launder only items that are incidental to the care of the client – not items used by other household members. Workers may shop for items that are "necessary for the client's maintenance in the home" and are "used

primarily by the client" or "by the client and other personal care program clients who reside in the same service delivery location." The rules clarify that services may overlap with those provided by home health aides but may not involve provision of any skilled activities. Personal care may also be provided as part of the Medicaid home health benefit.

Arkansas' personal care definition covers fewer tasks than other states, however, services can be supplemented through the Medicaid waiver for beneficiaries who meet its eligibility criteria, provided the program has space. The waiver covers homemaker services, including tasks dealing with menu planning, meal preparation, laundry, essential shopping and errands and chore services (washing windows, cleaning ceiling fans and light fixtures, cleaning refrigerators and washing inside walls), home delivered meals, adult day care, respite care and a personal emergency device system.

***Indiana*** uses the same definition of personal care in both its state-funded and Medicaid waiver programs. Both programs cover personal assistance and attendant care. Personal assistance is a broad category of care which "provides necessary help to meet daily living needs and to ensure adequate functioning in an independent living arrangement or within the family or alternative family home." The activities cover household maintenance such as cleaning and chore services, attendant care, supervision, reporting changes in the individual's condition and needs, extension of therapy services, ambulation and exercise, and ADL care.

Attendant care services "involve 'hands-on' assistance with physical dependency needs." The definition also includes homemaker activities essential to the client's health care needs to prevent or postpone institutionalization, if they are furnished in addition to other attendant care activities. Activities covered include personal assistance with bathing, oral hygiene, hair care, shaving, intact skin care, dressing, applications of cosmetics, and hand and foot care. Help with mobility, elimination, nutrition, identifying and eliminating safety hazards, medication reminders, escorting to medical appointments, and assistance with correspondence and bill payments are also allowed. Meal planning, preparation and clean up is covered as a nutrition service.

***Massachusetts'*** definition of personal care evolved over time. When the state-funded program was created in the mid-1970s, it covered homemaker services. In the early 1980s, personal care was added as a component of the state-funded homemaker service. In 1996, the Executive Office of Elder Affairs defined the two services separately. It now collects and reports data for each service. Personal care homemaker is defined as "assistance with bathing; dressing; shampoo and hair combing; foot care, excluding nail cutting; denture care; shaving; bedpan routines; eating; ambulation; and transfers." This definition covers assistance with "hands-on" activities. IADLs (laundry, housekeeping, menu planning, meal preparation, shopping, transportation, money management, mobility outside the home, using the telephone, training in home management, and socialization) are covered through the definition of homemaker. These definitions apply to the state's waiver program, as well. Elders needing assistance with both ADL and IADL tasks are served by a personal care/homemaker aide who has appropriate training to assist with both sets of activities.

***Washington*** has separate definitions for each program that covers personal care: the Medicaid HCBS waiver (called COPES), the Personal Care Option, and the state-funded Chore

Services Program. The personal care definition used for the COPES waiver covers both direct personal care services and household assistance activities. Personal care services are defined as both physical assistance and/or prompting and supervising the performance of direct personal care tasks and household assistance tasks listed in the regulations. Direct personal care services means "verbal or physical assistance with tasks involving direct client care which are directly related to the client's handicapping conditions." The list of direct tasks includes ambulation, bathing, body care, dressing, eating, personal hygiene, positioning, self-medication, toileting, and transfer. Household assistance tasks include essential shopping, housework, laundry, meal preparation, travel to medical services, and wood supply (chopping wood). People needing help only with household assistance tasks would not qualify for the program. These tasks can be covered as part of personal care when they are an integral, but subordinate, part of the care provided and it is "directly related to the client's medical or mental health condition," is part of the service plan, and is provided only "when the client is assessed as needing personal care assistance with one or more direct personal care tasks." Services may be provided for clients who are functionally unable to perform all or part of such tasks or who are incapable of performing the tasks without specific instructions. Personal care services do not include assistance with tasks performed by a licensed health professional.

The purpose of personal care under Washington's Personal Care Option is to "enable eligible individuals to remain in community residences through the provision of semi-skilled maintenance or supportive services." The authorizing statute indicates that the program defines personal care in accordance with the federal regulations and the eligible beneficiaries must have a medical condition requiring assistance with personal care tasks.

The state-funded Chore Services Program serves people who are not eligible for Medicaid and who need help with at least one of the following personal care tasks: ambulation; bathing; body care; dressing; eating; personal hygiene; positioning; self-medication; toileting; and transfer.

**Table 3: Personal Care Tasks/Activities Covered**

| Arkansas | Indiana | Massachusetts | Washington (waiver) |
|---|---|---|---|
| Bathing | Applying cosmetics | Ambulation | Ambulation |
| Bowel/bladder care | Bathing | Bathing | Bathing |
| Dressing | Dressing | Dressing | Body care |
| Eating | Elimination | Denture care | Dressing |
| Medication | Hair care | Eating | Eating |
| Mobility/ambulation | Hand/foot care | Foot care | Personal hygiene |
| Oral hygiene | Oral hygiene | Hair care/shampoo | Positioning |
| Personal hygiene | Mobility | Bed pan routines | Self-medication |
| Toileting | Medication reminders | Transfer | Toileting |
| *Shopping* | Nutrition | *Shopping* | Transfer |
| *Incidental housekeeping* | Safety | *Laundry* | *Essential shopping* |
| *Laundry* | Shaving | *Menu planning* | *Housework* |
| | Skin care | *Meal preparation* | *Laundry* |
| | *Correspondence* | *Housekeeping* | *Meal preparation* |
| | *Bill paying* | *Home management* | *Transportation (medical)* |
| | *Cleaning* | *Socialization* | *Wood supply* |
| | *Chore services* | | |
| | *Transportation (medical)* | | |

