

# **UNDERSTANDING MEDICAID LONG TERM CARE**

## **A PRIMER FOR ALZHEIMER ADVOCATES**



## INTRODUCTION

Among the most important decisions state officials make which affect the lives of Alzheimer families are decisions about the state's Medicaid program. Medicaid is the single largest private payer for long term care services in the United States. Long term care services accounted for 35% of Medicaid's \$194 billion in expenditures in 2000. It paid for half of total nursing home care (59%) and paid over \$12 billion for home and community based services provided through waivers. (Compiled by ADAPT from data supplied by The MEDSTAT Group, Inc. HCFA 64 data, Office of State Agency Financial Management)

Medicaid is not the ultimate answer to the devastating costs of long term care. It is a last resort for persons who have no other way to pay for the help they need. Medicaid covers the cost of nursing home care for persons who are poor or who "spend down" their resources on long term care, and covers home and community services for low income persons requiring nursing facility levels of care.

Medicaid is the only "safety net" for long term care, and it is likely to remain as such well into the future. States play a central role in the implementation of their long term care programs and the way in which the states define their Medicaid programs will shape the ultimate delivery systems for persons with Alzheimer's disease.

For all of these reasons, advocates interested in preserving and/or expanding long term care for persons with Alzheimer's disease must understand how Medicaid works in their state and where the opportunities for advocacy exist. That is why the Alzheimer's Association has developed this primer. It is a starting point. It does not provide a complete discussion of Medicaid law, nor does it provide specific details about your state's program. You will need to get that information from your state's Medicaid agency and from other Medicaid advocates in your state. (A list of suggested sources of information and potential allies in your state is included in Appendix A.)

### **The Inherent Tensions in Medicaid**

Alzheimer advocates think of Medicaid as a potential source of funding for long term care—to help pay the cost of nursing facility care primarily, but also as a funding stream for home and community based services. To be an effective advocate, however, it is important to understand that these long term care services are only one piece of a much larger program.

Medicaid is very complex. And it is very close to the breaking point in many states—called upon to do too much, for too many people, with too little money. While in theory there are opportunities to expand long term care through Medicaid advocacy, today, advocates in many states find themselves fighting to prevent reductions in the limited long term care now available. As the population needing long term care increases and the pressure to control costs rises, states will be looking for ways to streamline their programs.

The key to understanding Medicaid and to developing effective advocacy strategies is to realize that it is a program of constant tradeoff and tension. Expansion of services or eligibility in one part of the program will create pressure on eligibility and services somewhere else. This is especially true when states face budget crises.

### **Medicaid is a federal/state program**

Medicaid is established by federal law (Title XIX of the Social Security Act) and administered by the states. The federal government matches money the states spend on the program. Federal law and regulations establish certain requirements and guidelines within which each state must structure and operate its Medicaid program. But, states have many options to go beyond these federal minimums, and can also seek waivers from federal requirements to try particular innovations. As a result, each state's Medicaid program is unique. It is possible for a particular service to be covered in one state but not in another, and for a particular person to be eligible for coverage in one state but not in another.

### **Medicaid is designed to cover impoverished people**

Medicaid is a program for poor people and people with high medical costs. Congress established Medicaid to provide a "safety net" for people who had no other way to pay for their health care. In 1996, federal changes to welfare policy determined that Medicaid eligibility is not guaranteed for persons on welfare. States can provide Medicaid to other low income persons at their option, but the cost of the program has forced most states to set eligibility close to the poverty level. The federal government also recognizes that high medical costs—including high long term care costs—will impoverish many people who would not otherwise be poor, and gives states the option to extend Medicaid coverage to people who "spend down" their income and resources on medical care. This is the way many people qualify for Medicaid long term care, especially nursing home care. But this expanded access creates added pressure on limited state budgets. Available funds must be spread further, to a wider range of people.

### **Medicaid covers acute, preventive, and long term care**

Medicaid is the program that pays the hospital and doctor bills for very poor families. It is supposed to pay for preventive health care, particularly for pregnant women and children. And it is the long term care payer of last resort for the frail elderly, persons with mental retardation and those with physical or developmental disabilities. While states ideally should cover all the care needed by eligible persons, practically they cannot do so. Thus, they must piece together a package that equitably covers as many different groups as possible.

### **Medicaid is a combination of mandatory and optional services**

Federal law requires that certain persons be eligible for services in the state and that certain services be covered. These are the Medicaid mandates. But, states may cover additional persons and add services that go beyond the minimums. These are the Medicaid options. Most long term care and services such as prescription drugs, eyeglasses, and dental care is provided at the states' option. Thus, when money is scarce, these services may be the most vulnerable—not because of ill will on the part of the state decision-makers, but because there may be nowhere else to cut.

### **Dual Eligibles**

A group coming to Medicaid's attention is those persons dually eligible for both Medicare and Medicaid benefits. As of 2000, there were approximately 5.4 million dual eligibles. The majority of the 5.4 million qualify for both programs because they either receive Supplemental Security Income benefits or their cost of care relative to income qualifies them as "medically needy."

A small portion are “Qualified Medicare Beneficiaries” (QMBs) or “Specified Low Income Medicare Beneficiaries” (SLMBs). QMBs have incomes below the federal poverty guideline and limited financial assets. Medicaid pays QMBs’ Medicare premiums, copayments, and deductibles. SLMBs have incomes between 100% and 120% of poverty and limited financial assets as well. Medicaid pays SLMBs’ Medicare premiums for physician and outpatient coverage. (See Appendix B for a chart on the number of Dual Eligibles by state.)

