State Eligibility Rules and Assessment Instruments: Implications for People with Alzheimer's Disease

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Prepared for the Alzheimer's Association
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The Alzheimer’s Association is the only national voluntary organization dedicated to conquering Alzheimer’s disease through research, and providing education and support to more than 4 million Americans with Alzheimer’s disease and their families.
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Executive summary

The rising number of people with Alzheimer's disease presents significant challenges for family members, caregivers, advocates, public policy makers and service providers. Faced with budgetary pressures and concerns about access to care and continuity of care, states are developing managed care programs for elderly Medicaid beneficiaries, reviewing eligibility policies and fine tuning assessment tools used to measure need for long term care. This study focuses on the development of assessment tools and eligibility criteria and explores the implications of these developments for people with Alzheimer's disease and related disorders. The study examined three areas: Medicaid spending patterns, case studies based on activities in two states and the assessment instruments used in selected states.

The Alzheimer's Association identified initiatives in the state of Maine and in the City of Baltimore, Maryland that highlight the issues that concern advocates and policy makers. The state of Maine has revised its nursing home level of care criteria and the City of Baltimore has embarked on a pilot project to develop an assessment tool that facilitates care planning and coordination. We invited representatives from the Maine Bureau of Elder and Adult Services and the Baltimore City Commission on Aging and Retirement Education to discuss the initiatives. Representatives from the Alzheimer's Association chapters in Maine and Maryland and the Baltimore Mental Health System also attended the meeting to represent the perspective of individuals with Alzheimer's Disease. This report is based primarily on the discussion, a review of materials provided by each participant and a review of the assessment instrument used in selected states.

Findings

The experience in Maine and Maryland produced several key lessons for policy makers:

- Assessment instruments used to measure need, develop care plans and determine eligibility should generate the information needed to appropriately serve people with Alzheimer's disease and related disorders.

- Setting program eligibility criteria that assume or require use of lower levels of care requires:
  1. Funding for a full range of residential, community and in-home services;
  2. Availability of providers who are willing and able to participate in the programs.

- Eligibility criteria should recognize the need for supervision and cuing to perform an ADL as an impairment. Physical abilities alone do not accurately represent the care
needs of people with Alzheimer's Disease.

- People who need supervision and cuing may require more staff time than people needing direct physical assistance.

- Eligibility criteria should recognize the importance of behavior and cognitive capacity.

- Staffing patterns in facilities providing long term care services must be appropriate to meet the needs of people with Alzheimer's Disease.

- Staff responsible for assessment, authorization and care plan development and staff in facilities and agencies serving people with Alzheimer's disease should receive "dementia capable" training.

- Participation in Medicaid Home and Community Based Waiver Services programs is dependent on eligibility for admission to a nursing home. Changes in the nursing home level of care criteria affect eligibility for services that provide an alternative to nursing homes.

A number of approaches to identify the needs of people with Alzheimer's disease were extracted from a review of studies of assessment tools. The major components include:

- Using supervision and cuing to indicate an impairment.

- Assessing behaviors which are characteristic of people with Alzheimer's disease that require monitoring or intervention.

- Obtaining information about mental status and memory.

- Assessing the status of caregivers to understand the stresses and capacity to continue to provide care and to identify the need for supportive intervention that may extend the caregiver's ability to continue in this role.

Maine's experience highlights several key implications for people with Alzheimer's disease as policies that modify eligibility criteria are designed and implemented:

- Time pressures created by the need to generate budget savings limits public comment periods and time for informing the public, consumers and providers about pending changes. This particularly affects people who are very vulnerable such as people with Alzheimer's disease.

- Educating providers is a critical factor in implementing change since they are likely to have direct contact with family members and explain the new policy before other
sources of information are received.

- Time pressures also affect the development of appropriate alternatives to serve people, especially people with Alzheimer's disease, who will no longer be eligible for nursing home care. Expansion of appropriate community and residential capacity requires both funding and time to implement which may result in funding parallel capacity for a period of time.

- Adequate education is important to avoid misinformation. Some nursing home staff may not have informed family members of the range of community options and instead only communicated the change in policy and the need to find another placement. (Note: As a result of this experience, social workers in nursing homes now function more as discharge planners than they did in the past.)

- Tools that do not count the need for supervision and cuing as the basis for ADL impairments exclude people with Alzheimer's disease, thereby reducing available service options.

**Background**

Family members, advocates, state legislators and executive branch agencies struggle to address the challenges of meeting the needs of people with Alzheimer's disease and related disorders. A progressive, degenerative disorder resulting in impaired memory, thinking and behavior, Alzheimer's disease is the third most expensive disease.\(^1\) The initial symptoms of the disease include a gradual loss of memory, reduced ability to perform activities of daily living (eating, bathing, dressing, toileting, mobility) and instrumental activities of daily living (meal preparation, shopping, housework, managing money, using the telephone, mobility outside the home), disorientation, loss of language ability, impaired judgement and changes in personality.

Over 4 million Americans suffer from Alzheimer's disease or a related dementia including 10% of the population over 65 years of age and 50% of those over 85 years of age. Almost 75% of the care provided to people with Alzheimer's disease is delivered by family members and half the people residing in nursing home and assisted living facilities have the disease. Since Medicaid pays for about 60% of all nursing home spending, the disease poses significant financial challenges for states.

The needs of people with Alzheimer's disease differ significantly from others with functional impairments. People with Alzheimer's disease often retain their physical capacity but require extensive supervision and reminding to perform daily tasks. Often they cannot be left unattended because they are at risk of wandering away with no ability to return home on their

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own. Group residential facilities without secure perimeters, safe outdoor areas for walking and interior "wandering paths" must increase staffing patterns to accommodate the tendencies of people with Alzheimer's disease to leave the building. Loss of impulse control can lead to behavior which is intrusive or offensive to people nearby. The prevalence of nineteen behaviors were identified in the Medicare Alzheimer's Disease Demonstration, a study of 6,000 elderly people with Alzheimer’s disease or related dementias: forget current day, lose/misplace things, asks repetitive questions, has trouble recognizing people, leaves tasks uncompleted, is suspicious/accusative, hides things, relives the past, wakes the caregiver at night, is constantly restless, has unreasonable anger, has hallucination/delusions, is embarrassing to the caregiver, constantly talkative, wanders/gets lost, combative, danger to self, danger to others, and destroys property.\(^2\) Alzheimer's disease require almost constant care and cannot be left alone safely, regardless of whether they live with family members or in a residential or nursing facility, and require more direct attention than might cognitively intact residents with health conditions or physical impairments.

