

Alzheimer's Disease and the Family Caregiver: The Cost and Who Pays?

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What Is It?

Alzheimer's disease (AD) is an acquired, progressive neurodegenerative disorder that is the most common cause of dementia in older adults in the United States, constituting 50-60% of all cases of dementia.^{1,2} Dementia is a syndrome characterized by progressive decline in memory and other intellectual abilities, and typically results in a need for complete caregiving for the patient. Contemporary diagnostic criteria for AD were published in 1987.³ The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) identifies the following three criteria as being necessary for a diagnosis of dementia: (1) memory impairment, (2) cognitive dysfunction in at least one other area of cognitive functioning (aphasia, apraxia, agnosia, or inability to carry out executive functions), and (3) cognitive impairments severe enough to limit social or occupational functioning. Alzheimer's disease has a societal significance that is greater than simply being the leading cause of dementia. AD has come to symbolize worries about how the United States will deal with the aging of society.

How Common Is It?

There have been a variety of prevalence studies conducted over the past decade, with wide variance in the estimates.⁴⁻¹⁴ The most recent published estimate is that 4.5 million persons had AD at the 2000 Census.⁴ Comparing estimates is difficult because of differences in methods, settings, timing, and definitions of AD used across studies. There are four key points with respect to the prevalence of AD. (1) The true prevalence of the disease is unknown, and there are conflicting estimates. (2) All published prevalence estimates are based on geographically-based samples that are not representative of the entire United States. (3) All published estimates agree that prevalence increases with older age, and a general rule of thumb is that prevalence roughly doubles per decade of age with around half of those age 85 and older likely afflicted with AD.¹⁰ (4) The number of persons living with AD will dramatically increase given the

rapid increase in the number of Americans who are age 85 and older, and who, all studies agree, have the highest prevalence rates.

A recent study using Medicare claims records to track diagnosed prevalence of AD recorded in claims data found large increases across the 1990s using the same diagnosis method in all years.¹⁵ Such a study provides an opportunity to see how identification of AD is changing over time, but the case definition being based on ICD-9-CM codes in claims data produces a serious undercount of the overall true prevalence of the disease. There is no obvious reason to expect that the true prevalence of AD should have risen so sharply during this time frame, so the observed increases are most likely due to an increase in the probability of being diagnosed with AD, given the presence of the disease, particularly for persons with mild symptoms over time.

In addition to age, race and gender have been shown to be related to the prevalence of AD. Women have higher rates of AD than men. There is some epidemiological evidence that AD rates are higher among African Americans compared to whites.¹⁶⁻²³ For example, Folstein et al.¹⁹ found the AD rate for blacks to be 7.2% compared to 3.8% for whites. Other studies have not found differences in the prevalence of AD between African Americans and whites.²⁴⁻²⁵ Plausible explanations for a higher rate of AD among blacks are the community-based samples in studies finding differences (e.g., blacks are less likely to be institutionalized where rates of AD are much higher) as well as lower sensitivity of cognitive tests for identifying AD in blacks.²⁶ The study cited earlier showing an increase in prevalence of AD identified in Medicare claims records showed that the rate of increase was faster for blacks compared to whites.¹⁵ This may suggest an increase in awareness of AD in the African American community, an increase in access to care, changes in coding rules that allow a diagnosis of AD with a history of stroke, or all of these.

What Treatment Options Are Available?

AD is non-reversible, and the current therapy available to directly address the disease is limited to: (1) pharmaceuticals

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that may slow the decline of cognitive function and (2) the development of approaches to best care for persons with AD who suffer from extreme cognitive decline and disability. Developing methods for early diagnosis of AD are of critical importance to provide maximum opportunities for both existing and any future therapies to have the best chance of success.

A recent review outlines the present pharmaceutical treatment options for AD that are currently in use.¹ These drugs are commonly used to treat the signs and symptoms of AD: Donepezil, Rivastigmine, and Galantamine (all Cholinesterase inhibitors), and Memantine (a NMDA-receptor antagonist). Such treatment is currently the standard of care for the disease. Other pharmaceuticals are used to treat neuropsychiatric symptoms and behavioral disturbances of the disease, such as depression, psychosis, and anxiety.¹ Development of new pharmaceutical agents is an area of intense interest for all parties—for physicians, patients, and families who want an effective therapy to address the underlying mechanisms of the disease or to better treat symptoms, and for pharmaceutical companies who understand the large market for persons with AD and dementia, generally. In short, there are few therapies available to address AD, and most efforts are spent trying to best manage symptoms, treat comorbid illness, and help families deal with the disability of their loved one.