As people with Alzheimer’s tend to move back and forth between acute and long term care services, states may see limited value in managing the long term care (Medicaid) portion of the system without regard to the acute care (Medicare) portion. The ultimate solution may lie in the state level integration of both funding streams and services.

### **The Future of Medicaid**

Medicaid is a highly flawed program. States continue to make decisions about Medicaid that, among other things, will affect the amount of long term care assistance available in the state, the nature and number of persons eligible for that assistance, and the type of services that will be reimbursed. The way in which the states provide services under Medicaid will shape the delivery system on which more comprehensive long term care will be built.

## **Understanding Medicaid Long Term Care:**

### **A Primer for Alzheimer Advocates**

**How to use this primer**

This primer is divided into three sections: Financial Eligibility, Other Eligibility, and Long Term Care. In each section, key issues are discussed that affect the availability of Medicaid long term care services for persons with Alzheimer’s disease.

A state can expand or limit Medicaid long term care services for persons with Alzheimer’s disease in many ways. The most important are:

- the limits it sets on financial eligibility,
- the way it defines need for services, and
- the specific services it covers.

In each case, there are certain things that federal law says the state **must** do. But, there are also many things the state **may** do to shape the extent of its Medicaid long term care program. It is in the **may** category where effective Alzheimer advocates in the state can make a difference.

By completing the “checklist” included at the end of the text, you will be able to ascertain the current level of services in your state, and identify those areas where further advocacy is needed. The *Primer’s* appendices will assist you with learning where your state fits relative to others in specific areas of concern, as well as direct you toward persons within your state who could be of further assistance.

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## I. FINANCIAL ELIGIBILITY

Federal law defines a narrow and specific group of very low income people - the "categorically needy" - whom the state **must** include in its Medicaid program. But a state **may** go further and expand financial eligibility to two other groups of people - the "optional categorically needy," and the "medically needy."

**1. Categorically Needy.** Federal law requires that states participating in the Medicaid program cover persons who are receiving certain cash assistance benefits (primarily Temporary Assistance for Needy Families and Supplemental Security Income). These people are considered "categorically needy," and are financially eligible for any mandatory or optional services the state has included in its state plan.

Most categorically needy persons who receive long term care are receiving Supplemental Security Income (SSI) cash payments. SSI is available to certain persons who are aged (over age 65), blind or disabled (as defined by the law) and whose income and resources fall below standards set by the federal government. The SSI income standard in 2002 is \$545 a month for an individual and \$817 a month for a married couple. States may increase this payment level with a "state supplement" amount. The SSI resource standard is \$2,000 for an individual and \$3,000 for a married couple.

(A few states base eligibility on criteria other than SSI because they had more restrictive Medicaid eligibility standards in place when SSI was enacted. These states are known as "**209(b) states.**")

**2. The Optional Categorically Needy.** A state **may** provide long term care services in nursing facilities or private community settings to persons whose gross income (without any deductions) falls under an "income cap" set by the state. A state **may** set this income cap at any point between the monthly SSI standard (\$545 for an individual in 2002) and three times that standard (3 x \$545 or \$1,635). A person whose income falls within this cap must also meet the state's resource standard (see discussion below).

The eligible person must use what income she/he has (less certain allowable deductions discussed below) to pay the cost of nursing facility care. The state pays the balance of the cost.

The income cap is absolute. A person whose income is even 1 dollar above the cutoff cannot get any assistance from Medicaid even though she/he has no other way to pay for care. This is commonly known as the "Medicaid Gap." Thus, in a state that limits eligibility to the "optional categorically needy," no "spend down" is allowed.

**Example:** Jane Doe, a single woman, lives in a nursing home in a state that uses the 300 percent rule (3 x the SSI standard). Her monthly income is \$1,000 and she has very few assets. She is not eligible for SSI because her income is greater than \$545. However, she is eligible for Medicaid under the 300 percent rule because her income is less than \$1,635 and her assets are under the state limit. She pays her \$1,000 (minus a small personal needs allowance) to the nursing home. Medicaid pays the balance of her nursing home costs.

Jon Smythe is also single and lives in the same state as Jane Doe. His monthly income is \$1,700 and he has very few assets. Even though Mr. Smythe cannot pay the nursing home's private rate of \$3,000 a month, he cannot get any help from Medicaid because his income is greater than \$1,635. Mr. Smythe falls into the "Medicaid Gap."

**3. The Medically Needy.** A state **may** include in its Medicaid program persons who have too much income to be eligible for SSI but have high medical bills. They become eligible for Medicaid through what is known as "spend down." A state **may** establish a medically needy program for acute care, for long term care, or for both.

In a "medically needy" program, there is no strict income cap limit. The nursing home resident pays all of her/his income (after certain allowable deductions) to the nursing home. The state pays the rest of the bill (up to the maximum Medicaid payment).

**Example:** Margaret Miller is a widow who lives in a state that has a medically needy program.

Her monthly income is \$1,500 and she has few assets. Her nursing home bill is \$3,000. She pays her income (minus a personal needs allowance) to the nursing home and the state pays the remainder of her bill.

States are permitted, but not required, to cover the elderly under their medically needy programs.

### **Income And Assets**

Once a state has decided what financial eligibility rules it will use, the issue then becomes what counts as income and what counts as assets.