*Italics indicate tasks covered as an incidental part of personal care services.*

| Table 4: Definitions of Personal Care | | | |
|---|---|---|---|
| **Arkansas** | **Indiana** | **Massachusetts** | **Washington** |
| Broad, covers hands-on assistance and IADLs | Broad, covers hands-on assistance. Same service for waiver and state-funded services | Broad, covers ADLs and IADLs | Separate definition for each program, waiver is broad; Personal Care Option is more medical |

**Summary and Analysis:** Definitions of personal care are quite broad in three states (Arkansas, Indiana, and Massachusetts) and focused primarily on "hands-on" activities of daily living tasks in the fourth state (Washington). The authority of the program, waiver or Personal Care Option, may explain the difference in the scope of the definition. Programs that limit the number of participants and set caps on spending per participant have broad definitions. Coverage under the Personal Care Option, and its entitlement to service, leads to a narrower definition in order to place some controls on spending. However, looking at personal care services alone creates a misleading impression about Arkansas' long term care services. The state may supplement personal care under the Personal Care Option with homemaker and chore services through its Medicaid HCBS waiver. Similarly, in Arkansas and Massachusetts, transportation is covered elsewhere as a separate service while it is listed as a covered activity under personal care in Indiana and Washington.

Definitions for each task need to be reviewed in order to fully understand the scope of personal care tasks and to compare covered tasks among states. For example, Indiana lists hair care, hand/foot care, oral hygiene, shaving, and skin care as separate tasks. Massachusetts also lists tasks separately. However, Arkansas and Washington cover these tasks in their definition of personal hygiene.

Eligibility Criteria

States may decide to offer services broadly or to target services to a particular group of beneficiaries. State-funded programs tend to serve people with higher incomes than Medicaid allows. Functional eligibility criteria for state-funded and Medicaid Personal Care Option services may be more flexible than the criteria for receiving Medicaid waiver services, which are linked to nursing home eligibility.

***Arkansas*** – Beneficiaries in the personal care program must have impairments in two or more ADLs. ***Indiana*** requires a minimum of three medical conditions and/or ADL needs to receive waiver services or two medical conditions and/or ADL needs to receive services from the state-funded CHOICE program. In order to receive Medicaid waiver services, beneficiaries must have an unstable medical condition requiring at least one skilled service or the person must need help with three or more health and ADL needs. The health conditions include recording fluid and solid intake and output, administration of oxygen, passive range of motion exercise, positioning/ turning, or monitoring of a health care plan. The ADLs include eating, transferring, dressing, bathing, managing bowel/bladder functions, and ambulation.

***Massachusetts*** has had flexible income and functional eligibility criteria since the state started funding home care services in the 1970s. Services are provided to people 60 years of age and older who have:

- ADL and IADL impairments that meet specified criteria (see below).
- Critical unmet need (ADLs, meal preparation, shopping, or transportation for medical treatments and home health services).

The Massachusetts regulations measure a person's functional capacity for bathing, dressing, eating, toileting, continence, transferring and mobility. A Functional Impairment Level (FIL) system is used to determine eligibility for service.

**Table 5: Massachusetts Eligibility Criteria**

| Functional Impairment Level | Impairments |
|---|---|
| FIL I | 4-7 ADL impairments |
| FIL II | 2-3 ADL impairments |
| FIL III | 6-10 ADL/IADL impairments |
| FIL IV | 4-5 IADL impairments |

In 2000, only FIL I-III clients with critical unmet needs are being accepted for services. For example, an applicant with impairments in bathing, dressing and mobility living without family members to assist with the ADLs would be able to access services while someone with family supports may not receive services.

The Massachusetts Medicaid waiver program is part of the overall homecare program but has separate functional eligibility criteria. Applicants may apply for home care services and those that are eligible receive waiver services. The programs are seamless for the participant. The functional eligibility criteria for the waiver program include:

- A need for daily skilled nursing care in one of 12 areas or frequent nursing services (a least three days a week); and
- Direct assistance or supervision with two activities of daily living (bathing, dressing, toileting, transfer, mobility/ambulation and eating).

The regulations list eight nursing services, in addition to ADL needs, that qualify a person for waiver services:

- Any physician-ordered services from the list of 12 services;
- Physician-ordered licensed registered nurse observation and/or vital sign monitoring;
- Positioning in a bed or chair;
- Measurement of intake or output based on medical necessity;

- Administration of oral or injectable medications requiring a registered nurse to monitor dosage, frequency or adverse reactions;
- Staff intervention for behavior that is considered dependent or disruptive;
- Physician-ordered occupational, physical or speech/language therapy; and
- Treatments involving prescription medications for uninfected post-operative or chronic conditions or routine changing of dressings that require nursing care and monitoring.

In ***Washington***, eligibility for the COPES Medicaid Waiver program is determined based on a comprehensive assessment that shows whether an individual needs the level of care provided in a nursing facility (or will likely need the level of care within thirty days, unless COPES services are provided). To qualify the person must:

- Require care provided by or under the supervision of a registered nurse or a licensed practical nurse on a daily basis; or
- Have an unmet need requiring substantial or total assistance with at least two or more ADLs: ambulation; bathing; eating; self-medication; toileting; transfer; and positioning; or
- Have an unmet need requiring minimal, substantial, or total assistance in three or more of the ADLs; or
- Have a cognitive impairment and require supervision due to one or more of the following: disorientation; memory impairment; impaired judgment or wandering; and an unmet need requiring substantial or total assistance with one or more ADLs.