There are hopes that future therapies will be more effective at either forestalling cognitive decline or perhaps even reversing dementia. For existing pharmaceutical therapies, as well as future ones, early diagnosis of AD seems to be a key to maximizing the benefit of both current and potential approaches. Conclusive diagnosis of AD is only possible through a post-mortem autopsy. Prospectively, the diagnosis of AD is made when persons meet standard criteria for the diagnosis and have no other plausible explanations for their observed dementia.¹ The primary advances in diagnosis over the past two decades have been (1) the adoption of standard criteria for diagnosis, (2) an understanding by the medical community and the population in general that dementia, and AD in particular, is a disease and not a normal part of the aging process, and (3) the development of more advanced imaging techniques that are useful for diagnosis. In particular, the decision of the Medicare program to finance the use of Magnetic Resonance Imaging (MRI) scans for diagnosing AD, and more recently covering PET Positron Emission Tomography (PET) scanning for the same purpose, may yield more precise and potentially earlier diagnoses of AD. However, it is important to note that the use of a PET scan is not generally considered to be necessary for the diagnosis of AD, and Medicare will only cover PET scans in complex cases where a cognitive decline is noted, but a diagnosis of AD can not otherwise be easily made. The development of new pharmaceuticals or other therapeutic approaches to either slow or reverse dementia associated with AD will increase pressure to

diagnose the disease as early as possible, so new therapies and diagnostic procedures are likely to develop hand-in-hand.

There are non-medical treatment options designed to aid in the care of persons with AD, including placement of individuals in dementia care units that are long-term care facilities designed specifically to provide care for those suffering from AD and other dementias. This treatment is probably best understood as a means of dealing with the effects of AD in the most efficacious

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manner possible and doing so in a way that helps reduce the caregiving stress and burden on spouses and/or families of loved ones with AD. In reality, most persons with AD are living and being cared for in community settings. Families tend to seek institutional settings such as nursing homes/dementia care units for the care of their loved ones with AD when the difficulty, strain, and burden of caring for the patient in a community setting becomes too difficult. There are a variety of negative effects of caregiving for persons with AD that have been well-documented in the literature. A clearer understanding of these negative effects as well as the aging of the population with respect to the number of working-age persons for each person age 65 and over should lead to a societal discussion about the most appropriate manner in which to care for persons with AD and other sources of age-related disability.

Extent of Alzheimer’s Disease in North Carolina

The population of North Carolina is rapidly growing, with tremendous increases among both working age persons as well as retirees. The state is getting older, like the rest of the United States; the North Carolina median age rose from 33.0 in 1990 to 35.3 in 2000, and will increase to 38 by the year 2030.²⁷ During the 1990s, the proportion of the North Carolina population at highest risk of AD, those 85 and older, increased by 53% (from 69,000 to 105,000 persons).²⁷ At present, 28% of North Carolinians are age 50 or older, which means that they are either at substantial risk of developing AD or will be at-risk within 10-15 years. Twenty-five years from now, 35% of the state’s population will be age 50 or older; hence dealing with AD will become an increasingly important issue in North Carolina.²⁷ AD is the seventh leading cause of death in North Carolina at 27.7 per 100,000 (age-adjusted) population,²⁸ and was the primary cause of death in 4,996 deaths from 1999-2001.²⁷ The state’s number of nursing home residents (all ages) per 1,000 persons age 85 and older in 2001 was 322.6, compared to 317.5 for the United States as a whole.²⁷

Similarly, nursing home occupancy rates for North Carolina were 88% compared to 82.4% nationally.²⁷ As noted earlier, over half of nursing home residents suffer from AD or other dementias, but most persons with AD live in community settings.

