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What to Expect—From Medicare and from this Issue of the Journal

By Regina M Curran, MA

Some legislation, (e.g., the recently enacted “Medicare Prescription Drug and Modernization Act of 2003”—PL 108-173) receives extensive media coverage. Thus, geriatric care managers are aware of the need to be educated on how the legislation will impact them and their clients. There are many other legislative and regulatory initiatives which are less well publicized. However, any legislative and regulatory initiative can have an impact on geriatric care managers and their clients. Some of these issues are addressed in this issue of the Geriatric Care Management Journal.

The “Medicare Prescription Drug and Modernization Act of 2003” contains some provisions which will be implemented during the next several years. A brief summary of provisions which may be of interest to geriatric care managers follows. The section of PL 108-173 which contains the provision described is listed at the end of each summary.

“Medicare Discount Drug Cards”, available since June, 2004, were one of the first changes implemented. These cards are available to any Medicare beneficiary who does not have prescription drug coverage through the Medicaid program (including section 1115 waivers). The private companies which issue the cards set the fee for the card (the maximum annual fee is \$30) and the terms of the discount (the amount of the discount and the medications with discounted prices). The terms of the discount can be changed weekly. An annual credit of \$600 is included on the cards of those whose income is below 135% of the federal poverty level. “Medicare Discount Drug Cards” can be used through 2005. They will expire when a beneficiary enrolls for Medicare “part D” coverage but no later than May 15, 2006. (Section 101 of PL 108-173)

In 2006, Medicare “part D” prescription drug coverage will be available for everyone eligible for either Medicare “part A” or “part B”. A monthly premium will be charged. There will be an annual deductible (\$250 in 2006) and copayments for prescription drugs. In 2006, beneficiaries will pay 25% of the cost of their prescription drugs (after they have paid the \$250 deductible) until they reach the lower threshold of the infamous “donut hole”—\$2250. While the beneficiary’s annual prescription drug expenses fall within the “donut hole” (\$2250-\$5100 in 2006), the copayment amount will be 100%. (Note that the “part D” premium must be paid while the beneficiary’s copayment amount is 100%.) When the beneficiary’s prescription drug expenses exceed the upper threshold of the “donut hole” (\$5100 in 2006),

the beneficiary will pay a 5% copayment for prescription drugs. The “part D” benefit will be issued by private companies. There will be differences between the plans available in different areas. However, at least two competing plans (one of which can be a Medicare HMO which offers prescription drug coverage) will be available in all areas. (Section 101 of PL 108-173)

Effective January 1, 2006, insurance companies which issue Medigap policies will be prohibited from issuing new “H”, “I” or “J” policies which include prescription drug coverage. (The current Medigap “H”, “I” and “J” policies include modest prescription drug coverage.) Policies issued prior to December 31, 2005 can be renewed indefinitely. Insurance companies are also prohib-

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ited from issuing policies which would cover the “part D” deductibles or copayments. (Section 104 of PL 108-173)

The amount of the federal subsidy for Medicare “part B” premiums will decrease for high income beneficiaries will decrease beginning in 2007. All Medicare “part B” beneficiaries whose modified adjusted gross income is over \$80,000 will be impacted. The percentage of the subsidy will be decreased incrementally until reaching the maximum impact for those whose adjusted gross income is over \$200,000.

The decrease in the amount of the federal subsidy will result in an increase in the premiums that these beneficiaries must pay for “part B” coverage. This provision will be phased in from 2007-2011. (Section 811 of PL 108-173)

During 2010-2015, “comparative cost adjustment program demonstration projects” will be conducted. These demonstration projects will be conducted in a maximum of six “metropolitan statistical areas” (one will be a high-density population area, one will be a low-density population area, and one will be a multi-state area) where at least 25% of the eligible Medicare beneficiaries are enrolled in one of at least two Medicare managed care plans available in that area. The Medicare “part B” premium for these areas will be established by computing the weighted average of the cost of Medicare managed care plans and the weighted average of the cost of (non-prescription drug) services for “traditional” Medicare beneficiaries. (Section 241 of PL 108-173)

PL 108-173 includes three year demonstration projects for Medicare coverage of care management. The demonstration projects will be conducted at no more than four sites. (Two will be urban areas; one will be a rural area; and one will be in a state with a medical school with a Department of Geriatrics than manages rural outreach sites and is capable of managing patients with multiple chronic conditions, one of which is dementia.) It is anticipated that these demonstration projects will be implemented in late 2005. The goals of these demonstration projects are: promoting continuity of care; helping stabilize medical conditions; preventing or minimizing acute exacerbations of chronic conditions; and reducing adverse health outcomes, such as adverse drug interactions related to polypharmacy. (Section 649 of PL 108-173)

The impact of the “Medicare Prescription Drug and Modernization Act of 2003” on caregivers is among the topics discussed by Ronda C Talley and Shirley S Davis in *The Impact of Federal Legislative and Regulatory Initiatives on Family and Professional Caregivers*. Also discussed are other federal programs for caregivers, such as the family caregiver support program, incorporated into the Older Americans Act in 2000, which can provide valuable options for geriatric care managers when developing a care plan for a client.