Medicaid Personal Care Option and state-funded services in Washington are provided to people who need help with one or more ADL (ambulation, bathing, body care, dressing, eating, personal hygiene, positioning, self-medication, toileting, and transfer). State-funded personal care services have an added requirement that participants must not be eligible for Medicaid.

| Table 6: Washington - Comparison of Eligibility by Program | | | |
|---|---|---|---|
| **Type of Impairment** | **Medicaid Waiver** | **Personal Care Option** | **State-funded Program** |
| **Functional** | Require daily care or supervision of an RN or LPN; or<br>Need substantial or total assistance with 2 or more ADLs; or<br>Need minimal, substantial, or total assistance with 3 or more ADLs. | Need assistance with 1 or more ADL. | Cannot be eligible for Medicaid, Medicare home health services, or personal care under any other program. |
| **Cognitive** | Cognitive impairment and substantial or total assistance with 1 critical self-care task. | Not available based solely on cognitive impairments. | Not available based solely on cognitive impairments. |

| Table 7: Summary of Functional Eligibility Criteria | | | | |
|---|---|---|---|---|
| **Coverage** | **Arkansas** | **Indiana** | **Massachusetts** | **Washington** |
| **Medicaid Waiver** | NA | Requires a combination of 3 or more needs in medical and/or ADL tasks | Requires one skilled service and 2 ADL needs | Requires impairments in 1, 2, or 3 ADLs, based on degree of impairment and presence of a cognitive condition |
| **Medicaid Personal Care Option** | Must have impairments in 2 or more ADLs | NA | NA | Impairment in 1 or more ADLs |
| **State-Funded** | **NA** | Requires a combination of 2 or more needs in medical and/or ADL tasks | Must meet critical unmet needs threshold | Impairment in 1 or more ADL and not eligible for Medicaid |

**Summary and Analysis:** States vary in the type of functional eligibility criteria they use for providing personal care services, yet all states have at least one program that provides personal care based strictly on ADL needs. For example, Indiana's waiver and state-funded programs both use medical or ADL criteria as the basis for eligibility. Arkansas, Massachusetts, and Washington use ADL criteria. However, the Massachusetts waiver program also requires beneficiaries to need a skilled service.

Eligibility and Cognition

Often people with cognitive impairments are physically capable of performing ADLs and IADLs but, because of their impairment, need supervision and reminding to complete a task. Unless functional eligibility requirements allow for this level of assistance and the assessment process measures this need, people with cognitive impairments will not be eligible for personal care services.

***Arkansas'*** personal care program requires a physical basis for eligibility; therefore, people with dementia must also have a physical impairment to be served.

***Indiana's*** assessment instrument for the Medicaid waiver and state-funded programs includes a need for 24 hour supervision and/or direct assistance to maintain safety due to confusion or disorientation that is not related to a mental illness. As a result, some people with cognitive impairments will qualify for personal care services. Confusion resulting from a mental illness qualifies as one of the conditions for participation in the CHOICE program.

***Massachusetts'*** eligibility assessment measures a person's need for physical assistance, supervision or cueing to complete a task. Supervision/verbal cueing means "an individual is able to perform an activity without hands on assistance of another person but must have another person present to supervise and/or remind them to safely complete" the activity.

The assessment instrument in Massachusetts rates the person's ability to perform ADLs from 0-4.[6] People who need supervision or verbal cueing are coded "2." A person is scored as dependent in an ADL if supervision/cueing, limited physical assistance, or extensive physical assistance are needed. Eligibility for services is based on the number and type of ADL and IADL impairments.

The Massachusetts tool also has an extensive section for mental/emotional functioning in order to respond to people with dementia. Assessors use three response options (always, sometimes, never) to record seven areas of cognitive functioning: orientation to time, place, people, recent memory/recall, distant memory, sound judgment, and comprehension. In addition, assessors may also use a ten question mental status questionnaire which asks:

- How old are you?
- What year were you born?
- Probe if there is a discrepancy.

[6] 0 = independent; 1 = independent with difficulty; 2 = supervision/verbal cueing; 3 = limited physical assistance needed; 4 = extensive physical assistance.

- What is your address?
- How long have you lived at this address?
- I'd like you to remember my name - state name.
- What is the name of the President of the US?
- What month is it?
- What year is it?
- Do you remember my name?
- What is it?

Dementia is indicated for individuals who answer four or more questions incorrectly.

***Washington*** – People with only cognitive impairments are not eligible for Personal Care Option or state-funded services. To be eligible for waiver services, applicants with dementia must:

- Have a cognitive impairment and require supervision due to one or more of the following: disorientation; memory impairment; impaired judgment or wandering; and
- Have an unmet care need requiring substantial or total assistance with one or more critical self-care tasks (eating, toileting, ambulation, transfer, positioning, bathing, and self-medication); or
- Have an unmet need requiring minimal, substantial, or total assistance with three or more critical self-care tasks.

Supervision is included as a personal care services task. Supervision is defined as "being available to help the client with personal care tasks that cannot be scheduled, including toileting, ambulation, transfer, positioning, some medication assistance and provide protective supervision to a client who cannot be left alone because of confusion, forgetfulness, or lack of judgment." Applicants with dementia may qualify based on their need for minimal assistance which can include supervision or reminding in the following tasks:

- Bathing: requires oversight help or reminding only.
- Body care: requires oversight help or reminding only or occasional assistance.
- Dressing: may need to be reminded or supervised to do so on some days.
- Eating: can feed self, but needs reminding to maintain adequate intake.
- Housework: Needs assistance, cueing or supervision in self-performance of essential housework one or two times a month.
- Laundry: requires cueing or reminding.
- Personal hygiene: must be reminded or supervised at least some of the time.
- Meal preparation: requires some instruction.
- Self-medication: requires another person to remind, monitor or observe.
- Toileting: may need standby assistance for safety or encouragement.

Applicants meeting the eligibility requirements because they only need supervision in a number of tasks would receive a lower assessment score and, when the score is converted according to the scoring conversion chart, qualify for a lower number of service hours per month. However, the regulations do allow the assessor to approve additional hours for

supervision because of impaired judgment and the need for standby assistance for unscheduled tasks. This provision recognizes that although the need is "minimal" in terms of actual assistance, the frequency and timing of the assistance is not comparable to the service hours needed by a person who needs assistance due to specific physical impairments. Cognitive impairments require additional service hours that cannot be met using measures that rely solely on physical functioning.