**Income.** Medicaid beneficiaries who live in nursing homes must apply their income to the cost of their care. This includes earned income (e.g., wages, salaries and commissions) and unearned income (e.g., Social Security, pensions, interest on savings, investment income and income from trust funds).

The state must allow three types of deductions from an eligible resident's income:

1. A state **must** allow a resident to keep at least \$30 a month for personal needs ("personal needs allowance"). A state **may** set this personal needs allowance at a level higher than \$30. The personal needs allowance is to be used for such items as clothing, entertainment and other personal needs.
2. A state **must** also deduct from a Medicaid beneficiary's income the amount the individual needs to pay for uncovered medical benefits. This includes funds used for Medicare premiums and cost-sharing charges.
3. A state **must** deduct income under spousal impoverishment rules (*discussed below*).

**Resources (Assets).** In addition to income, a state **must** take into account a person's (or couple's in the case of married applicants) resources or assets when determining Medicaid eligibility. These can be liquid (e.g., money in a bank account) or nonliquid resources (e.g., real estate, whole life insurance or stocks). Most resources are countable for Medicaid purposes. This means they are considered available as liquid or able to be liquidated and used to pay for care.

The state **must** exempt certain resources:

- the applicant's home, if it is his/her principal place of residence,
- a car with a market value of less than \$4,500, and
- a burial space.

If the applicant has a spouse living in the community, a car and household and personal goods of any value are exempt.

### **Spousal Impoverishment**

Medicaid recognizes that married persons are considered legally and financially responsible for each other. When one spouse lives in a nursing facility and the other spouse lives in the community, Medicaid law seeks to avoid complete impoverishment of the community spouse by protecting some funds to meet her/his fundamental living costs. Spousal impoverishment provisions consider income and

resources held by both the institutionalized and community spouse. Spousal impoverishment provisions may also apply to individuals eligible for home and community based care waivers. (*See discussion of home and community based care below.*)

**Consideration of Income.** The state **must** allow the community spouse a certain amount of monthly income. If the community spouse does not have enough income in her/his own name to meet this allowance, then the state **must** allow her/him to keep enough of the income of the nursing home spouse to meet the monthly maintenance needs allowance/spousal impoverishment level in the state. The state **must** set the monthly maintenance needs allowance to at least \$1,451 a month (in 2002). It **may** set the amount higher, up to \$2,232 a month (in 2002).

**Consideration of Resources.** The state **must** allow the community spouse to keep a minimum amount of resources (the resource allowance) which is \$17,856 (in 2002) and it **may** allow them to keep as much as 5 times that amount \$89,280 (in 2002). (The standard is adjusted annually for inflation.) A state must allow additional resources needed to generate income up to the spousal level. (*See Appendix C for a list of spousal impoverishment protections by state.*)

### **Transfer Of Asset Rules**

When a person applies for Medicaid to pay for long term care, federal law **requires** the state to consider recent transfers of assets for less than fair market value. (These "transfer of asset" rules were changed as part of the Omnibus Budget Reconciliation Act passed in August 1993.)

If a person or his or her spouse has transferred assets for less than fair market value in the 36 months prior to applying for Medicaid, or at any time after applying, the applicant may be considered ineligible for a period of time based on the amount transferred and the cost of nursing facility care in that state. In the case of assets transferred to a trust, the "look back period" is 60 months.

The penalty period is determined by dividing the amount transferred by the average monthly private pay cost of nursing home care. The state may use a statewide average or a local average. If, for example, Mr. Jones gave away \$60,000 in January 2001, and the average monthly cost of care is \$3,000, he would be ineligible for Medicaid for 20 months, until September 2002.

Transfer of asset penalties do not apply if an applicant transferred resources to his or her spouse (or disabled or blind child) or if the applicant transferred the home to certain other relatives under limited conditions. If an applicant can show that he or she intended to dispose of the resource for fair market value, that the resource was transferred solely for a reason other than becoming eligible for Medicaid, or if denying eligibility would result in an undue hardship, a penalty period may not be imposed.

Advocates for persons seeking Medicaid have contended that many states do not fairly consider hardship during the eligibility determination process. With changes in federal law enacted in August 1993, the state **must** establish procedures for determining hardship, on the basis of criteria to be established by the Secretary of Health and Human Services.

Transfer of assets provisions are established by federal law and **must** be followed by all participating states.

**NOTE:** The Balanced Budget Act of 1997 made it illegal for lawyers to advise clients on how to

transfer assets in order to become eligible for Medicaid. While the transfer itself is legal, lawyers counseling or assisting in this transfer will be subject to criminal and civil penalties. This provision is likely to be challenged in the courts due to its first amendment implications.

### **Liens On Property And Estate Recovery**

A state **may** put a lien on property of a Medicaid beneficiary in certain limited circumstances. A state can put a lien on a beneficiary's property at any time if a court determines that benefits were improperly paid. If benefits were properly paid, a state **may** place a lien on real property of certain institutionalized beneficiaries whose physicians determine that they are not reasonably likely to return home, but only if the beneficiary's spouse or certain other family members do not live in the house. It **may** also seek recovery from an estate if property on which a lien had been imposed has been sold. A state **may not** force the sale of a recipient's house if the recipient intends to return home.

With the changes in federal law enacted in August 1993, the state **must** seek recovery of Medicaid expenditures from the estate of a deceased individual who was 55 or older when she/he received assistance. In defining the estate for the purposes of recovery, the state **must** include all real and personal property and other assets included within an estate under the state's probate law. The state **may** include other property in which the individual had an interest at the time of death.