As it progresses, people with Alzheimer's disease have difficulty sleeping and interrupt the sleep patterns of caregivers. Many people with Alzheimer's disease are admitted to nursing facilities if they do not have a spouse or other family member to provide care, or when caregivers become ill or can no longer provide the 24 hour care required. Although assisted living as a residential long term care model is expanding, this option is either not available or is too costly for many people with Alzheimer's Disease. When available and affordable, it can offer many an appropriate alternative to admission to a nursing facility.

**Approach**

The dynamic patterns of state finances and long term care policy have generated concern among advocates about the impact of these changes on people with Alzheimer's disease. This paper reviews the state budget implications of long term care spending, examines the key role of assessment instrument and eligibility criteria, discusses initiatives in Maine and Maryland and reviews the assessment instruments of selected states.

**State budget and policy context**

Family members and state policy makers have common goals for serving people with Alzheimer's disease - that is, to provide the most cost effective and appropriate amount of care in the most appropriate setting. However, the enormous demand and the cost of care create strains between family members and advocates seeking adequate access for those who need support and state officials who are concerned about balancing need with available revenue. Too often, states have limited resources and have not appropriated sufficient funds to meet the growing need. As a

result, despite the availability of well established programs and services, many people with Alzheimer's disease cannot be served through public programs. The conflicts intensify as states seek ways of reducing spending or limiting the growth of state spending for long term care.

Since the early 1980s, states have developed and expanded community based services through general revenues and Medicaid waivers to serve more people in their own homes and communities. Eligibility for Medicaid home and community based services waiver programs is linked to eligibility for admission to a nursing facility. To be served in the Medicaid waiver, participants must be Medicaid eligible and meet the level of care criteria to enter a nursing home. As a result, any changes in the criteria for entering a nursing home mean that people with Alzheimer's disease who no longer qualify for admission to a nursing home cannot be served through the Medicaid waiver programs.

State experience indicates that people with Alzheimer's disease can be served at home and by assisted living facilities or other residential facilities during the early to mid, and sometimes later, stages of the disease. Many states have implemented respite care programs to support family caregivers and recent state initiatives have expanded access to assisted living for people with Alzheimer's Disease. In 1996, twenty two states either covered or planned to cover assisted living as a Medicaid service.3 Some states are examining the needs of people with Alzheimer's disease in assisted living and the state of California has developed specific guidelines for facilities concerning egress devices on exterior doors and perimeter fence gates as well as resident supervision devices such as wrist bracelets.

**Medicaid spending**

As budgetary pressures have forced states to examine spending patterns and priorities, advocates and policy makers have been concerned about the impact of changes on vulnerable populations, especially people with Alzheimer's disease and related disorders. State Medicaid programs have been a major focus of efforts to control spending. Because Medicaid accounts, on average, for nearly 19% of state budgets, it has been a frequent focus of efforts to reduce state spending. States have approached cost reductions through changes in four areas: eligibility, financing, the scope of covered services and the organization of the delivery system.

In fiscal year 1994, long term care expenditures comprised 35.8% of all Medicaid

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3 Robert Mollica and Kimberly Snow. "Assisted Living State Policy: 1996." National Academy for State Health Policy. The study was supported by a contact from the US Department of Health and Human Services, the Office of the Assistant Secretary for Planning and Evaluation, contract number HHSH-100-94-0024. Additional funding for the project was provided by the Administration on Aging, the National Institute on Aging and the Alzheimer's Association.
spending, yet they comprised 76.5% of all Medicaid spending for aged beneficiaries. Spending on elderly beneficiaries totalled $9,437 per capita while blind and disabled beneficiaries accounted for $8,421 per beneficiary.

<table>
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<th>Medicaid Spending by Category, FY 1994</th>
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<tr>
<td><strong>Elderly</strong></td>
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<tr>
<td>Total spending</td>
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<tr>
<td>All long term care</td>
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<td>Nursing home</td>
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Of the total amount spent on elderly beneficiaries, $7,230 or 77%, was spent on long term care. However, spending varied widely among eligibility categories. Elderly beneficiaries who received cash assistance (SSI) cost $5,002 a year of which $2,612 was spent on long term care while medically needy (spend down) beneficiaries cost $12,534 a year of which $9,353 was spent for care in nursing homes. Elderly medically needy beneficiaries spend more on long term care than any other group of beneficiaries. Long term care is, therefore, a major focus of cost control strategies.

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<th>Spending per elderly by category</th>
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<tr>
<td><strong>Elderly cash assistance</strong></td>
</tr>
<tr>
<td>Total spending</td>
</tr>
<tr>
<td>Long term care</td>
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<tr>
<td>Nursing home</td>
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State policy makers have developed differential strategies to control Medicaid spending. By 1996, 48 states had implemented delivery system changes through managed care programs for AFDC and related categories of beneficiaries. Managed care programs have been more difficult to design for elderly beneficiaries since the vast majority of beneficiaries are also eligible for Medicare. Conflicts between Medicaid and Medicare have posed challenges for states, however, Medicaid managed care programs are being implemented in Arizona, Minnesota, Oregon and Wisconsin while programs have been proposed or are being designed in many other states. Twenty six states have designed Medicaid risk based programs for aged, blind

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and disabled beneficiaries. Only Arizona, Minnesota and Wisconsin have included long term care as part of a capitated benefit through managed care organizations.

As many states explore managed care options, other strategies to control long term care spending have received attention. Nearly every state has implemented Home and Community Based Waiver Services programs for elders to provide community rather than institutional care. Services generally covered under 1915(c) waiver for the elderly include personal care, respite care, assisted living, homemaker, home health, adult day care, home delivered meals, and transportation. Moratoriums on constructing new nursing home beds, bed "buy back" programs, expansion of home and community based waiver programs, and the addition of assisted living as a covered Medicaid service have been adopted.