**Table 8: Eligibility and Cognition**

| Arkansas | Indiana | Massachusetts | Washington |
|---|---|---|---|
| Must also have physical need for assistance | Covered | Covered | Covered for waiver services but not Personal Care Option or state-funded services |

**<u>Summary and Analysis</u>:** Eligibility criteria that consider persons impaired in an activity if they need cueing or supervision are more likely to serve people in the early to middle stage of Alzheimer's disease or related disorders than criteria that require physical inability to complete a task. Because of the added flexibility available to state-funded programs and Medicaid waiver programs, eligibility criteria in Indiana, Massachusetts and Washington's HCBS waiver allow people with dementia to qualify for services due to the need for supervision. These states give equal weight to cognitive and physical functioning. Washington's standards allow for cognitive supervision combined with physical functioning. They set a lower threshold for physical assistance with self-care tasks when the need for supervision is taken into account. Because of the state plan basis for coverage in Arkansas, dementia alone is not considered a basis for an impairment. Dementia does not qualify an applicant for personal care under the Personal Care Option or the state-funded Chore Services Program in Washington.

<u>Benefit Limits</u>

States often have to balance conflicting objectives: to offer people a flexible menu of services in order to maintain their independence; to avoid costly nursing home admission; and to control long term care spending. Once coverage decisions are made to achieve the first two objectives, benefits may be narrowly targeted or limited in order to control spending.

***Arkansas and Washington*** set limits on the amount of personal care that can be received each month through their state-plan programs. Beginning August 1, 1997, Arkansas limited benefits to 64 hours per month per client. One unit of service equals one hour and providers may bill in increments of 15 minutes. The benefit limit may be exceeded if the request is made by a physician and the increase receives prior authorization approval by the Peer Review Organization. Limits in Washington are based on an assessment score that is converted to hours.

Other types of limits are used in state-funded programs in ***Washington and Massachusetts***. The state-funded Chore Services Program in Washington also has limits that govern access to the program. The state agency sets a monthly spending limit based on the appropriation. When projections exceed expenditures, waiting lists can be established and beneficiaries are served from the list based on a set of priorities which include:

- Priority to individuals receiving services prior to June 1995;
- People who need services to return to the community from a nursing home;
- People who need services to prevent unnecessary nursing home placement; and
- People for whom services are necessary as a protective measure based on referrals from an adult protective services investigation.

Aging Services Access Points (ASAPs) in Massachusetts receive a fixed amount per month for each participant in the program for case management and purchased services. ASAPs receive $91.64 per month per client for case management and $211 per client per month for purchased services. The per capita payments are not fixed service limits and ASAPs have the flexibility to manage spending and balance clients that may need higher amount with those that need lower-cost care plans. The state also uses a peer review process for reviewing assessments and care plans.

***Indiana's*** waiver and state-funded programs do not set individual limits, but care plans are monitored against program caps and plans that exceed expected boundaries are reviewed.

**Table 9: Benefit Limits**

| Arkansas | Indiana | Massachusetts | Washington |
|---|---|---|---|
| 64 hours per month for Personal Care Option services (extensions are available) | No individual cap; care plans are monitored against program caps | Indirectly capped by monthly payment for ASAPs | Varies by provider type: cost cap for independent providers; hour cap for agencies |

**Summary and Analysis:** Spending limits can take a number of forms. Waiver programs generally limit expenditures to a specified amount for each beneficiary. Within the limit, beneficiaries may receive care from a flexible menu of services based on need and beneficiary choice. Limits may also be set based on a flat number of hours of service per month or by establishing a service cap that varies based on the unmet needs of the beneficiary. States may also reimburse single entry point organizations in a way that sets per capita spending targets but gives case managers the flexibility to exceed the cap. In these cases, spending for the total caseload is managed within the aggregate amount of funds available to the agency.

The approach to setting benefit caps is different for agencies delivering only personal care than for agencies authorizing a broader menu of services. A fixed benefit is easier to establish when the only service covered is personal care, typically under the Personal Care Option. A fixed benefit per person, either hours of service or dollar amount, is

easier to manage, however, aggregate budget caps give case management agencies flexibility.

Setting limits also involves fairness. It is more difficult for programs, either Medicaid or state-funded, that offer a menu of services to establish a fixed benefit that is fair. A varied menu means some services will cost more than others. For example, a unit of assisted living (by month), or adult day care (by day), will cost more than a unit of personal care (by hour), or home delivered meals (by meal). Limits have to be flexible enough to allow a person for whom assisted living or adult day care is more appropriate to receive those services. Aggregate budgets based on per capita payment systems to an administering agency allow this flexibility.

The other approach to limits involves access. State-funded and waiver programs operate within fixed appropriations or federal financial participation limits. When enrollment and care plan spending projections exceed the appropriation or federal reimbursement limits, states use waiting lists to manage spending. Washington provides an example of a state that establishes criteria that are intended to prioritize new clients based on their risk and other factors that meet state goals.

Personal Care in Residential Settings

The Omnibus Budget and Reconciliation Act of 1993 gave states the added flexibility to pay for personal care services covered under the Personal Care Option in residential settings such as personal care homes, residential care facilities, and assisted living. Only a few states have used this flexibility (Arkansas, Maine, Missouri, New York, and North Carolina).

***Arkansas*** allows personal care services to be provided in a person's home "or other setting" such as a residential care facility (RCF). The state expanded the service to meet the needs of SSI beneficiaries who were leaving RCFs and entering nursing facilities because the SSI payment was not sufficient to pay for care when residents developed a higher service need. When the program started, RCFs in Arkansas were able to provide personal care at an hourly rate if a physician approved a plan of care and the amount of care needed was less than 64 hours a month. Over time, nearly all facilities were billing the full authorized amount of 64 hours. An audit was conducted that found that facilities did not have the staff capacity to provide each resident 64 hours of care for the number of residents billed to Medicaid.