Conceptualizing the Cost of Alzheimer's Disease

AD has a broad effect on American society, and discussion of the disease has ceased being only a clinical topic and become a part of the cultural dialogue of the United States. It is useful to distinguish three distinct perspectives of cost and burden when considering AD. Cost need not imply monetized cost estimates, but could. The first cost perspective is the private or individual level that encompasses the cost experienced by the person with AD. The second level is what can be called quasi-external costs, notably the costs borne by spouses and/or other family members who are engaged in caring for a person with AD. Taken together, the individual and the quasi-external costs could be viewed as a unified household perspective, but they are separately identified here because the preferences, potential costs, and wellbeing of all members of the household are not likely to be identical when choosing a particular way to care for a person with AD. Finally, there is the purely external cost, or the cost of AD to persons outside of the household. This perspective is largely comprised by the effect of AD on programs, such as Medicare and Medicaid, and any additional costs borne by others outside of the household experiencing AD, such as lost work productivity for companies whose employees are caring for a parent with AD. It is necessary to consider the private, quasi-external, and external perspectives to fully understand the social cost of AD on the larger society. Considering these different perspectives is useful because it illustrates that using one to the exclusion of the others provides an incomplete understanding of the cost of AD and may lead to suboptimal policy.

Private Costs of Alzheimer's Disease

AD most directly and profoundly affects persons who are stricken with the disease. Such persons have their lifespan shortened. Prior to death they suffer from a tremendous morbidity burden that greatly diminishes their quality of life. After onset of the disease, persons generally suffer from impaired memory, lose the ability to communicate via spoken language and otherwise, and become unable to complete executive functions. As the disease progresses they may suffer from sensory problems, lose their ability to walk normally, and may suffer from seizures later in the course of the disease. Higher-level functioning is lost as the clinical symptoms progress, resulting in the inability to complete Instrumental Activities of Daily Living (IADLs) such as driving, shopping, cooking, maintaining personal records, and the ability to appropriately take medicines. Further decline results in the loss of ability to complete Basic Activities of Daily Living (BADLs), such as dressing, bathing, going to the toilet, and eating. Behavioral disturbances, such as wandering, outbursts of anger, or an increase in socially inappropriate actions (e.g. disrobing in public places), can onset across different phases of the disease

progression, and psychotic behavior and extreme agitation often come during later phases of the disease. The private costs of AD are profound, and the development of therapies, such as pharmaceuticals, aim to ease the burden of the disease on persons afflicted with AD.

Quasi-External Cost of Alzheimer's Disease

Quasi-external costs are those borne by persons other than the patient in either the immediate (spouse) or inter-generational household (e.g., adult children, siblings of the afflicted). The primary cost is the magnitude of informal caregiving that persons are likely to provide to a family member with AD. This care is not static, but increases steadily throughout the disease course. A past estimate of the cost of informal caregiving in the United States found that their costs ranged from \$117-\$292 billion (1998 dollars), depending upon the assumptions about the hourly price used in the calculation.²⁹ This estimate showed the cost of informal caregiving to be larger than the total spent on nursing homes in the same year, in spite of the fact that it represented a replacement-cost estimate (how much it would cost to replace informal care with paid care) and assigned a value of zero to the well-known negative effects of caregiving on the health, emotional, and financial status of caregivers. In short, the quasi-external costs of AD are staggering.

The informal caregiving cost estimate noted above was for all caregiving, not only that provided to persons with Alzheimer's disease. However, there is reason to expect that caring for persons with AD and other dementias is a large contributor to this total and is more burdensome on a per-case basis than caregiving for persons with other diseases and ailments. Most persons with AD are being cared for in non-institutional settings in the community. A recent annual estimate of the cost of providing care for a person with dementia was \$18,395 in 1998.³⁰ The two largest sources of cost were caregiver time (\$6,295/year) and lost earnings (\$10,709/year) due to reductions in market work in order to provide care. A recent paper illustrated that Medicare-financed care represented less than half of the total cost of dementia care,³¹ illustrating that ignoring the quasi-external perspective in favor of the external perspective only (e.g., cost to the Medicare program) gives a skewed view of the burden of the disease on society as a whole (i.e., the social cost of the disease).

The other major source of quasi-external costs are the physical, emotional, and financial harm that befalls caregivers of persons with AD. Caregiving for a person with dementia has been found to be more deleterious to the caregivers' health than is caregiving for a family member with cancer across a variety of domains, including stress, depression, isolation, and delay in the seeking of medical care by the caregiver him/herself.³² More recent work has shown that dementia caregivers provide more care and suffer great self-reported strain, mental and physical problems, and family conflict linked to the care of their loved one than do persons caring for persons afflicted with other diseases.³⁰ Caregiving and perceived stress in this role has even been found to increase mortality among caregivers.³³ Such costs need not be monetized to demonstrate that the quasi-external cost of AD is immense.