To control spending, several states have revised their assessment instrument used to determine the need and eligibility for long term care services and others have modified the eligibility threshold for accessing services. The following sections describe the key role of assessment and eligibility criteria for long term care programs.

Assessment and eligibility studies

States use health and functional criteria to determine eligibility for nursing facility and home and community based services waiver services. The information collected on assessment tools and manner in which the information is reflected in program eligibility rules has a significant impact on the participation rates of people with Alzheimer's disease. Criteria must not only address need, but the conditions which trigger need. Setting thresholds based on a person's functional ability to perform ADLs has serious implications for people with Alzheimer's disease. A study by Kane, et.al. found dramatic differences depending on whether a person who needed cuing or supervision to perform ADLs was considered impaired. Using a sample of nursing home and home care clients from Oregon, the study examined the impact of using two or three ADL impairments as the threshold for eligibility with and without counting the need for cuing and/or supervision as the basis of the impairment. Counting cuing/supervision doubles the proportion of people who would be found eligible using either two or three ADLs as the threshold. While using cuing and supervision is far more sensitive to identifying people with Alzheimer's disease, the expanded eligibility may pose problems for policy makers. The study found that using a threshold of two ADLs without supervision incorporated 66% of the people with a clear diagnosis of dementia who wandered while using a three ADL threshold and including


6 Robert L. Kane, MD, Michael G. Saslow, PhD, and Thomas Brundage, MA. Using ADLs to Establish Eligibility for Long Term Care Among the Cognitively Impaired. The Gerontologist. Volume 31, Number 1. 1991.
supervision covered 85% of the same group. Applying the same criteria to a group that was identified as "probably demented" covered 52% using two ADLs without supervision and 69% with supervision.

On the other hand, using a two ADL threshold, 66% of people who wandered without counting supervision would be covered as demented while 93% of those who wandered counting supervision would be covered. The study also calculated the percentage of people identified who needed assistance at night, made behavior demands, and posed a danger to self or others.

Data from the Medicare Alzheimer’s Disease Demonstration Program\(^7\) also highlights the importance of considering cognitive and behavioral factors. Based on data from treatment and control groups for two separate models, the interim report shows that 44% of the people with Alzheimer's disease had difficulty with bathing for cognitive reasons and 46.3% were impaired for cognitive and physical reasons. Physical capacity alone accounted for only 9.7% of the people who were impaired. Physical capacity accounted for only 8% of the people with impairments in dressing while 50% had a cognitive basis for the impairment and 42% had a combination of cognitive and physical reasons.

The need for supervision is also a critical factor in understanding people with Alzheimer’s disease. The Interim Report from the Medicare Alzheimer’s Disease Demonstration shows that 24.6% of the sample needed minimal supervision, 18.3% needed daytime supervision and 57.1% required supervision 24 hours a day.

The Interim Report found a high incidence of nineteen types of problem behaviors among people with Alzheimer's disease. Over 92% of the sample forget what day it is and 75% regularly lose or misplace things (see Table).

Once cognitive and behavioral factors are used to determine whether a person has an impairment in a particular tasks, setting the threshold for program eligibility plays a crucial role in determining who can be served. A forthcoming analysis based on data from the Medicare Alzheimer’s Disease Demonstration\(^8\) suggests that about two-thirds of the sample would be included if eligibility was based on two of five ADLs and about one-half would be covered if the threshold was three of five ADLs. Using behavioral factors apart from ADL impairments in determining eligibility would extend coverage to people who may not have two or three ADL impairments yet need supervision and oversight for their behaviors.

\(^7\) Robert Newcomer, Ph.D., Patrick Fox, Ph.D., et. al., Ibid.

\(^8\) Conversation with Katie Maslow, Alzheimer's Disease and Related Disorders Association.
<table>
<thead>
<tr>
<th>Behavior</th>
<th>%</th>
<th>Behavior</th>
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<tbody>
<tr>
<td>Forget current day</td>
<td>92.7</td>
<td>Unreasonable anger</td>
<td>45.8</td>
</tr>
<tr>
<td>Lose, misplace things</td>
<td>74.9</td>
<td>Hallucinations/illusions</td>
<td>42.9</td>
</tr>
<tr>
<td>Asks repetitive questions</td>
<td>67.4</td>
<td>Embarrassing to caregiver</td>
<td>38.7</td>
</tr>
<tr>
<td>Trouble recognizing people</td>
<td>57.7</td>
<td>Constantly talkative</td>
<td>27.6</td>
</tr>
<tr>
<td>Leaves tasks uncompleted</td>
<td>53.7</td>
<td>Wanders/gets lost</td>
<td>26.8</td>
</tr>
<tr>
<td>Suspicious, accusative</td>
<td>50.8</td>
<td>Combative</td>
<td>25.5</td>
</tr>
<tr>
<td>Hides things</td>
<td>47.0</td>
<td>Danger to self</td>
<td>19.4</td>
</tr>
<tr>
<td>Relives past</td>
<td>47.8</td>
<td>Danger to others</td>
<td>9.8</td>
</tr>
<tr>
<td>Wakes caregiver at night</td>
<td>46.2</td>
<td>Destroys property</td>
<td>9.6</td>
</tr>
<tr>
<td>Constantly restless</td>
<td>46.0</td>
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Eligibility rules

States use assessment tools to evaluate need and eligibility for three primary programs: nursing home admission; Medicaid Home and Community Based Waiver service programs; and in home service programs financed through state general revenues, the Older Americans Act, Social Services Block Grant and sometimes county or local sources. Many states use a standard assessment instrument to collect information for multiple programs and funding sources. Once collected, the information is measured against varying criteria depending upon the type of service and the source of financing being considered.

States approach setting eligibility thresholds for nursing home admission differently. A 50 state study by Snow\(^9\) found that states use one of three approaches to establish nursing home eligibility: medical necessity only, medical/functional criteria and comprehensive criteria. The comprehensive criteria consider cognitive impairment, behavioral factors and social factors in addition to medical and functional factors. Two states use what would be characterized as medical only factors, 25 states use a combination of medical and functional factors and 24 states (including the District of Columbia) use comprehensive factors.