## **II. OTHER ELIGIBILITY FACTORS**

Even if an individual meets the state's financial eligibility test, she/he may not necessarily be eligible for long term care. A state also sets certain non-financial criteria that determine whether a person will qualify for Medicaid.

**Need for Care.** Federal law requires that a financially eligible applicant meet the state's definition of need for long term care. A state has considerable flexibility in defining that need. For most long term care services a state provides, the critical issue is how the state defines need for nursing home care. Since nursing homes operate around a medical model of care, this can sometimes work against a person with Alzheimer's disease -- whose care needs may be largely non-medical in nature.

Persons with Alzheimer's disease may be excluded if a state limits nursing home coverage to persons who need "skilled nursing care". Similarly, they may be excluded if the state relies on a test of functional disability that measures only the person's physical ability to perform certain Activities of Daily Living (ADLs) -- bathing, dressing, toileting, transferring and eating. To assure coverage for persons with Alzheimer's disease, state measurements of need must recognize those needs that arise from a cognitive impairment -- e.g. the need for supervision, verbal reminding, and/or physical cueing.

The state's definition of need for nursing facility care will also determine whether a person is eligible for most home and community based services. For services provided under 1915(c) and (d) waivers, the state **must** apply the same need for service requirement it uses for nursing home services. A state **may** apply a different standard for services provided as a state plan option. (See discussion of home and community based services below.)

**Example:** The state of Virginia issued emergency regulations that raised the threshold of

medical need for nursing home care, to limit eligibility to persons who need "daily medical attention" from a licensed nurse or physician, or who showed "clinical evidence" of malnutrition or dehydration. The new rules specified that "functional dependency" would not be sufficient to demonstrate the need for nursing facility care. Persons with dementia who would have been eligible for care under the old rules were being denied eligibility. Alzheimer advocates were successful in persuading the state to revise the new rules to allow coverage for persons with dementia.

**Age or Disability.** A state **must** provide mandatory services to every eligible person. A state **may** limit services provided under waivers and those provided under a frail elderly state plan option to persons of a certain age or disability. Under 1915(d) waivers and the frail elderly option, states **must** limit coverage to persons age 65 and over. (*See discussion below.*)

**Residency or Citizenship.** Federal law limits full Medicaid coverage to U.S. citizens and legal permanent residents in the country as of August 22, 1996. Undocumented immigrants are eligible for emergency services, but states have the option of providing Medicaid to undocumented immigrants if they choose to do so. To receive Medicaid benefits from a particular state, a person must be a resident of that state. States may not impose a minimum residency requirement for purposes of Medicaid eligibility. A person who moves into the state can qualify for benefits immediately. In most states, applicants are not required to establish residence before applying for Medicaid to cover nursing facility services. They can establish residency by moving into nursing homes in those states.

### III. LONG TERM CARE SERVICES

Federal law requires that the state cover certain "mandatory services" for anyone who is determined eligible under the state's rules. Most mandatory services are acute care services (e.g. physician and hospital services, early screening for children, prenatal care). Nursing facility services for persons over age 21 are mandatory services.

A state **may** offer services beyond the mandatory core. These "optional services" then become part of the state plan and must be provided to everyone who is determined eligible. A state has even more flexibility if it applies for a waiver from specific provisions of federal law, to offer some creative or innovative approach to service delivery, eligibility, or reimbursement.

#### Nursing Home Care

A state **must** provide nursing facility care, which includes **a)** skilled nursing care for eligible persons who require medical and nursing care, and **b)** health-related care for eligible persons who need services above the level of room and board that can only be provided in an institution. For Medicaid purposes, federal law has eliminated the distinction between skilled nursing facility (SNF) services and intermediate care facility (ICF) services and refers to both inclusively as "nursing facility" services. This is different from Medicare, which pays only for skilled nursing facility services, and only for a limited number of days following a hospital stay. Thus, while it is very difficult for a person with Alzheimer's to qualify for any nursing facility care under Medicare, many do qualify for care under Medicaid, provided they meet two tests - the state's financial eligibility rules, and its definition of need for care.

Another factor that may influence the availability of Medicaid payments for nursing home care for

persons with Alzheimer's disease is the method the state uses to reimburse nursing facilities for the care they provide. "Case mix" systems reimburse according to a set formula based on diagnosis or health condition of the individual resident. If the state uses a case mix formula that does not fairly measure the type of services (including non-nursing services) that a person with Alzheimer's disease needs, this can result in a lower level of reimbursement, further discouraging nursing facilities from accepting persons with dementia.

Other forms of congregate or residential care such as foster care homes, board and care facilities and assisted living facilities, do not meet the Medicaid definition of nursing facility. A state **may** apply for a waiver to pay for room and board in alternative care settings. A state **may** also pay for services for persons living in such facilities through a home and community care waiver.

### **Home And Community Care**

Under federal law, the state **must** provide home health care as a mandatory service. Home health benefits **must** be provided when necessary to maintain a patient's function or prevent deterioration. Home health care **must** be medical and rehabilitative in nature and (like Medicare home health benefits) generally excludes services for persons with dementia. In fact, federal law expressly states that mandatory home health services are not designed to provide personal care or other non medical support services to persons with chronic illnesses or disorders.

A state **may** cover some home and community-based long term care, either as an optional service or through special waivers.

**1. The Personal Care Option.** A state **may** include personal care services in its state plan. These services **must** be prescribed by a physician according to the beneficiary's plan of care, rendered by someone qualified to provide the service, and, in most states, supervised by a registered nurse. This can be a significant option for persons with Alzheimer's disease, depending upon the way the state defines the service and the type of providers it will reimburse. This varies substantially from state to state.