Spouses and adult children typically suffer financial strain due to caregiving. This is shown through the reduction of market work, out-of-pocket payments for house modifications to aid with caregiving, and interruptions of the retirement savings of adult children. While some studies document the lost wages associated with caregiving as a cost of AD,³⁰ this review did not identify estimates of the effect of reduced contributions to retirement plans, and what effect such a reduction could ultimately have on either retirement decisions (timing) or the amount of retirement savings. This effect would most likely be seen through reduced private savings through vehicles such as 401-K or 403-B retirement plans. This issue could be of great consequence, since caregiving may interrupt the retirement savings of persons who are likely to be in their highest wage-earning years (50-somethings caring for their 70- and 80-something parents). Interruptions or decreases in retirement savings are not easily made up, even through accelerated contributions at a later date, given the effect of the compounding interest principle. Reduced retirement savings could also be viewed as an external cost to the Medicaid program as a person with reduced savings could be expected to “spend down” to Medicaid eligibility levels sooner than would a person with more retirement assets (see below).

Other quasi-external effects of AD are not as tangible, nor are they easily monetized. For example, the loss of grandchildren being able to interact with and learn from their grandparent with dementia is easily understood as a “cost” in the most general sense, but assigning an economic value to such a cost is difficult. AD robs younger members of the inter-generational household from being able to learn from the wisdom and experience of the older members.

External Costs of Alzheimer's Disease

External costs are those costs that are neither private nor quasi-external. These are costs borne by society, defined as persons outside of the inter-generational household. A very common perspective when considering the external cost of AD, is the impact of the disease on a program such as Medicare. Recent work shows that persons who are diagnosed with AD cost the Medicare program around 60% more per year compared to a similar beneficiary (in terms of age, gender, and disability level) who does not have such a diagnosis.³⁴ However, the time path of the cost effect is complex. Costs increase in the year that AD is first noted in Medicare claims. As the disease progresses, the cost effect reduces, eventually falling below average per-beneficiary costs, suggesting a reduced propensity to use Medicare-financed healthcare services at more advanced stages of the disease. Further, there is some evidence that the presence of AD may influence the manner in which an acute medical condition may be treated. For example, a heart attack may be treated less aggressively for a person with AD compared to one who does not have AD. Thus, a precise estimate of the effect of AD on the Medicare program would need to account for several types of effects: the costs of diagnosis that would be expected to increase costs; the morbidity burden associated with AD that would be expected to increase costs; the effect of disease stage on the propensity to

use formal medical care, which likely declines as the disease progresses; and the fact that some illnesses may be treated less aggressively given the presence of AD, which would be expected to reduce costs. While it seems certain that the presence of AD results in higher Medicare program costs, the mechanisms underlying such increases are more difficult to measure precisely, and are best considered longitudinally and not in cross-section, as is most easily done. A future issue with respect to Medicare costs is the impact of the prescription drug plans developed through the Medicare Modernization Act of 2003, which will be in place in 2006. It is not clear if existing or future drugs designed to treat AD and/or symptoms of AD will be routinely included in plan formularies.

The Medicaid program serves as a de facto nursing home insurance scheme for the entire United States, with the deductible essentially being non-housing wealth. The Medicaid program pays for approximately 40% of the national nursing home bill.³⁵ And given that over half the persons living in nursing homes suffer from AD or a related form of dementia, it is clear that the effect of AD on state Medicaid programs is large. The Medicaid program is also involved in financing acute medical services, but for persons age 65 and over who are both Medicare and Medicaid beneficiaries (“dual eligibles”), the Medicare program is the primary payor for acute care. For this reason, the burden of AD on the acute-care expenditures of state Medicaid programs would be expected to be modest.

The effect of AD on Social Security is more ambiguous. Social Security is an inherently more simple program than Medicare in that it simply provides cash payments to a person age 65 and over and therefore doesn't have the uncertainty of medical innovations, the propensity to seek medical care, and the unit price of services that Medicare faces. A recent book on the cost of smoking to society points out that smokers actually cross-subsidize non-smokers with respect to Social Security in that they contribute through the payroll tax over the course of their life at similar rates to non-smokers, but die substantially earlier.³⁶ This means they take out less than they put into the Social Security system. A similar analysis could be undertaken for persons who later develop AD—comparing what those with AD contribute versus what they receive in benefits. But it seems that persons living to an older age and developing AD prior to death are precisely the type of persons who are being cross-subsidized by smokers and others who die either prior to retirement age or relatively soon after the receipt of Social Security retirement benefits (age 62 or 65 depending upon the choice of the individual). Thus, it seems that persons with AD are likely to be among the persons who will cost the Social Security program relatively more over the course of their lifetimes.