\(^9\) Newcomer and Fox, ibid.

A study conducted by O'Keeffe for AARP\textsuperscript{11} found that some states set restrictive criteria for nursing home admission in order to control spending. Since Medicaid Waiver eligibility for home and community based services is contingent on meeting the nursing home level of care criteria, people in states with strict criteria will have higher care needs which may be too expensive to serve in the community. Other states set looser criteria in order to serve more people in the community and reserve nursing home beds for people who cannot be appropriately served in other settings. The O'Keeffe study highlighted the variety of approaches taken by states to assess need and to set eligibility criteria. The study organized state criteria according to medical conditions and nursing needs; physical impairments; and cognitive, emotional/mental impairments. Half of the 42 responding states use behavior problems as a factor in setting level of care criteria. A review of the assessment tools and eligibility criteria submitted by 42 states showed consensus on the use of ADLs though there was wide variation in the number, definition, and measurement of ADLs.

Six states in the O'Keeffe study used a scoring system to establish eligibility thresholds while 19 states used a minimum number of impairments and 17 states used a combination of definitions and guidelines to establish eligibility.

Of the 19 states requiring a minimum number of impairments for admission to nursing homes, 16 count cognitive impairments, 11 consider behavior problems and supervision needs and four consider psychological or emotional problems. Five of the six states that use a scoring system include cognitive impairment while four allow behavior problems and supervision and three consider psychological or emotional problems.\textsuperscript{12}

Case studies

Maine - revising eligibility criteria

The state of Maine has a long history of support for home and community based services. However, during the recession of the early 1990s, as in states across the nation, funding for community services was difficult to secure. Advocates indicated that nursing homes were reluctant to accept people with Alzheimer's disease because their staff were not properly trained and providers claimed that the care needed exceeded the level of reimbursement available from Medicaid. In 1993, about 800 "heavy care" beneficiaries in hospitals were awaiting a nursing home placement. Development of a case mix reimbursement system created an incentive for nursing homes to admit residents with more intense needs and, once implemented.


\textsuperscript{12} O'Keeffe. Ibid.
Budget savings through eligibility revisions

In 1993 Maine faced a projected $1 billion deficit in its biennial budget fueled, in part, by a doubling of spending for long term care over a five year period. One of the governor's proposals to reduce the deficit would have eliminated the Medicaid medically needy category for people with incomes above 100% of the federal poverty level which would have affected between 6000 and 8000 nursing home residents. Instead, a compromise plan (L.D. 418) sought to save $7 million a year in Medicaid spending by diverting people from nursing homes to residential and in-home services. Funds would be shifted from institutions to expand other options. Achieving savings while expanding capacity proved a challenge. In order to realize savings, state officials revised the eligibility criteria for beneficiaries seeking admission to a nursing home to make it more difficult to qualify. Additional changes restructured the organization of the community care delivery system, and tightened estate recovery procedures.

Prior to the 1993 initiative, eligibility for nursing home admission was described as loose and fairly subjective, although a standardized assessment tool was used, although interpretations of the guidelines varied across the state. Because of a nursing facility case mix demonstration project, Medicaid agency officials had two years of Minimum Data Set (MDS+) data to develop the new criteria and to estimate the eligibility and financial impact of the new criteria. The revised assessment tool, MED 94, was implemented in January 1994.

MED 94 was based primarily on functional abilities in ADLs and how much support was required to complete the ADL. It required that applicants must have a medical condition requiring extensive nursing care or treatment; require extensive or total assistance with three of five ADLs or have memory or behavior problems that required RN intervention at least three times a week and limited physical assistance with ADLS. Information concerning the need for supervision and cuing for performing ADLs was recorded but not counted as an impairment for the purposes of entering a nursing facility.

Impact on people with Alzheimer's disease

Under MED 94, cognitive and behavioral problems qualified a person to enter a nursing facility only if professional nursing assessment, observation and management was required at least three days a week. Advocates believed that the tool did not adequately measure behaviors that represented health or safety risks which left many people with Alzheimer's disease who needed a structured environment ineligible for Medicaid reimbursement in nursing facilities. Because eligibility for HCBS services is tied to nursing home eligibility, waived services would not be available. MDS+ data showed that 17% of the existing nursing home residents had cognitive/behavior losses and many were no longer eligible under the new rules. An attempt was

made to grandfather existing residents but the request was not approved by the US Health Care Financing Administration because federal rules require that the criteria for current and future residents must be the same. MED 94 criteria allowed persons with late stage Alzheimer's disease to enter a nursing facility and people with the early and mid-stage symptoms were referred to community and residential alternatives.

Coordinating the expansion of alternative services with implementation of new nursing facility level of care criteria has proven to be complex and challenging. Home and community based services received additional Medicaid funding. Expanding the existing supply was relatively easier than creating new residential options since agencies and programs can more readily hire new staff and renovating or constructing new buildings takes far longer.

Residential care facilities were viewed as the primary option for many residents who lacked family members or a place to move in the community. Yet only 55 residential care facility units for specialized Alzheimer's care existed in 1994 and other residential care facilities either did not accept people with Alzheimer's disease or lacked staff with appropriate training to provide quality care. As a result, the new criteria left 300 residents ineligible for continued stay in a nursing facility and a shortage of residential options left those without family members at risk. In response, the state Medicaid agency, with legislative approval, continued to reimburse nursing facilities at a lower rate for residents who no longer met the level of care criteria and could not be placed in a community or residential setting.

Expanding residential options takes far longer than adding capacity to in-home services agencies. New buildings must be constructed or existing facilities must be converted. Funding was approved to expedite the conversion of nursing homes and residential care facilities to provide specialized care. By the end of 1996, 300 special care units were available yet advocates noted that waiting lists up to 18 months have been experienced.