A state **may** make services available under a personal care state plan option to persons who do not need nursing facility care. However, financial eligibility rules are narrower for the personal care option than for nursing facility care or waiver services. A state **may not** use the "300 percent rule" or apply spousal impoverishment rules for personal care services provided as a state plan option.

**2. Home and Community Care Waivers.** A state **may** submit a formal written application to the federal government to obtain exemption from certain provisions of the Social Security Act. By obtaining waivers, states are able to streamline eligibility, expand coverage to the uninsured, and experiment with managed care delivery systems.

Federal law requires that states must limit these waiver services to persons "at risk of institutionalization". This means the person must meet the state's test of "need" for nursing facility services.

A state **may** set financial eligibility for waiver services at any point up to 300 percent of SSI, **may** provide services to the "medically needy", and **may** apply spousal impoverishment rules. One type of waiver is referred to as a "home and community care" waiver. Home and community

based service (HCBS) waivers, granted under section 1915 (c), enable states to provide a broader range of long term care services for persons who are eligible for nursing home care, but prefer to remain in the community. Services include: case management, homemakers, home health aides, personal care, adult day health, rehabilitation, and respite care. HCBS waiver programs are initially approved for 3 years and may be renewed at 5-year intervals. In 2000, 49 states and the District of Columbia operated over 240 HCBS waiver programs. (*See Appendix D for a list of states with 1915 (c) waiver programs.*) Arizona, runs a 1115 waiver program which is equivalent to the HCBS programs.

**3. Research and Demonstration Waivers.** The second type of waiver that the Health Care Financing Administration approves is the "research and demonstration" waiver. Research and demonstration waivers, granted under section 1115 of the Act, permit broad experimentation in organizing, financing, and delivering health services to low-income populations.

As of March 2002, comprehensive Medicaid 1115 waiver programs were implemented in 20 states. 1115 waivers are increasingly popular because they can be granted for up to 5 years, which gives states freedom to experiment with a comprehensive range of policies including managed care services. States running 1115 waiver programs can forgo most Medicaid state plan requirements, including, statewideness, freedom of choice of provider, income and categorical requirements, the 75-25 rule (HMOs serving Medicaid beneficiaries must have 25% private patients), and the anti-lock-in statute (recipients are not required to remain in programs for a set period of time). The President's 1998 budget proposal includes provisions to allow states to mandate managed care enrollment and eliminate the 75/25 rule without seeking a waiver.

The other type of waiver is the 1915(d) waiver. Unlike 1915(c) waivers, services under a 1915(d) waiver are limited to persons age 65 and older. The state **must** show that their program is budget neutral, i.e. that its total Medicaid spending for home and community care is no higher than what it would have spent on nursing facility services in the absence of a waiver.

**3. The Frail Elderly Option.** In 1990, Congress enacted the "frail elderly option," which was intended to make it easier for states to provide home and community based services without going through the waiver process. A state has substantial discretion to define the services it will provide under the frail elderly option. However, states have been reluctant to use this option because it is a "capped entitlement." This means the amount of federal matching funds a state can receive is limited, which could expose the state to financial risk if the number of persons entitled to services exceeds the state's projections. To reduce the risk, a state **may** limit services to older persons of a certain age, level of disability, or geographic area.

The state **must** limit services under the frail elderly option to individuals age 65 or older who are functionally disabled. To meet the test of functional disability a person must be either: **a)** unable to perform two of three ADLs (toileting, transferring and eating); **b)** an Alzheimer patient (primary or secondary diagnosis) who is unable to perform at least two of five ADLs (bathing, dressing, toileting, transferring and eating) absent any assistance including cuing; or **c)** an Alzheimer patient who needs substantial supervision because she or he engages in behaviors that pose a serious threat to the safety of herself or himself or others.

## A FINAL WORD

Medicaid advocacy can be complicated and difficult. Alzheimer advocates cannot do it alone, but must join forces with others in the state who are interested in improving the delivery of health and long term care services to those in the state who are most vulnerable and least able to pay. There are opportunities for alliances with advocates for persons with other disabilities, and for other health, aging, and family advocacy groups who share the concerns of the Alzheimer's Association -- to provide high quality, appropriate and affordable health care, including long term care, for all Americans in need.

**Advocate's Checklist**

**EXAMINING A STATE'S MEDICAID PROGRAM  
AN ALZHEIMER ADVOCATE'S CHECKLIST**

The state agency responsible for Medicaid in my state  
is: \_\_\_\_\_  
\_\_\_\_\_

The agency responsible for Medicaid funded home and community based care in my state  
is: \_\_\_\_\_  
\_\_\_\_\_

The amount my state spends on Medicaid is: \$\_\_\_\_\_

The amount my state spends on Medicaid long term care is: \$\_\_\_\_\_

The amount my state spends on Medicaid long term care for the elderly is: \$\_\_\_\_\_