Social Cost and Next Steps

The social cost perspective takes account of all aspects of cost and burden of AD—private, quasi-external, and external. Excluding one type of cost will result in an incomplete understanding of the cost of AD to society and may result in an under-investment in strategies to address the cost of AD. A

complete understanding of social costs can also help identify areas in which policy attention is warranted, but which may not often garner much attention. The point of this Issue Brief is not to produce an estimate of the social cost of AD, but instead to identify the different types of costs and policy considerations that emerge from doing so.

In the case of AD, both the private and external cost perspectives have generated much (warranted) attention. The burden suffered by individuals with AD is immense, and it is clearly a societal priority to develop improved means of treating AD and/or symptoms of the disease. Pharmaceutical companies and clinical researchers will continue to seek new treatments and more effective ways to diagnose AD earlier, which is likely a precursor to any effective treatment.

Likewise, the external cost perspective has received a great deal of attention in recent years as researchers and policy makers worry about the effect of AD on the future solvency of programs such as Medicare and Medicaid. Identifying the cost burden of AD on such programs is a legitimate endeavor, but it is not clear what such estimates can do other than underscore the seriousness of AD and its current and potential impact on the system. It is not clear that there are many left who need to be convinced. However, there is a need for conceptual clarity about what is being measured in such work. Are the costs of persons *with AD* of interest? Obviously, some of them also have heart disease and cancer as well. Or, is it more important to focus on the cost of *AD per se*? In other words, are we measuring the cost of treating a person with AD compared to what it would have been otherwise? While related, these two external cost perspectives are not identical, and they should be kept separate. The answer may not be that important, given that the Medicare program will have to finance acute care for such persons in any event.

The area in which there is too little policy concern is in identifying and responding to the quasi-external costs associated with AD. A body of research literature exists that documents the physical, emotional, and economic effects on a family caring for a person with AD, but there has not been a serious national or state discussion around what to do about it. This is an area needing focused discussion around the issue of how will persons with AD be cared for and whose responsibility will it be? While the hope for future pharmaceutical agents to address the processes of the disease itself is real, so is the fact that several million people are likely to live through and die with or from AD before such therapies are developed. Their families will be left primarily to deal with the effects of the disease on their loved ones. Therefore, a top priority should be to directly address the issue of informal caregiving and determine how society views it. Currently, we have made the policy decision by not addressing the issue head-on. As life expectancy has continued to rise and the proportion of the population that is retired compared to those who are working is also rising, we can no longer afford to avoid directly addressing this issue.

Policy Options: The Case of Germany and Japan

Two nations (Germany and Japan) have recently adopted long-term care financing strategies that are instructive for outlining some of the key issues related to how to care for persons with AD in the absence of any pharmaceutical or other therapy that drastically slows cognitive decline and/or improves functioning. It is important to note that the magnitude of the aging of the population is greater in both Germany and Japan than in the United States, so the situation we face is not unique. While the need to address population aging issues and long-term care is similar in Germany and Japan, their respective approaches are fairly different. Their differences provide food-for-thought for considering how AD might best be cared for in the United States context.

Germany³⁷ has developed a voucher-based approach whereby persons are eligible for a fixed subsidy based on their level of disability, regardless of age. The voucher amount is not expected to pay for the full cost of market-provided long-term care (such as a nursing home or home health), and families are responsible for the rest unless they are totally impoverished. The most innovative aspect of the German system is the ability for families to continue providing long-term care services in the community and to “cash out” their voucher for money to be used to defray the cost of caring for their loved one. The cash-out value is approximately two-thirds of the voucher amount, providing a cost-savings for government when families choose to provide care informally. The German approach to determining eligibility has been criticized as being too simplistic (it places people in very broad categories based on ADL limitations) and does not take direct account of the extent of cognition/dementia. It has generally been affirmed for identifying family-provided care as the preference of large segments of German society and moving through policy to make such care more sustainable—basically by identifying quasi-external costs as worthy of policy action.