Based on MDS+ data, 300 nursing facility residents with Alzheimer's disease no longer required nursing facility level of care under the new rules. Exceptions criteria allowed a person to remain in a facility if an appropriate placement was not available within 60 miles. The criteria was reduced to 30 miles in June 1996. About 150 people were reimbursed through the safety net exceptions criteria.

Because of time constraints imposed by the budget savings target, state officials were not adequately able to prepare providers, advocates and families for the changes. Nursing home discharge planners, pressed to move residents who no longer qualified for Medicaid reimbursement, may not have been aware of the process and the options, nor the exceptions criteria. As a result, family members, advocates and legislators quickly responded to an "emerging crisis" that threatened to move people from nursing facilities who had no place to move.

Family members and advocacy organizations aggressively monitored implementation of
the changes for people with Alzheimer's disease and presented their findings to state policy makers and legislators. The Department of Human Services and the legislature responded. A new governor took office and both he and the legislature made long term care a high priority. New resources were needed to serve people who were no longer eligible for nursing facility care and the criteria for approving nursing home admission were reviewed. The 1996-1997 biennial budget approved $13 million for expanded community services that included:

- Adding a supplemented screen to the MED 94 assessment instrument that provided a method to substitute cognitive and behavioral factors when professional nursing intervention was not needed by the consumer.

- Appropriated nearly $1 million for Alzheimer's disease respite care and adult day care services.

- Financing to expedite conversion of nursing facilities and residential care facilities to specialize in services to people with Alzheimer's Disease.

- Funds to create 5 unit adult family care homes.

- Additional funds for nursing facilities to train their staff to better serve people with dementia.

- Nursing homes that voluntarily close beds may later re-license the closed beds with a certificate of need approval.

In addition, funding for three specialized geriatric evaluation units to improve the accuracy of diagnosis for people with Alzheimer's disease was obtained from other sources.

**MED 96 - responsive to people with Alzheimer's Disease**

MED 94 asked questions concerning short and long term memory recall, and decision making ability. Short term memory and long term recall were scored 0 if intact or 1 if impaired. Applicants were also asked to name the current season, the location of their room, if they recognized names and faces of people and if they knew where they were. Cognitive skills for daily decision making were rated 0 to 3.

MED 94 also rated wandering, verbally and physically abusive behavior and socially inappropriate/disruptive behaviors. The scale is: 0 = not exhibited n last 7 days; 1 = occurred 1-2 days only; 2 = occurred 3-6 days but not every day; and 3 = occurred daily or more frequently.

Under previous MED 94 rules, a person had to meet a separate threshold score based on the more limited areas for cognition and behavior and required RN intervention at least 3 days a week in order to qualify for nursing home admission.
The MED 96 instrument retains modules for demographic information; medical eligibility; assessment of ADLs, environmental issues and a recommended care plan; a section which summarizes the outcome of the assessment; and a section dealing with the Preadmission Screening and Annual Resident Review (PASARR) requirements which identify clients with mental health and mental retardation needs. The key change in MED 96 for people with Alzheimer's disease was the addition of a supplemental screening section for cognition and behavior for people whose mental and cognitive capacities did not require the intervention of a professional nurse. Responding to and working with advocates as they developed MED 96, the Bureau of Elder and Adult Services sought to include items that captured the real issues in addressing supervision, safety and danger such as sleep patterns, night behavior, wandering, response to hallucinations, and combative behaviors. The revised tool emphasizes functioning and unmet needs rather than diagnosis.

The supplemental cognition section rates a person's memory for events (0-3), memory and use of information (0-4), global confusion (0-3), spatial orientation and verbal communication each on a scale of 0-3. Supplemental behavior questions address sleep patterns (0-4), wandering (0-4), behavioral demands on others (0-5), the degree of danger to self or others (0-4) and awareness of needs and judgement (0-4). The ratings for each item on both scales is specific to the item rated. For example, for global confusion, a person rated 3 is nearly always confused; 2 if there is periodic confusion; 1 if there is nocturnal confusion on awakening; and 0 if they are appropriately responsive to environment. The verbal communication variable is rated 0 for people that speak normally; 1 if there is minor difficulty with speech or word finding; 2 if the person is able to carry out simple conversation only; and 3 if they are unable to speak coherently or make their needs known.

A score of 13 or more of a possible 16 points on cognition and a score of 14 or more of a possible 20 points on behavior is needed for a person to be considered impaired for nursing home placement.

Under the MED 96 revised rules, a person who does not require RN intervention may qualify for a nursing home admission under one of three conditions:

- The cognition and behavior scores are met and the person requires limited assistance in self performance and support in one of five ADLs;

- The cognition score is met, and the person needs limited assistance in self-performance and support in two of five ADLs;

- The behavior score is met and the person needs limited assistance in self performance and support in two of five ADLs.

Supervision and cuing in ADLs is not counted toward impairment for nursing home admission unless the person also has a professional nursing need or requires some physical assistance with
ADLs. This information is used in assessing the appropriateness for adult family care (level I), home based care and adult day care. The revisions have made the criteria more flexible. The implementation of MED 96 has resulted in 551 additional residents qualifying for nursing home admission in 1996.

State officials are planning to introduce "MED 97" which will be a computerized form of the assessment instrument.

**Maryland - developing a uniform assessment instrument**

Frustration, duplication, lack of coordination and the threat of impending Medicaid cuts, rather than a budget crisis, spurred an initiative in the City of Baltimore. Baltimore City has an Inter-Agency Committee on Aging Services (IAC). Comprised of major public and private non-profit agencies that provide services to the elderly, the IAC coordinates and collaborates to improve the service delivery system. The Baltimore City Commission on Aging and Retirement Education (CARE), which is the local Area Agency on Aging, serves as the lead agency for the IAC.

There are three major public programs in Baltimore City that provide community-based in-home and respite care services. The Department of Social Services, with funding from the State Department of Human Resources, manages the In-Home Aide Services (IHAS) program. The Maryland Office on Aging funds the Senior Care and Medicaid Waiver/Group Senior Assisted Housing program, which are administered locally by CARE. The State Department of Health and Mental Hygiene funds the Medicaid Personal Care Program. The Medicaid personal care program provides "non-technical medically oriented care to allow recipients to be treated by their physicians on an outpatient basis." The program was "developed for long term maintenance of patients who are physically or mentally chronically ill or disabled or frail elderly." Guidelines require that participants:

"must be at moderate risk of institutionalization, require hands on personal care and be under a physician's care for chronic illness or physical or mental disability. Services include escort to medical appointments, household tasks incidental to home care and monitoring activities for safety."