**FINANCIAL ELIGIBILITY**

1. My state is a **209 (b)** state: **Y N**  
If yes, eligibility is  
set at \$\_\_\_\_\_

2. My state is an **"income cap"** state: **Y N**  
If yes, eligibility is  
set at  
the maximum  
(300% of  
SSI)\_\_\_\_\_

less than the  
maximum:  
\_\_\_\_\_% of SSI

3. My state has a **"medically  
needy"** program (ie allows  
spend down):

for long term care **Y N**

for some benefits, but not for  
long term care **Y**

long term care

N

Cont. next page

4. The **personal needs allowance** for nursing home residents is:

\$30 a month (the minimum required by law)\_\_\_\_\_

more than the minimum:  
\$\_\_\_\_\_

5. My states **monthly maintenance needs allowance/spousal impoverishment level** is:

\$2,232 (the 2002 maximum)\_\_\_\_\_

less than the maximum:  
\$\_\_\_\_\_

6. My state's **resource allowance** is:

\$89,280 (the 2002 maximum)  
\_\_\_\_\_

less than the maximum: \$\_\_\_\_\_

7. My state has established procedures for determining when consideration of **asset transfers or estate recovery** could create undue hardship:

Y N

8. My state requires **liens** on the property of persons who receive Medicaid:

Y N

9. My state limits **long term care** coverage to persons with strict medical needs (e.g. skilled nursing care):

Y N

Cont. next page

10. My state uses a **test of functional disability** that: a. measures only the person's physical ability to perform certain Activities of Daily Living **Y or N**

b. measures the needs of persons who are cognitively impaired (e.g. need for supervision) **Y or N**

11. My state defines "need for service" for nursing home and home and community care: the same \_\_\_\_\_ in different ways\_\_\_\_\_

12. My state limits long term care services to: a. persons of a certain **age** **Y or N**

b. persons of a certain **level of disability** **Y or N**

### HOME AND COMMUNITY CARE

My state offers personal care services as a state plan option: **Y N**  
If yes, the plan covers persons with dementia \_\_\_\_\_

My state has one or more approved **waivers** for long term care services: **Y N**  
If yes, it provides for the following services\_\_\_\_\_

If yes, the number of people that may

receive services  
is \_\_\_\_\_

If yes, services are available to persons in congregate living arrangements (e.g. board and care, assisted living: **Y or N**

My state defines **eligibility for waiver services** in the following ways:

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My state has added **the frail elderly option** to its plan:

**Y N**  
If yes, it provides the following services:

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These services are limited to:

- a. persons of a certain age **Y or N**
- b. persons of certain level of disability **Y or N**
- c. persons in specific geographic area **Y or N**

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## Appendix A Sources of Information and Potential Allies

### SOURCES OF INFORMATION AND POTENTIAL ALLIES

The following are sources of information about Medicaid in your state. Many are potential allies for

effective Medicaid advocacy.

- **State Officials**

The director of the state agency responsible for Medicaid

The person responsible for administering home and community based services under Medicaid in your state (see Appendix C)

The head of the State Agency on Aging. (In some states this person will be responsible for Medicaid home and community based services)

The person responsible for Alzheimer programs or the Alzheimer’s Disease Task Force (only in some states)

The person in the governor’s office responsible for aging and possibly Alzheimer’s disease issues

- **Advocates**

Long term care ombudsmen (contact through the state Agency on Aging)

Legal services lawyers who represent low income elderly and disabled (check your phone directory for Legal Aid, Legal Services, Legal Counsel for the Elderly, or contact your state bar association for the program in your area)

Organizations representing older persons (e.g. AARP, the Older Women’s League)

Organizations representing persons with other disabilities (e.g. the Arc, the Multiple Sclerosis Society, United Cerebral Palsy, the state Mental Health Association)

- **Provider groups**

Nursing home associations, day care operators, community care providers—may be potential allies on specific issues

## Appendix B Dual Eligibles Population, 2000

Rank	State	#
1	California	821,489
2	New York	387,633
3	Texas	360,810
4	Florida	343,996
5	North Carolina	224,093

6	Pennsylvania	207,353
7	Tennessee	182,942
8	Georgia	176,746
9	Ohio	171,527
10	Illinois	154,892
11	Massachusetts	153,048
12	New Jersey	146,525
13	Michigan	145,582
14	Alabama	137,264
15	Kentucky	117,569
16	Louisiana	117,258
17	Virginia	113,398
18	South Carolina	112,478
19	Mississippi	108,580
20	Washington	97,941
21	Missouri	88,401
22	Indiana	88,031
23	Arkansas	79,640
24	Wisconsin	73,938
25	Oklahoma	67,220
26	Maryland	65,286
27	Minnesota	63,831
28	Oregon	59,405
29	Arizona	57,696
30	Colorado	55,634
31	Connecticut	53,405
32	Iowa	52,060
33	West Virginia	46,338
34	Kansas	41,227
35	New Mexico	37,448
36	Maine	37,056
37	Nebraska	20,573
38	Hawaii	20,197
39	Rhode Island	20,053

<b>Rank</b>	<b>State</b>	<b>#</b>
40	Nevada	19,286
41	Idaho	17,164
42	Utah	16,260
43	District of Columbia	14,242
44	Vermont	13,744
45	South Dakota	13,177
46	Montana	12,833
47	Delaware	11,077
48	Alaska	8,540
49	New Hampshire	7,446
50	Wyoming	6,476
51	North Dakota	5,866