Most federal programs are implemented by state or local entities. In this issue of the Journal, we have included articles on three topics with authors from three different states. Legal issues are discussed from the “California perspective”, dementia care is discussed from the “Maryland

perspective” and maintaining older and disabled individuals “in the community” is discussed from the “Florida perspective”. Although there may be differences in the ways that states address these topics, the topics are universal.

In “*What Do We Do About Mom?*” *Helping Clients Through The Legal Maze*, Patricia Tobin provides an overview on a variety of legal issues faced by older individuals and their families/caregivers, including Medicaid. Although state Medicaid programs vary, the underlining principles apply in all states.

Medicaid eligibility for those with dementia is can be a challenging issue. Qualifying individuals with dementia for Medicaid may be difficult because they do not require the minimum degree of assistance required for Medicaid eligibility. This topic is explored by Karen Kauffman and Michele Douglas in *Alzheimer’s Disease and Public Policy*. They also address the importance of regulations for assisted living arrangements—especially for residents with dementia.

Assisted living might be an favorable option to nursing home care. In *Promises To Keep: The Successful Implementation of the Olmstead Act To Care For Frail Elders*, Gema Hernandez discusses efforts to enable older and disabled individuals to live in the “least restrictive setting” appropriate for their circumstances.

The 109th Congress convenes in January 2005. Many issues, such as reforming Medicare, Medicaid and social security, will be considered by the 109th Congress—and subsequent Congresses. Geriatric care managers who are well informed on the issues being considered by Congress are a valuable asset in the effort to achieve the best possible legislative results for our profession and for our clients.

Regina M Curran, MA is a geriatric care manager and a member of the Associate Faculty at the College of Notre Dame of Maryland. She chaired the GCM Public Policy Committee for 1999-2004 and represents GCM at the Leadership Council of Aging Organizations.

Qualifying individuals with dementia for Medicaid may be difficult because they do not require the minimum degree of assistance required for Medicaid eligibility.

The Impact of Federal Legislative and Regulatory Initiatives on Family and Professional Caregivers

By *Ronda C. Talley, PhD, MPH¹* and *Shirley S. Travis, PhD, APRN, FAAN²*

Abstract

It is well documented that the requirements of caregiving are increasingly complex and the education and support needs of caregivers are largely unmet. Most current policy and regulatory initiatives to help family caregivers are available only to those “in the greatest social and/or economic need.” In fact, one of the great health and human service conundrums is that only a fraction of the number of long-term family caregivers who need support are receiving assistance from state and federally funded programs and initiatives. In addition, professional caregivers, such as geriatric care managers, report challenges in dealing with their caregiving roles, but these needs receive little attention in regulatory of legislative initiatives. This article discusses existing public policy initiatives designed to assist contemporary family caregivers, the entitlement barriers and challenges faced by professional geriatric care managers, and the persistent unmet needs of family caregivers who have been left behind.

Key Words: caregiver education, long-term family caregiving, geriatric case management

Over the past 25 years, numerous studies documented a condition that Feinberg (1997) termed the financial and emotional “bankruptcy”

of long-term family caregiving. Thus, the call for assistance to family caregivers and related public policy imperatives is not new to the 21st century. However, the burgeoning population of family caregivers who are often engaged in heavy care situations for long periods of time has created a growing sense of urgency to find ways to support family carers (Feinberg, 2003).

The most up-to-date profile of American caregivers was recently reported by the National Alliance for Caregiving and the AARP (2004). According to this national study, of the 44.4 million American caregivers (21% of the adult population) age 18 and over who provide unpaid care to an adult age 18 and over, more than one in five say they provide more than 40 hours of care per week. Most caregivers (83%) are helping people who are related to them and one in four lives with the care recipient. Slightly under half (45%) of caregivers of people who take medications say

their care-recipients need someone to oversee or manage their medication usage.

In addition to emotional and physical demands on caregivers, the cost of caring for a dependent family member includes both costs to caregivers from direct out-of-pocket expenses and lost wages and salaries, and substantial costs to employers (MetLife, 1999). A 1997 report by MetLife estimated that making accommodations for working caregivers cost U.S. employers between \$11.4 and \$29 billion per year. Replacement costs for employees who must eventually quit

their jobs accounted for almost \$5 billion in costs (MetLife, 1997).

The growing crisis in long-term caregiving both drives policy initiatives to help caregivers and creates tension among policy makers who must consider the diverse needs of a complex society (Conway-Giustra, Crowley, & Gorin, 2002; McCann, Hebert, Beckett, et al., 2000). Caught in the middle between policy and service

Long-term caregiving for dependent older adults involves both attending to health issues associated with chronic debilitating conditions and meeting the social needs of the individual and his or her family caregivers.

delivery are professional caregivers, such as geriatric case managers, who understand how to support family caregivers in their caring work over the long haul, but cannot always find the programs, services, and means to do so.