In 1995, Baltimore Mayor Kurt L. Schmoke determined that a uniform assessment tool was needed to standardize practices across agencies and funding streams. To accomplish this, Baltimore City organized a subcommittee of the IAC, which includes four City agencies and several private, non-profit agencies. Public agencies represented on the IAC assessment subcommittee are CARE, the Social Services Department, the Health Department and the Baltimore Mental Health System, Inc. which is a public mental health authority. Private sector agencies include Family and Children's Services, the Alzheimer's Association, Jewish Family Services and Catholic Charities.
The subcommittee revised the existing statewide assessment instrument to create a universal assessment tool for use in Baltimore City. The new tool includes "trigger points" that lead the assessor to use supplemental forms. A separate committee was formed to create the trigger and the supplemental forms for issues related to Alzheimer's Disease.

Two assessment instruments are used in Maryland: Form 3871 and the Statewide Evaluation and Planning Services Tool (STEPS). Form 3871, the Medicaid Eligibility Review Form, is used to determine Medicaid nursing facility level of care eligibility and eligibility for some Medicaid community based services such as adult day care and Group Senior Assisted Housing Waiver program. This form has a cognitive/behavioral section that contains six memory and orientation questions (short term recall, season, name, present location, knows family member/caretaker and long term recall). Cognitive skills for daily decision making are rated independent, modified (some difficulty in new situations), moderately impaired and severely impaired. Space is available to note the frequency of behaviors and whether they are easily altered. The forms, which may be completed by physicians, nursing homes and other providers, are reviewed by the Delmarva Foundation which makes eligibility decisions for nursing facility admission, adult day care and Medicaid waiver services. Level of care decisions must be made prior to admission to any program or service.

People who need health related services are eligible for nursing facility admission. Health related services "mean services to maintain, improve or protect health or lessen disability or pain and must be performed by, or under, the supervision of licensed health professionals." The examples that affect people with Alzheimer's disease include:

- "Medication administration when patient's medical condition or cognitive deficits require a skilled observation and judgement of a licensed health professional."

- The development, management and evaluation of an individual’s care plan based upon the physician's order when the individual's physical or mental condition require the involvement of technical or professional personnel on a 24 hour institutional basis to meet the individual's need, promote recovery and ensure medical safety.

The second instrument is the Statewide Evaluation and Planning Services tool (STEPS) which was initially developed for statewide use in 1982 and revised in 1993 to determine eligibility for Medicaid personal care, in-home aide (Department of Social Services) and state Senior Care Services (Department on Aging). The section on activities of daily living provides three ratings for each activity: independent, needs assistance, dependent. Scores for eating, transfer (bed/chair), dressing, bathing, and toileting are counted (see table). Scores for grooming, walking, preparing a light meal, light chores, grocery shopping, travels, taking medication, using the telephone, planning and making decisions are also recorded and used for service planning.

Eligibility for the Senior Care Program is generally 20 or lower (severe disability) although some clients have been grandfathered and exceptions are made for people who need
limited intervention (medical supplies) to remain at home. Eligibility for the In-Home Aide program is based on functional factors and the availability of services to meet the client's functional and environmental needs. The STEPS tool is not being used to determine eligibility for this program.

For mental status, the STEPS tool notes mood and affect, verbal behavior, orientation (time, space and person), symptoms (wanders, depressed, hallucinates, incoherent, suspicious, delusional, agitated, angry, combative, withdrawn, anxious, and memory loss), and changes in last six months (sleeping habits, personal life, financial loss, relocations, losses or other changes). The form also records the individual's perception of the problem and the family or caregiver's perception of the problem. Local service agencies felt the STEPS instrument was medically oriented and lacked information needed for service planning and coordination.

<table>
<thead>
<tr>
<th>STEPS scoring system</th>
<th>Score</th>
</tr>
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<tbody>
<tr>
<td>Level of disability</td>
<td></td>
</tr>
<tr>
<td>No disability</td>
<td>30</td>
</tr>
<tr>
<td>Mild disability</td>
<td>25-29</td>
</tr>
<tr>
<td>Moderate disability</td>
<td>20-24</td>
</tr>
<tr>
<td>Severe disability</td>
<td>0-19</td>
</tr>
</tbody>
</table>

State agencies allowed Baltimore City to develop a new instrument as a pilot project to replace STEPS to assess eligibility for Baltimore City clients as long as it contained the same information as the STEPS tool. The new instrument could alter the format and add information but could not delete any information from the STEPS tool. The revised instrument, the Uniform Assessment Tool (UAT), includes the STEPS format for ADL and IADL items from the STEPS tool as well as the mini-mental status examination score and the mental health items listed above. The UAT adds supplemental or modular assessment items for caregivers, depression, cognitive/behavioral status, environment and financial information.

Scores of 23 or less on the mini-mental status examination trigger the cognitive/behavioral status supplemental form. This supplemental form records whether a person never, sometimes or often exhibits disorientation, impaired judgement, hallucinations, delusions, receptive/expressive aphasia, anxiety, depression, withdrawal, wandering, sleep disturbance, verbally abusive behavior, disruptive behavior, assaultive behavior, safety judgement, danger to self or others. The supplemental information is used by programs and agencies serving people with Alzheimer's Disease.

The caregiver component provides a profile of caregivers including health problems,
tasks performed for an elder, sources of assistance including formal services, level of stress and other observations. The environmental component identifies safety threats posed by cords, rugs, and space heaters as well as the availability of smoke detectors, an emergency exit plan and the condition of bedrooms, kitchen, bathroom and the overall environment.

While the new instrument is used during the pilot to inform and coordinate service planning, each agency uses the information for its own program. All participating agencies have agreed to use it. The Interagency Advisory Committee is interested in developing comprehensive eligibility criteria based on the information collected on the assessment instrument.