The state now requires that personal care services be billed in 15 minute increments. It also is developing a per diem rate that will eliminate incentives to over-bill and create a more feasible payment system. About half of the state's 400 licensed RCFs participate in the program.

Clients may sometimes receive services in more than one setting, for example in their home and adult day care. In these instances, the service identifies which tasks are performed in each setting. If different providers are used in each setting, each provider must conduct an assessment and receive physician approval. Clients may be served in their residence, boarding home, residential care facility, group home or community-based residential home. The latter two categories serve people with developmental disabilities. Services cannot be delivered in a hospital, nursing facility, Intermediate Care Facilities for the Mentally Retarded, or Institutions for Mental Disease or to clients who are residents of these institutions in any location.

***Massachusetts and Washington*** also serve people in residential settings. Personal care in residential settings in these states is included as a bundled service. Washington covers assisted living as a Medicaid waiver service. Washington pays assisted living providers based on the level of care needed. Rates are set for three levels of functional capacity. They also vary by region of the state. Personal care is included as part of the operations component.

In Massachusetts, services are not provided under the waiver or the Personal Care Option, but are included as part of the "Group Adult Foster Care" (GAFC) Program, which is covered as a separate optional service under the Medicaid state plan. The Massachusetts Division of Medical Assistance pays a flat rate that includes personal care and other services. The GAFC program provides an average of $33.70 per day for services and administrative costs. To support low income residents who do not have sufficient income to pay for room and board, the state has created and funded a special SSI supplement for people in assisted living residences. The special SSI payment standard is $948 a month for a single individual. The regular community payment standard for an aged person living alone is approximately $620 a month.

In ***Indiana***, beneficiaries may receive Medicaid waiver services only in facilities marketed but not licensed as assisted living facilities. A license is not required if the facility provides housing but all services are arranged between the resident and an outside agency. The state's waiver does not cover services in licensed facilities; however, non-licensed settings are treated like elderly housing buildings.

**Table 10: Personal Care in Residential Settings**

| Arkansas | Indiana | Massachusetts | Washington |
|---|---|---|---|
| Covers services in residential care facilities under the Personal Care Option | Services may be delivered by community agencies to residents in unlicensed facilities under the waiver program | Covers services in a range of residential settings using a special Medicaid state plan option | Covered in residential care and assisted living facilities under the waiver program |

**<u>Summary and Analysis</u>:** Providing services in residential settings can be a cost-effective way for states to offer beneficiaries a full range of long term care choices. Residential settings complement services provided in a person's single family home or apartment. Often residents who live alone and need help at night or on weekends, and do not have family members or friends near enough to help, must enter a nursing facility. Residential settings provide additional options for people who have unscheduled needs. In the past, state licensing regulations often did not allow residential facilities to serve anyone who qualified to be in a nursing facility. Ironically, persons could remain in their own homes and receive a nursing home level of care through home health agencies and family members. In some states, a resident who qualified for placement in a nursing facility might live in a residential setting but services were provided by an outside home health agency. These situations exist in some states today, but many states have broadened their licensing rules to allow residents to age-in-place and to receive a level of care that was

previously only available in a nursing home. Licensing changes now allow residential facilities to offer that level of care.

All four states provide support for beneficiaries living in residential settings; however, the approaches vary across states. The policies are more explicit in Arkansas and Washington which reimburse for services in residential care facilities (Arkansas) and licensed boarding homes that meet requirements that exceed the licensing rules (Washington). The Massachusetts Medicaid program covers services in subsidized elderly housing and in facilities that could be registered as assisted living residences using a special option under their state plan. Beneficiaries in Indiana may be served in residential settings only to the extent they are not licensed, yet are marketed as "assisted living." Coverage in Arkansas is available as a Personal Care Option service while Indiana, and Washington cover care under the Medicaid waiver program.

Authorization Process

Once a person is found to be eligible to receive services, there is a separate process for authorizing the actual services to be received. Systems for authorizing personal care services differ based on the scope of the program. Personal care services are authorized by physicians in Arkansas and single entry point agencies in Indiana, Massachusetts and Washington.

In ***Arkansas***, physicians authorize services as part of a plan of care. The physician determines whether the plan of care is appropriate, and how much personal care is needed, based on an assessment completed by a registered nurse. The physician must have seen the client before authorizing personal care services, unless the physician has seen the person within 60 days. The physician evaluates the relationship between the client's health status, physical dependency needs, and daily routines and activities. Service plans may be authorized for six months and must be re-authorized every six months. Service plans are reviewed if the client's average daily service time varies from the plan's maximum or minimum estimated service time by 10% or more over a period not to exceed 30 days. Service interruptions or variations have to be documented. The need for assistance with each task must be documented in the assessment.

Area Agencies on Aging (AAAs) perform the assessment, eligibility, and authorization functions in ***Indiana*** while in ***Massachusetts***, they are the responsibility of Aging Services Access Points (ASAPs). Responsibilities are split in ***Washington***. State social workers complete the assessment, determine eligibility, and establish an initial care plan. Once the plan of care is established, clients are transferred to AAAs for ongoing case management.

In ***Indiana***, AAAs function as the single entry point and serve people of all ages. Since the Medicaid waiver program covers case management as a service rather than as an administrative cost, participants must have a choice of providers. Indiana offers a choice of the AAA or independent case managers, however, most older participants select the AAA as their case management provider. Services are based on individual care plans, determined through an assessment by a case manager. All available funding sources for needed services in the care plan can be accessed through the coordinated case management system.