The Japanese approach is quite different.³⁸ Whereas Germany has sought to continue giving emphasis to a system based on family-provided long-term care, Japan has moved to aggressively increase the supply of formally-provided long-term care services with the explicit purpose of reducing the reliance upon informal care. The political discussion of the Japanese long-term care system was euphemistically known as “the daughter-in-law bill.” This highlights concern among political elites that gender equity issues were particularly acute in the area of long-term care, in the nation with the longest life expectancy in the world. The Japanese approach also differs from Germany in having a very detailed disability assessment approach that categorizes persons on numerous metrics, including the extent of dementia/cognition. Further, age is an explicit aspect of benefit determination, with those age 65+ presumed to qualify, but those age 40-64 are also able to qualify if they suffer disability due to an “age-related” condition.

Table 1.
Useful Information on Alzheimer's Disease and Long-Term Care for North Carolinians

Organization	Contact Information
Alzheimer's Association	800-272-3900 or www.alz.org (National) 800-888-6671 (North Carolina – Western/Piedmont Chapter) 800-228-8738 (North Carolina – Eastern North Carolina Chapter)
North Carolina Department of Insurance	http://www.ncdoi.com/
The Seniors' Health Insurance Information Program (SHIIP)	http://www.ncdoi.com/consumer/shiip/shiipwhat.asp 800-443-9354 (in state only) or 919 733-0111
North Carolina State Employees Health Plan Long-term Care Insurance Option	http://www.ncdoi.com/home/pdf/SHP_LTC.pdf
North Carolina Division on Aging	919-733-0440 or www.dhhs.state.nc.us/aging
Duke Alzheimer's Family Support Program	800-522-2451
North Carolina Area Agencies on Aging	www.dhhs.state.nc.us/aging/aaa/htm
North Carolina Regional Long-term Care Ombudsman	www.dhhs.state.nc.us/aging/ombud.htm

Adapted from Seniors' Health Insurance Information Program (SHIIP) materials.

The Policy Questions Ahead

These two approaches raise a series of questions that are useful for considering how to appropriately care for persons with AD. The questions are important even though it is unlikely that the United States would seriously consider a social insurance response to the provision of long-term care at any point in the foreseeable future.

First, given that family-provided care in the community is likely to remain the preference for many, is public policy intervention (e.g., public money) acceptable to defray the costs of such care?

Second, in determining eligibility of services/subsidies for long-term care for persons with AD, how will eligibility for services be determined? There is generally a trade-off between simple assessment (Germany), which is relatively cheap, and more precise assessment (Japan) that includes more data on a larger proportion of program costs on administration.

Third, what is of paramount importance in determining the best setting in which to care for a person with AD—the patient with AD or the caregiver(s)? This is another way of asking whether it is the role of the family to care for persons with AD or the family in conjunction with society as a whole.

There are certainly other questions that can be asked, but these are key ones to discuss and answer if the United States is going to more directly consider the quasi-external costs of AD.

What Policy Options Are Available for North Carolina?

Answering the questions posed above with respect to how to conceptualize the cost of AD and how such costs should be

borne are prerequisites for good policy. A national discussion and approach are needed to prepare the United States for the coming increases in persons with AD, but this is likely to require a long-term discussion. At present, most acute care is financed by the Medicare program, and families provide most of the caregiving, with the Medicaid program financing nursing home stays of persons with AD after the point of personal spend down. Large-scale changes in this mix seem unlikely, and the development of a long-term care financing scheme based on social insurance principles similar to Germany or Japan's is not likely in the near future. Given this backdrop, North Carolina has two primary means of addressing the AD situation, long-term care insurance regulation and alterations of the state Medicaid program with respect to eligibility for nursing home and other services for persons with AD. Expanding Medicaid, while a possibility, seems unlikely given the fiscal situation of the state, so the remainder of this Issue Brief discusses long-term care insurance in North Carolina.

Long-term care insurance is often noted as a key to preparing for the aging of society and dealing with increased numbers of persons with AD and fewer workers to help support same. If North Carolina could develop policies that would lead to the expanded purchase of such insurance it would be helpful in dealing with AD. However, determining how to expand such coverage is not clear. Private long-term care insurance enrollment rates are very low, around 5% of the population.*

Insurance is commonly used to spread the risk of potentially large and catastrophic losses when the occurrence of loss is unpredictable, but plausible. If a potential loss is very small, individuals don't bother with insurance. If the likelihood of a loss is extremely small, then likewise, they do not bother with

* Note: Among North Carolina's state employees and teachers, only 2,700 State Health Plan members subscribed to a long-term care group insurance plan offered to more than 550,000 plan members in 2004.

insurance. When potential losses are large and the likelihood of occurrence is more common, then a market for insurance is more likely to develop. Long-term care clearly fits the description of a potentially catastrophic cost that is fairly common, yet the market for private insurance is very small. Why is this the case? There are several possibilities.