Assessment instruments - selected states

Many states have developed uniform assessment instruments to determine eligibility and develop care plans for a range of long term care services. Tools from a small sample of additional states are summarized to highlight the different approaches used that help identify the care needs of people with Alzheimer's Disease.

Massachusetts

The assessment instrument in Massachusetts is used to determine eligibility for nursing home placement and eligibility and service planning for Medicaid HCBS services and state funded home care services. The instrument was revised in 1990 and rates performance of ADLs from 0-4. People who need supervision or verbal cuing are coded "2." A person is scored as dependent in an ADL if supervision/cuing, 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 a section for mental/emotional functioning. 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 judgement, 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.
- What is your address?
- How long have you lived at this address?

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14 O = independent; 1 = independent with difficulty; 2 = supervision/verbal cuing; 3 = limited physical assistance needed; 4 = extensive physical assistance.
• 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?

A question of dementia is indicated for individuals who receive a score of four or more.

A separate section of the Massachusetts assessment instrument is used to determine nursing home eligibility. At a minimum, a person needs at least one nursing service and impairment in two ADLs to be eligible. One of the eligible nursing services required at least three times a week is --

"staff intervention required for selected types of behavior that are generally considered dependent or disruptive, such as disrobing, screaming or being physically abusive to oneself or others; getting lost or wandering into inappropriate places; being unable to avoid simple dangers; or requiring a consistent staff one-to-one ratio for reality orientation when it relates to a specific diagnosis or behavior as determined by a mental health professional."

This definition qualifies many people with Alzheimer's disease for nursing home care.

Illinois

In 1996, Illinois expanded its statewide nursing home pre-admission screening program to include private pay applicants. The assessment tool, developed in 1991, measures functional status in 15 areas covering ADLs, IADLs and health. For routine health needs, clients are rated based on their ability to follow directions from a physicians, therapist or nurse in performing routine health care tasks such as changing dressings, special diet planning, monitoring of symptoms, posturing and exercise. Special health needs cover the person's ability to participate in tasks which are performed by professionals such as complex catheter and ostomy care, complex dressing and decubitus care, therapies, and intravenous care. The functional section of the assessment rates the level of impairment from 0 to 3 and the level of unmet need from 0 to 3. Impairment may be due to either physical or cognitive conditions. Assessors are trained to probe for cognitive impairments. For example, assessors will not only ask if a person can bathe

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15 Eating, bathing, grooming, dressing, transferring, continence, managing money, telephoning, preparing meals, laundry, housework, outside home, routine health, special health, and being alone.
themself, but also whether they can recognize that they need a bath, can they determine how warm the water is and can they follow the steps necessary to take a bath or do they need cuing and supervision.

The instrument also uses a modified mini-mental status exam. The protocol includes orientation questions and the assessor names three objects and asks the client to repeat them. Clients are then asked to spell WORLD backwards. If the person scores five or more on these questions, with one point for each incorrect response, additional questions are asked until a score of eleven is reached. The assessor then asks:

<table>
<thead>
<tr>
<th>Illinois scoring system</th>
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<tbody>
<tr>
<td><strong>Level of impairment</strong></td>
</tr>
<tr>
<td>Independent</td>
</tr>
<tr>
<td>Performs or can perform most essential components...some supervision or physical assistance</td>
</tr>
<tr>
<td>cannot perform most of the essential components of the activity...requires a great deal of supervision or physical assistance</td>
</tr>
<tr>
<td>Requires constant supervision or physical assistance</td>
</tr>
</tbody>
</table>

- Please repeat the three items mentioned earlier.
- Can you identify these objects (pencil and watch).
- Repeat the following: "No ifs, ands or buts."
- Follow this command - "Take a paper in your right hand, fold it in half and put it in your lap."
- Read and obey the following: "close your eyes," write a sentence and copy of design.

A score of 30 is possible if a person responds incorrectly to all the questions. If a person scores 8 or greater on the first four questions which have a maximum potential score of 18, the assessor seeks an informant to complete the remainder of the assessment.

Eligibility for services is based on a combined score for mental status and functional capacity. If the mini-mental status examination score is lower than 10, the person receives zero
for that component. A score of 10 is credited for people scoring 11 or more. The combined mini-
mental and level of impairment score must be 15 or higher and the unmet need for care score,
plus the functional score, must exceed 29 to qualify for placement.

Wisconsin

The assessment tool used for Wisconsin’s Community Options Program (COP) considers
a person impaired in performing an ADL if they need physical assistance, supervision or cuing.
A person without ADL impairments may qualify if daily supervision or ongoing assertive case
management to ensure safety or the safety of others is required and if one of eight
behaviors/conditions has been experienced: wandering, confuses days and nights,
combative/disruptive, isolated or avoid social situations, unable to make decisions affecting
health, safety or welfare, hallucinates, denies having a mental illness or emotional problem,
exhibited behaviors so severe as to require crisis or judicial intervention, or misuses drugs or
alcohol.

People who do not meet the earlier requirements may be eligible if they are diagnosed
with Alzheimer’s disease or a related dementia. The tool has a separate section for Alzheimer’s
disease which notes whether a person has a written statement from a physician that the person
has Alzheimer’s disease or another qualifying dementia, and that the person needs personal
assistance, supervision and protection and periodic medical services or observation and
consultation but not regular nursing care. Persons eligible through this section may receive state
funded home care services but do not qualify for Medicaid waiver services.

Discussion

A review of the literature and state approaches suggests that establishing eligibility
criteria for long term care services is more art than science and assessment is not a stand alone
policy tool. There is no one "right" way. Once an assessment determines need, and rules
determine eligibility, capacity is required to facilitate access to care. The approaches taken by
states reflect a blending of factors: meeting the needs of people who need assistance and
controlling spending within specified, predictable parameters. Obviously the two factors conflict
and some balance needs to be established. Balancing access among eligible populations means
that assessment tools and eligibility criteria need to address the issues that give rise to a need for
long term care. Those issues vary by population subgroup. Factors such as supervision and cuing
for performance of ADLs and cognitive and behavioral measures must be included to address the
needs of people with Alzheimer’s disease.