Plans of care in ***Washington*** are reviewed by registered nurses in all three programs: COPES Medicaid waiver, Medicaid Personal Care Option and the state-funded Chore Services Program. Registered nurses conduct assessments and reassessments, instruct care providers and clients, coordinate care, and evaluate client health needs. Nursing services are not provided if they duplicate services provided by a registered nurse from another agency.

**Summary and Analysis:** Single entry point agencies are used to assess need and authorize services in Indiana, Massachusetts and Washington. Physicians perform these functions in Arkansas. Single entry point agencies tend to be used when states establish programs that offer a menu of services. The entry agencies allow beneficiaries to select from a number of services and providers based on the assessment, the appropriateness of the service options, and the beneficiary's preferences. These agencies also are designed to reduce fragmentation, simplify access to services, and reduce the number of case managers and assessments an individual receives. Single service programs do not require the same structure.

The assessment, care planning, authorization, and monitoring functions are performed by a single agency in Indiana and Massachusetts and they are split between the state agency and Area Agencies on Aging in Washington. Area Agencies on Aging perform all single entry functions in Indiana and most of the Aging Services Access Points in Massachusetts are also Area Agencies on Aging.

**Table 11: Authorization**

| Arkansas | Indiana | Massachusetts | Washington |
|---|---|---|---|
| Physicians | Single entry: Area Agencies on Aging or an independent case manager | Single entry: Aging Service Access Points | Single entry: State case managers and Area Agencies on Aging |

Family Members, Independent Providers, and Other Supports

Historically, personal care services have been provided by staff that are hired, trained and supervised by home care agencies. However, several states allow beneficiaries to receive services from "independent providers," such as family members or other individuals who are not employed or supervised by an agency. States are able to pay some family members as personal care providers under state-funded programs, the Medicaid Personal Care Option, or under Medicaid waivers. However, Medicaid rules do not allow states to make payments to a beneficiary's spouse or to parents of minor children. Adult children and other family members may be paid. States also have to specify whether they will use the same or different qualification and training requirements for family members. HCFA policy guidelines generally discourage the use of family members as providers of personal care services, except to the extent that other providers are not available or there are special circumstances.

It must be noted that, in all states, the assessment process documents that all other sources of support have been identified and explored before assistance will be provided. "Other sources" include household members, nearby relatives and friends, as well volunteer or paid services provided by public and private community organizations. The assessment documents the reasons why other members of the household cannot provide assistance or can only provide limited assistance. Services are only approved for unmet needs. During the assessment process, income-eligible applicants who have qualifying impairments may meet the financial test. However, services are only authorized if the applicant lacks family members or other supports willing to assist with the critical unmet needs. This requirement can potentially complicate authorizing payment of family members as caregivers.

***Arkansas*** allows reimbursement for adult children of the client or other family members who are not a spouse or guardian. Adult children, brothers or sisters, cousins, or other relatives may provide services if they meet the qualifications for personal care aides. ***Massachusetts*** does not allow the use of independent providers.

Under waiver and state-funded programs, ***Indiana and Washington*** reimburse family members, except a spouse or a parent of minor child, to provide personal care services. Beneficiaries in Indiana and Washington may choose between contracted agencies or independent providers. Independent providers may be family members, friends/neighbors, or individuals. Indiana's payment rate for personal care was $14.70 an hour in 1999 for home health agencies and $9 an hour for non-agency (i.e., independent) providers. Independent providers are enrolled as Medicaid providers and are placed on the vendor list of the AAA. participants who are very frail, with changing health conditions, generally select a home health agency as their provider because supervision is available every two weeks as part of the service. Participants with routine needs are more likely to choose an independent provider and they may receive a higher number of service hours because the cost is lower.

Indiana implemented a pilot program in November 1999 through the CHOICE program to test a "consumer directed" model for delivering personal care. Consumer direction can allow even more flexibility for beneficiaries, sometimes providing cash payments directly to the individuals.

In ***Washington***, about 7,000 individuals have received training to provide care and about 50 percent of these providers are family members. The maximum rate paid to independent providers is $6 an hour, compared to $11 an hour for contracted agencies. The percentage of clients using independent providers in Washington varies by program. In the COPES waiver program, 60 percent of the clients are served by Independent Providers compared to 54 percent for Personal Care Option services and only 19 percent of state–funded Chore Services Program clients.

While clients in Washington make the final decision to hire an independent provider, the traditional system still plays a significant role. Case managers and nurses conduct monitoring visits, determine that the provider is capable and is completing the needed tasks, and mediate resolution of issues or complaints that arise. AAAs help recruit independent providers and monitor completion of the training requirements, initiate the background check, and maintain a list of approved providers. AAAs teach the providers how to complete required paper work.

Providers are also informed about whom they should call when problems or changes in a client's conditions arise. Providers must give two weeks notice before terminating with a client.

Case managers and provider agencies in Washington contend that very frail Medicaid waiver clients have a financial incentive to select an independent provider over an agency worker. Medicaid waiver services operate under a financial cap. A client whose care plan exceeds the expenditure cap may increase the hours of service if he or she selects an independent provider at a lower hourly rate rather than an agency worker. Provider agencies expressed concern that, over time, these incentives will weaken the agency system.

Home care agencies in Washington are concerned that the use of independent providers is driven by cost considerations rather than client choice. Provider agencies contend that some of the costs included in the agency rate are shifted to case management agencies when independent providers are used. Home care agencies provide back up coverage, insurance coverage through the Basic Health Plan[7], training, travel reimbursement, supervision, liability coverage, payment for attending staff meetings, and the costs of hiring personnel for their services. In the independent provider program, some of the home care provider agency costs are present but are hidden, since the case manager and oversight nurse provide some of the supervision and support normally provided by the home care agencies. In addition, independent providers do not receive benefits (health insurance, vacation, sick time). AASA is conducting a study to identify the real costs of both programs and the benefits of any differential costs attributed to contracted agencies. Independent providers may join the Basic Health Plan but they are not subsidized and pay the full premium. Thus, a number of important quality issues have been raised in the use of independently contracted providers. However, research information to address these important questions is not yet available. With the growth in consumer directed care, the experiences in monitoring the quality of these services has considerable policy implications for the states.