The public may fully understand the risks associated with needing long-term care due to AD, and most may choose to self-insure via family caregiving, turning to Medicaid via spend down if necessary. Arguing against this conclusion is the myopia of many persons in thinking about long-term care.

Long-term care insurance may simply be too expensive for many persons, hence the low rates of coverage. It is also possible that many North Carolinians have not thought clearly about long-term care insurance (myopia), but would choose not to purchase it even if they did because of its cost. For example, the median wealth of households headed by persons age 70 and older across the nation in 1998 was around \$35,000 according to the Asset and Health Dynamics among the Oldest Old (AHEAD) database, a nationally representative survey of elders. At such low rates of wealth (less than the cost of one year in a nursing home), long-term care insurance is neither affordable, nor reasonable, from a wealth-protection perspective. The North Carolina Department of Insurance consumer guidelines for the purchase of long-term care insurance advises persons with less than \$100,000 of wealth (excluding their house, which is generally exempt from Medicaid spend down rules) against the purchase of such insurance. According to the AHEAD survey, persons at the 80th percentile of overall wealth had just \$60,000 of non-housing wealth, on average, meaning that no more than 15% of the population might be expected to reasonably purchase long-term care insurance using the North Carolina Department of Insurance's conservative guidelines. Long-term care insurance can offer protection against catastrophic costs and can provide some control in where and how a person with AD receives care, but the vast majority of North Carolinians can't afford such coverage.

Long-term care insurance premiums are cheaper if purchased at a younger age. Persons who begin thinking about their need for long-term care in their 40s and 50s will therefore get a lower premium than will persons who purchase policies in later years. However, there is a subtle risk in purchasing long-term care insurance at younger ages due to the nature of the insurance products that are currently offered in the state of North Carolina (and in other states). Long-term care benefits are denominated in dollars per day, as opposed to care required, as is the case with major medical insurance. A 40-year-old purchasing a policy will most likely not use a long-term care insurance benefit for 30+ years. Even with a 5% annual inflation rider on a policy, which is the most common inflation protection chosen by consumers (policies sold in North Carolina must offer one of three types of inflation

protection), the purchasing value of a policy will be substantially less than when enrollment occurred if long-term care costs rise at just 5.1% annually for 30 or 40 years. Paradoxically, long-term care insurance purchased at younger ages provides lower premiums, more uncertainty with respect to what you are actually purchasing given the age at which most persons with AD need care, and perhaps a sense of unwarranted security.

There are at least two other motivations other than asset protection for purchasing long-term care insurance—control over some aspect of future care needs uncertainty and protecting family members from having to provide care. Long-term care insurance provides control over where long-term care is received and affords an individual the maximum amount of choice in receiving such care. In addition, long-term care insurance can prevent family members from having to provide care if needed. While many families may prefer to provide long-term care informally, others may explicitly not want to take this route for a variety of reasons, including the negative effect that caregiving has been shown to have on many caregivers. However, in order to act upon such motivations, an individual or family must have the financial resources necessary to afford such policies.

In the end, it is likely that only 15% or less of middle-aged or elderly persons in North Carolina might conceivably purchase long-term care insurance, based on wealth and income levels necessary to afford such a policy. The state Department of Insurance has some excellent materials on its Website, www.ncshiip.com, to guide consumers in considering whether or not to purchase long-term care insurance. The biggest advancement would be for more long-term care insurance policies to be denominated in terms of care provided, instead of dollars per day. In this way, the time/risk uncertainty involved with purchasing policies at younger ages when premiums are lower would be reduced.

AD is a large and growing concern for the people of North Carolina and the nation as the cost of this disease for society is enormous. Future advances in diagnosis and treatment are hoped for, but the fruition of same is uncertain. In the meantime, society must more clearly understand the costs of AD, and particularly the degree to which a large portion is borne by the intergenerational household of those affected with the disease. A societal discussion is needed to determine whether we will continue to let the epidemiology of the disease spread this part of the burden or whether society would be better served to develop a direct means of spreading these costs in a more systematic manner. Such discussions are needed every bit as much as research designed to develop new treatments for AD. State-level experimentation is often the preferred approach to tackling difficult policy issues. What will North Carolina do? **NCMJ**

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