Kaiser Family Foundation, State Health Facts Online

## Appendix C Spousal Impoverishment Protections, 2001

State	Your asset allowance for nursing home/HCBS waiver	Spouse's protected asset allowance	Your personal monthly needs allowance (Nursing home)	Spouse's monthly protected income allowance
Alabama*	\$ 2,000/2,000	\$ 25,000	\$ 30	\$ 1,407
Alaska*	2,000/2,000	87,000	75	2,175
Arizona*	2,000/2,000	17,400	75	2,175
Arkansas*	2,000/2,000	17,400	40	1,407
California	2,000/2,000	87,000	35	2,175
Colorado*	2,000/2,000	87,000	34	1,407
Connecticut	1,600/1,600	17,400	30	1,407
Delaware*	2,000/2,000	25,000	42	1,407
District of Columbia	2,600/ <b>DC-1</b>	87,000	70	2,175
Florida* <b>FL-1</b>	2,000/2,000	87,000	35	1,407
Georgia	2,000/2,000	87,000	30	2,175
Hawaii	2,000/2,000	87,000	30	2,175
Idaho*	2,000/2,000	17,400	30	1,407
Illinois	2,000/2,000	87,000	30	2,175
Indiana	1,500/1,500	17,400	50	1,407
Iowa*	2,000/2,000	24,000	30	2,175
Kansas	2,000/2,000	17,400	30	1,407
Kentucky	2,000/2,000	87,000	40	2,175
Louisiana*	2,000/2,000	87,000	38	2,175
Maine	2,000/2,000	87,000	40	1,407
Maryland	2,500/2,000	17,400	40	1,407
Massachusetts	2,000/2,000	87,000	60	1,407
Michigan	2,000/2,000	17,400	30	1,407
Minnesota	3,000/3,000	24,607	69	1,407
Mississippi*	2,000/2,000	87,000	44	2,175
Missouri	999.99/999.99	17,400	30	1,407
Montana	2,000/2,000	17,400	40	1,407
Nebraska	4,000/4,000	17,400	40	2,175
Nevada*	2,000/2,000	17,400	35	1,407
New Hampshire	2,500/2,500	17,400	40	1,407
New Jersey	2,000/2,000	17,400	35	1,407
New Mexico*	2,000/2,000	31,290	30	1,407
New York	3,750/3,750	74,820	50	2,175
North Carolina	2,000/2,000	17,400	30	1,407
North Dakota	3,000/3,000	87,000	40	2,175
Ohio	1,500/1,500	17,400	40	1,407
Okalahoma*	2,000/2,000	25,000	50	2,175
Oregon*	2,000/2,000	17,400	30	1,407
Pennsylvania	2,400/2,000	17,400	30	1,407
Rhode Island	4,000/4,000	17,400	40	1,407

South Carolina*	2,000/2,000	66,480	30	1,662
South Dakota*	2,000/2,000	20,000	30	1,407
Tennessee	2,000/2,000	17,400	30	1,407
Texas*	2,000/2,000	17,400	30	2,175
Utah	2,000/2,000	17,400	45	1,407
Vermont	2,000/2,000	87,000	45	1,407
Virginia	2,000/2,000	17,400	30	1,407
Washington	2,000/2,000	87,000	41.62	1,407
West Virginia	2,000/2,000	17,400	30	1,407
Wisconsin	2,000/2,000	50,000	40	2,175
Wyoming*	2,000/2,000	87,000	30	2,175

DC-1 At the time of the survey, DC did not have a HCBS waiver for the aged/disabled population

FL-1 Individuals eligible for nursing home care or waiver services under the Medicaid Expansion (MEDS-AD) program, which serves aged and disabled populations with incomes up to 90% of the federal poverty level are able to retain \$5,000 in resources. All other individuals who are eligible for nursing home care or waiver services are able to keep up to \$2,000 in resources.

States with an asterisk (\*) indicate an income cap state. If your income was over \$1,590 per month, you cannot qualify for Medicaid even if all of your assets were spent down to an acceptable level.

*Information compiled from statistics found at [http://www.floridalongtermcare.com/content/medicaid\\_keep.htm](http://www.floridalongtermcare.com/content/medicaid_keep.htm) and [http://research.aarp.org/health/2000\\_06\\_medicaid.pdf](http://research.aarp.org/health/2000_06_medicaid.pdf)*

**Appendix D**

**HOME AND COMMUNITY BASED CARE WAIVERS –1915 (C) 2001**

Waivers Targeting the Elderly and the Aging and Disabled

<b>STATE &amp; TARGET POPULATION</b>	<b>CLIENTS</b>	<b>ADMINISTRATIVE AGENCY</b>	<b>CONTACT NUMBER</b>
<b>Alabama</b>			
Aging and Disabled (A/D)	6,455	Dept. of Public Health	(334) 206-5300
<b>Alaska</b>			
elderly	411	Div. of Senior Services, Dept. of Human Services	(907) 465-3355
<b>Arkansas</b>			
elderly	7,771	Dept. of Human Services	(501) 682-2441
<b>California</b>			
A/D	30	Dept. of Health Services	(916) 445-4171
elderly	8,004	Dept. of Aging	(916) 324-1909
<b>Colorado</b>			
A/D	8,608	Dept. of Health Care Policy and Finance	(303) 866-2993
<b>Connecticut</b>			
elderly	6,500	Dept. of Social Services	(860) 424-5177
elderly	6,526	Dept. of Social Services	(860) 424-5177
<b>Delaware</b>			
A/D	391	Div. of Aging	(302) 453-3820
<b>Florida</b>			
A/D	12,700	Dept. of Elder Affairs	(850) 414-2000
elderly	1,250	Agency for Health Care Administration	(904) 487-2618
elderly (60+)	926	Dept. of Elder Affairs	(850) 414-2000
frail elderly	2,300	Dept. of Elder Affairs	(850) 414-2000
<b>Georgia</b>			
A/D	14,194	Dept. of Medical Assistance	(404) 656-4479
<b>Hawaii</b>			
A/D	133	Dept. of Human Services	(808) 586-5560
A/D	498	Dept. of Human Services	(808) 586-5560
<b>Idaho</b>			
A/D	1,452	Dept. of Health and Welfare	(208) 334-5795
<b>Illinois</b>			
elderly	16,448	Dept. on Aging	(217) 785-3356