**Table 12: Services Provided by Family Members and Individuals**

| Arkansas | Indiana | Massachusetts | Washington |
|---|---|---|---|
| Yes | Yes | No | Yes, major source of providers |

**<u>Summary and Analysis</u>:** A basic tenet of home and community based services is to authorize service plans based on unmet need. Limited funding and a shortage of home care staff require that all programs operate efficiently and effectively to maximize their use. Policy makers are also concerned that publicly funded services not replace the care and support that is provided by family members and friends. As a result, the assessment and care planning process in the study state programs (and elsewhere) identify the applicant's impairment and all sources of support and assistance. Care plans are developed and authorized for the services that are not provided by informal or other formal programs. Resources available through Medicaid and state funds are authorized

[7] The Basic Health Plan is a state operated insurance program that subsidizes coverage for people with incomes below 200% of the federal poverty level.

only when other resources are not available.

Facing funding constraints, labor shortages, and support from consumers to become more involved in managing aspects of their care, states have allowed individuals to provide services to specific consumers without being employed by a provider agency. In addition, states often allow consumers to select, hire, train, manage and replace their independent service provider. The push for consumer direction has been more pronounced in programs serving adults with physical disabilities than in programs serving older adults. However, after 12 months of operation, 69 percent of the participants in Arkansas' consumer-directed care program were 65 years of age or older and 31 percent were 21-64 years of age.

Washington has made extensive use of independent providers to deliver personal care services. Indiana also uses independent providers. Rates of payment are considerably lower for independent providers than for agencies and may allow beneficiaries to receive more hours of care, if the overall cost of the care plan is capped. The availability of independent providers gives beneficiaries more autonomy and flexibility and helps to address labor shortages. However, it may shift, or at least increase, responsibility for supervision and monitoring quality of care from provider agencies to care coordination systems and family members. Independent providers or family members are not reimbursed under the Massachusetts program.

Arkansas is testing a new version of consumer direction that gives beneficiaries a cash allowance to use on services that address personal care needs. The demonstration will evaluate the use of a counseling agency to assist consumers, and evaluate consumer satisfaction with the process. It also will compare the costs of beneficiaries receiving a cash allowance and beneficiaries receiving services from the traditional program.

Provider Requirements

In ***Arkansas*** all provider agencies must meet Medicare home health agency certification requirements. Medicare requires that Registered nurses supervise personal care workers and supervisors be responsible for instructing workers concerning the routines, activities and tasks to perform, the minimum frequency, and the maximum hours per month. The RN reviews the aide's record at least monthly and provides further instruction, as indicated by the review. At least one supervisory visit is required every six months during which the RN observes and documents the condition of the client, the type and quality of service provision, and the interaction between the aide and the client.

Workers must be certified, receive in-service training, and maintain a satisfactory competency evaluation from their supervisors. Trainees must pass a certification examination and demonstrate the ability to perform all tasks required. Training may be conducted by individuals or organizations whose training program has been approved by the state Medicaid agency. A minimum of 40 hours is required, covering classroom instruction (24 hours) and supervised practical training (16 hours). The topics covered include: conduct toward the client; communication skills; understanding spoken and written instructions; record keeping; observing and reporting changes in the client's condition; laws regarding delegation, transfer and ambulation techniques; basic elements of body function and changes in body function that must

be reported to supervisor; range of motion and positioning; household safety and fire prevention; maintaining a clean, safe and healthy environment; and instruction in the safe techniques for providing services to meet personal care activities and tasks. At least 12 hours of in-service training must be received annually.

In ***Indiana***, attendant care workers must be 18 years of age or older, and complete an approved Medicaid training module. The state has developed a 40 hour training curriculum that is available from educational facilities and other organizations around the state. Workers must demonstrate an ability to read and write adequately to complete required activities. Independent providers in Indiana must meet the same training requirements as staff hired by agencies.

In ***Massachusetts***, standardized training requirements for workers are specified in contracts between provider agencies and ASAPs. Workers receive a total of 60 hours of training. Forty hours are dedicated to homemaker tasks and 20 hours to personal care. Curriculum for the training was developed by the Massachusetts Council of Homemaker/Home Health Aide Services in collaboration with the Executive Office of Elder Affairs. The homemaker component includes a three hour orientation session and 37 hours of classroom instruction. The personal care section requires 17 hours of instruction by a registered nurse and a three hour curriculum that includes a competency assessment. Workers must also receive at least six hours of ongoing training a year from supervisors or other professionals. Provider agencies are required to conduct background checks for all direct care workers.

***Washington's*** Medicaid home care contract rules require that agency and independent care providers complete the department's "fundamentals in caregiving" training and complete a minimum of ten hours of continuing education a year. Topics for the training include the role of the caregiver, client's rights, mental and physical conditions, observation and reporting, ensuring a safe environment, common chronic diseases, Alzheimer's disease, infection control and universal precautions, personal care, nutrition, assistance with medications, and caregiver resources. Caregivers must earn a certificate of completion to receive credit for the training.

**Table 13: Provider Requirements**

| Arkansas | Indiana | Massachusetts | Washington |
|---|---|---|---|
| Require 40 hours training and pass exam | Require 40 hours training and demonstrate ability | Require 60 hours training (20 on personal care) with competency exam | Must pass competency exam after completing required curriculum (20 hours) |

**<u>Summary and Analysis</u>:** Training requirements vary among the study states. Each of the states sets a slightly different requirement for the number of hours of training. Washington and Massachusetts have developed their own curricula for the training which can be provided by a variety of organizations, including, in Washington, Area Agencies on Aging.