The study states represent two separate aspects of assessment and eligibility criteria.
Officials in Baltimore launched their project to collect information in a standardized manner that
is needed to determine eligibility for multiple programs, to formulate care plans and to inform all
agencies serving the same person. The multi-agency use of the same tool and the agreement
among agencies to construct a tool and share it among agencies serving the same person is innovative. Also innovative is the creation of a special subcommittee to develop the sections of the tool that deal with Alzheimer's disease and the ability of agencies operating different programs and services to reach agreement on the content of the instrument.

The experience in Maine and Maryland produced several key lessons for policy makers:

- Assessment instruments used to measure need, develop care plans and determine eligibility should generate the information needed to appropriately serve people with Alzheimer's disease and related disorders.

- Setting program eligibility criteria that assume or require use of lower levels of care requires:
  - Funding for a full range of residential, community and in-home services;
  - Availability of providers who are willing and able to participate in the programs.

- Eligibility criteria should recognize the need for supervision and cuing to perform an ADL as an impairment. Physical abilities alone do not accurately represent the care needs of people with Alzheimer's Disease.

- People who need supervision and cuing may require more staff time than people needing direct physical assistance.

- Eligibility criteria should recognize the importance of behavior and cognitive capacity.

- Staffing patterns in facilities providing long term care services must be appropriate to meet the needs of people with Alzheimer's Disease.

- Staff responsible for assessment, authorization and care plan development and staff in facilities and agencies serving people with Alzheimer's disease should receive "dementia capable" training.

- Participation in Medicaid Home and Community Based Waiver Services programs is dependent on eligibility for admission to a nursing home. Changes in the nursing home level of care criteria affect eligibility for services that provide an alternative to nursing homes.

A study of assessment instruments and a review of the instruments from selected states suggests that four components are needed to respond to the needs of people with Alzheimer's disease:
• Supervision and cuing should be used to indicate an impairment.

• Behaviors which are characteristic of people with Alzheimer's disease that require monitoring or intervention should be assessed.

• Information about mental status and memory should be obtained.

• The capacity of the caregiver to continue to provide care should be assessed to identify the need for supportive intervention that may extend the caregiver's ability to continue in this role.

While the Kane and Newcomer studies highlight the importance of using cuing and supervision as a measure of impairment for people with Alzheimer's disease, the resulting increased demand generated by more responsive criteria may lead states to set higher thresholds in the number of ADL impairments needed in order to control spending. The studies also underscore the importance of including adequate measures in an assessment tool that will be used for multiple programs. Assessment instruments used by multiple programs allow case managers to match the assessment information with eligibility information across programs. Setting a higher threshold for nursing facility admission has fewer consequences if the person can also access a number of residential or in-home services. Without more service options and funding sources, setting the higher threshold means people simply cannot be served. If nursing home level of care thresholds are raised, alternative services may be covered by Medicaid state plan services such as home health and personal care, but these services may not be appropriate for people who need supervision. Unless state funded home care services are available, raising the threshold for nursing home-eligibility and Home and Community Based Waiver Services means that respite care, assisted living, residential care facilities and in-home services cannot be accessed by people with Alzheimer's disease who no longer qualify for nursing home placement.

Advocates contend that lack of access to care shifts the caregiving burden for people with Alzheimer's disease to family members who may leave jobs, reduce working hours and experience higher stress reduces quality of life for caregivers and, in some instances, can lead to an increase in neglect and abuse. In the absence of state general revenue funding for community and residential options, a lower threshold will allow people with Alzheimer's disease to access Medicaid HCBS services while the total cost is controlled through supply controls. Clearly, broader policy and programmatic options are easier to implement when decisions are not driven solely by budget deficits. However, within a specified budget context, the number of people served is a function of the cost per person which reflects the mix and availability of service options. Fewer people can be served for a specified amount of funding if nursing facilities are the only resource. If nursing homes, residential and in home options exist, more people can be served at a lower average cost per person. As policy makers and legislators know, shifting fixed resources from institutional to community and residential options is difficult.

Maine's approach reflects a more difficult conflict between public policy goals that seek
to provide services to people who need assistance and very limited state funding. The course of
the policy decisions changed dramatically as the legislature and advocacy groups responded to
dramatic proposals from the governor. A change in governors, modest economic improvements
and concerted action by family members and advocates created a new environment within which
alternatives could be developed.

State policy makers, consumers and advocates have an enormous interest in developing
cost effective and appropriate long term care systems. Because of its complexity, changes in one
aspect of the long term care system have to be considered in relation to the entire system in order
to avoid unintended consequences. As states seek to shift the balance from institutional to
residential and home care settings, they may have to operate parallel systems for a time while
new service resources are created or expanded.

Once the desired mix of services are available, designing eligibility rules based on an
understanding of the full need for long term care determines who can access care. Assessment
instruments that collect appropriate information to measure functional, cognitive, emotional and
behavior variables is essential in understanding how alternative eligibility criteria will affect
access to care. Generally driven by budgetary implications, eligibility criteria determine how
people can be served and where they may be served. Both the source of financing, the array of
service and their availability across the state affect access to services for people with Alzheimer's
disease. Medicaid nursing home eligibility criteria not only determine who may enter a nursing
home but also who may receive in-home services through Medicaid waiver programs. Since
Medicaid Home and Community Based Services Waiver program eligibility is tied to nursing
home eligibility, lower thresholds mean more people with Alzheimer's disease will qualify for
nursing home admission and Medicaid waiver services. Setting a low threshold without other
funding and an adequate array and distribution of alternative services means people who no
longer qualify for admission will not have access to needed services. If residential and
community services are both covered and available, nursing admissions for people with
Alzheimer's disease would be lower.

State Medicaid policy may set higher nursing home level of care thresholds if other
sources of long term care are available - State general revenues for home care services, Social
Services Block Grant or Older Americans Act. Setting eligibility thresholds is best accomplished
over the full spectrum of institutional, residential and in-home long term care services rather than
for a single program or service. In setting thresholds, policy makers also need to examine the
array of services and their available across the state to avoid setting policies that assume access
to services that may not be available.