<b>STATE &amp; TARGET POPULATION</b>	<b>CLIENTS</b>	<b>ADMINISTRATIVE AGENCY</b>	<b>CONTACT NUMBER</b>
<b>Indiana</b>			
A/D	2,476	Bureau of Aging, In-Home Services	(317) 232-7020
<b>Iowa</b>			
elderly	2,874	Dept of Human Services	(515) 281-5189
<b>Kansas</b>			
frail elderly	5,662	Dept. of Aging	(785) 296-4986
<b>Kentucky</b>			
A/D	10,924	Dept. of Medicaid Services	(502) 564-5564
<b>Maine</b>			
elderly	554	Dept. of Human Services	(207) 624-5518
<b>Maryland</b>			
elderly	85	Dept. of Health and Office on Aging	(410) 767-5220
<b>Massachusetts</b>			
elderly	3,174	Div. Of Medical Assistance and Office of Elder Affairs	(617) 348-5214
<b>Michigan</b>			
A/D	2,000	Office of Services to the Aging	(517) 335-5124
<b>Michigan</b>			
A/D	3,321	Dept. of Community Health	(517) 373-0408
<b>Minnesota</b>			
elderly	6,923	Dept. of Human Services, Health Care Division	(612) 296-5867
<b>Mississippi</b>			
A/D	3,500	Div. Of Aging and Adult Services	(601) 359-6050
<b>Missouri</b>			
elderly	18,946	Dept. of Social Services, Div. Of Aging	(314) 751-3277
<b>Montana</b>			
A/D	1,300	Dept. of Health and Human Services	(406) 444-5622
<b>Nebraska</b>			
A/D	836	Health and Human Services	(402) 471-9345
<b>Nevada</b>			
elderly	65	Dept. of Human Resources, Div. Of Aging Services	(702) 486-3545
elderly	955	Dept. of Human Resources, Div. Of Aging Services	(702) 486-3545

<b>STATE &amp; TARGET POPULATION</b>	<b>CLIENTS</b>	<b>ADMINISTRATIVE AGENCY</b>	<b>CONTACT NUMBER</b>
<b>New Hampshire</b> elderly & chronically ill	1,295	Div. Of Elderly and Adult Services	(603) 271-4680
<b>New Jersey</b> A/D	203	Dept. of Health and Senior Services	(609) 292-7874
A/D	3,827	Dept. of Health and Senior Services	(609) 292-7874
A/D	50	Dept. of Human Services	(609) 292-3717
A/D	156	Dept. of Human Services	(609) 292-3717
A/D	50	Dept. of Human Services	(609) 292-3717
<b>New Mexico</b> Elderly and Disabled	1,650	Dept. of Health	(609) 292-2613
<b>New York</b> A/D	18,848	Dept. of Social Services	(518) 473-5565
<b>North Carolina</b>	9,485	Dept. of Human Resources	(919) 733-3945
<b>New York</b> A/D	18,649	Dept. of Health	(518) 474-7354
<b>North Carolina</b> A/D	8,700	Div. Of Medicaid Assistance	(919) 733-3983
<b>North Dakota</b> A/D	284	Dept. of Human Services	(701) 328-5454
<b>Ohio</b> A/D	4,092	Dept. of Human Services	(614) 466-6650
elderly	19,666	Dept. of Aging	(614) 466-6742
<b>Oklahoma</b> A/D	7,500	Aging Services Division	(405) 530-3476
<b>Oregon</b> A/D	29,119	Senior and Disabled Services Division	(503) 945-6392
<b>Pennsylvania</b> elderly	1,298	Dept. of Aging	(717) 783-1550
<b>Rhode Island</b> A/D	1,704	Dept. of Human Services	(401) 464-3361
Elderly	600	Dept. of Elderly Affairs	(401) 222-2858
<b>South Carolina</b> A/D	9,771	Dept. of Health and Human Services	(803) 898-2500
<b>South Dakota</b> elderly	302	Dept. of Social Services	(605) 773-3656

<b>STATE &amp; TARGET POPULATION</b>	<b>CLIENTS</b>	<b>ADMINISTRATIVE AGENCY</b>	<b>CONTACT NUMBER</b>
<b>Tennessee</b>			
A/D	400	Dept. of Health, Medicaid Bureau	(615) 741-3111
A/D	8	Dept. of Health, Medicaid Bureau	(615) 741-3111
<b>Texas</b>			
A/D	24,045	Dept. of Human Services	(512) 438-3195
<b>Utah</b>			
elderly	542	Dept. of Human Services	(801) 538-6636
<b>Vermont</b>			
A/D	95	Dept. of Aging and Disabilities	(802) 241-2335
A/D	938	Dept. of Aging and Disabilities	(802) 241-2335
<b>Virginia</b>			
A/D	10,885	Medicaid Agency	(804) 786-8099
<b>Washington</b>			
A/D	14,959	Aging And Adult Svcs. Administration	(360) 493-2500
<b>Wyoming</b>			
A/D	973	Dept. of Health, Medicaid Agency	(307) 777-7656

**SOURCE: American Public Human Services Association**

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