**Conclusions**

The purpose of the study was to describe and compare the many ways of funding and providing personal care services. Personal care is an essential service that enables people with functional impairments to live in the community. The scope and nature of personal care depends, to some extent, on the source of the program. State-funded programs are more flexible and serve people with incomes that make them ineligible for Medicaid. States may limit expenditures to the amount appropriated and accurately project how much will be spent.

Services based on the Medicaid Personal Care Option serve people on an entitlement basis. They are likely to be narrower in scope to improve control over expenditures. With the advent of Medicaid home and community based services waivers, states sought to combine the flexibility of state-funded programs with the federal matching funds available through Medicaid to expand services. Changes to the Medicaid Personal Care Option in 1993 eliminated the requirement for service authorization by a physician and, importantly, allowed services to be provided in residential settings. These changes brought much of the flexibility of state-funded services and Medicaid waiver services to the Personal Care Option.

Arkansas continues to use physicians to authorize services and serve as gatekeepers since the service is a stand-alone program. But prior to the federal change, elders in residential settings had to move to receive services, unless the state paid the facility a supplement under SSI to continue providing care. Now residents may age-in-place.

The tables after each section highlight the many similarities among programs. Yet states facing financial pressures are more likely to expand personal care through Medicaid waiver programs than through the Personal Care Option or state-funded programs. Waiver programs give states greater ability to control spending and target services to people who meet the nursing facility level of care criteria. States that have set a higher threshold for admission to a nursing facility may be interested in using the Personal Care Option to serve people who have ADL needs that do not meet the nursing facility criteria. States seeking to find the balance between expanding services and controlling costs may use the Personal Care Option and set limits on the number of hours of service that can be delivered or use other requirements to target services such as setting a minimum threshold of need. Finding this balance, however, may make the program more cumbersome to operate, since the goals work at cross purposes.

The study found differences among states in the way they view functional eligibility. However, all states have at least one program that provides personal care based strictly on ADL needs. Cost control may override service goals when programs use restrictive medical or physical criteria to determine eligibility. However, financial controls available for waiver programs allow states to use broader definitions that serve people with a wider range of needs. Washington uses a medically based definition for services under the Medicaid Personal Care Option. Indiana uses the same definition for its state-funded and waiver programs, although the state-funded program requires less stringent functional eligibility criteria.

Allowing people who need supervision and cueing to perform ADLs means more people may be eligible and spending will increase. However, looking at how states provide personal care in isolation from their overall long-term care system may obscure the larger impact on aggregate state spending for long term care services. If, because services are not available for people with

cognitive impairments, people enter a nursing facility, aggregate spending may be higher than if services were available. States generally use this broader perspective when they design their Medicaid waiver programs. By covering people with cognitive impairments who are physically able to perform ADLs, they provide alternatives to nursing home admission. In addition, especially for people with cognitive impairments, states covering services in residential settings provide useful options for people with dementia who do not have family members available to provide support on nights and weekends.

The study also highlights the variations among states in the tasks or activities that are considered part of personal care services. Some states are very explicit in listing the activities while others include a number of specific tasks under a broad heading such as "personal hygiene." States recognize that people with ADL impairments may also need help with IADLs such as housekeeping, shopping, and laundry: these activities are allowed when they are part of the "hands on" tasks performed by a worker for a client.

Perhaps the most important conclusion from the study of personal care services is the need to understand their place in the state's total program. Although states were initially selected for this study because of the characteristics of their programs, it became very clear that differences among programs covering personal care in these four states may be artificial and misleading when focusing only on a single source of delivering these services. Each service has to be seen in the context of the state's total long-term care system. Services that may seem narrow and limited when viewed on their own are likely to be part of system that, seen in its totality, covers the same scope of care as a system that adopts a broad personal care service.

That said, the adequacy of the overall system may still leave gaps in coverage from the perspective of a person with disabilities. While the full range of personal care services may be available through the various programs offered in a state, an individual may not be eligible for all the different programs. For example, an individual may meet the *financial* eligibility criteria for waiver services, but not for the Personal Care Option. If this person meets the *functional* eligibility criteria for the Personal Care Option, but not for the waiver program, he or she may be ineligible for services under Medicaid. States should examine the extent to which both their overall systems and individual programs provide adequate personal care services to people with disabilities.

A common theme emerged from each program area in the states reviewed. Policy decisions involve balancing meeting people's needs and allocating resources. The balance involves multiple factors that affect a program: financial and functional eligibility, services, service limits, and the authorization process. Each area can be examined along a continuum from cost control to maximum access. Decisions in one area can be balanced in another. For example, eligibility decisions may be drawn tightly so as to limit the number of people potentially eligible for a service or program. The service package can be designed quite broadly to allow the target population to receive the most flexible and appropriate service to meet their assessed need. For example, Washington has made a clear choice to focus its Personal Care Option on people with medical conditions who need help with ADLs. Arkansas uses caps on the authorized service level and a limited list of measured ADLs to control spending. In its waiver program, Washington opted to offer a broad range of services in multiple settings to people with fewer ADL impairments due to physical and cognitive conditions.

Policies that shaped these programs could have been driven by concerns about spending however, the waiver programs were cast in the broad framework of the total long term care system in which a more flexible eligibility and service policy can help to reduce occupancy in and spending on nursing homes. The Personal Care Option is less directly linked to a state's total long-term care system and may, therefore, be designed with more limitations.

States are very individualized in the scope, structure, organization, and funding of community-based long-term care programs. However, as they examine, refine, and expand delivery systems, states look to one another for best practices and experience. Much of the information available from states is descriptive, as many face significant limitations in their ability to collect, store, and analyze data on long-term care programs, which often are given low priority when revenues are allocated. Further efforts are needed to help states report on and disseminate their experience with initiatives that expand the availability of long-term care services. States also need assistance building data systems that will support more detailed research on the impact of these initiatives.

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