The Policy Landscape of the Late 20th and Early 21st Century

Long-term caregiving for dependent older adults involves both attending to health issues associated with chronic debilitating conditions and meeting the social needs of the

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individual and his or her family caregivers. It is this mix of health and social issues that complicates the task of creating and funding federal and state assistance programs for family caregivers. The holistic approaches that are needed in long-term care scenarios will drive future innovations. For now, case managers are faced with a patchwork of programs and services on which to select their care for long-term family caregivers. Below we briefly describe current and pending legislation designed to assist family caregivers.

The Family and Medical Leave Act (FMLA) of 1993. The first major initiative by the federal government to protect the jobs and work benefits of employees who have family care responsibilities was the Family and Medical Leave Act of 1993 (FMLA) (Public Law 103-3). The law permits full-time employees to take up to 12 weeks of unpaid leave during any 12 month period for a birth or adoption, or to care for an ill child, spouse, or parent (Commission on Leave, 1996). Although this legislation offered important basic job security for millions of American workers it left out those individuals who work in businesses not covered by the federal law, carers of aunts, uncles, siblings, grandparents, or an unmarried partner, and those who cannot afford to take unpaid leave (Feinberg, 1997). Current pending Bills to amend FMLA would permit leave to care for a domestic partner, parent-in-law, adult child, sibling, or grandparent with a serious health condition. To monitor bills introduced in Congress go to: <http://www.gpoaccess.gov/index.html>.

National Family Caregiver Support Program (NFCSP) under the Older Americans Act. The Older Americans Act (OAA) was enacted in 1965 to provide funding to State Units on Aging (SUAs) for a range of services to older Americans. In 1973,

local Area Agencies on Aging (AAA) were added to create comprehensive networks of support for aging adults in every local community. As part of the OAA amendment process of 2000, Congress included funds for states to offer support services for family members caring for persons with disabilities and grandparents caring for grandchildren.

This piece of federal legislation was the first time that SUAs and AAAs were required to focus on the caregiver instead of older consumers in their service areas (Link, 2003). The new program components of NFCSP were designed to target caregivers of older relatives who were beginning to experience significant physical decline in 2 or more activities of daily living (Administration on Aging, 2002). State initiatives can include education and training, individual counseling, support groups, and respite care. Individual states and their AAA networks have flexibility to determine how funding will be allocated under the program (Wacker, Roberto, & Piper, 2002). To maximize the effectiveness of the FCSP, many states have merged their FCSP initiatives with local home and community-based services infrastructures, including state-funded caregiver initiatives. In this way, collaborative programs have effectively addressed the needs of both caregivers and their dependent care-recipients (Link, 2003).

For more information about the NFCSP and reports on the implementation process go to the website for the National Association of Area Agencies on Aging (<http://www.n4a.org>).

Temporary Assistance to Needy Families (TANF). The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 provided states with federal block grants to assist eligible state welfare residents to transition from entitlement to self-sufficiency (Landry, 1999). The program has been particularly beneficial to low income grandparents who are caregivers to

grandchildren.

Dependent care assistance plans and dependent care tax credits. A dependent care assistance plan (DCAP) is one mechanism that employers can use to assist family caregivers with the economic costs of caregiving (Wacker, et al., 2002). Although the plans can cover any dependent family member, the individual must spend at least 8 hours a day in the employee's household. This criterion may be difficult to meet for employed adult children who have responsibility for aging parents' care, but whose parents do not live in their households.

Dependent care tax credits (DCTC) allow employees who incur dependent care expense to offset a portion of these employment-related expenses against their federal income tax liability. Like the DCAP, the program guidelines strongly favor child care circumstances. However, elder care may be allowed under certain circumstances and conditions. State tax credit programs build on the federal tax credit and define the state credit as a percentage of the federal credit (Coleman & Pandya, 2002).

Medicare Prescription Drug, Improvement and Modernization Act of 2003. After many years of debate regarding needed updates to Medicare, legislation passed in December, 2003 offers new benefits to millions of individuals age 65 and over and to certain other groups of individuals with disabilities. Perhaps the most widely publicized benefit is discounts on prescription drugs, starting Spring of 2004, and comprehensive Medicare prescription drug coverage effective January 1, 2006. The prescription medication program requires an application for a discount card that beneficiaries can use to discount their prescription drugs. In addition, certain enrollees may also qualify for up to \$600 in purchasing assistance. Information about the drug discount card applications, approved card sponsors, and related press releases and fact sheets can be found at: (<http://www.cms.hhs.gov/medicarereform/drugcard>).

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The Lifespan Respite Care Act/Ronald Reagan Alzheimer's Breakthrough Act of 2004 (pending).

Respite care allows family caregivers to have time out from their caregiving duties. Until recently purchasing in-home or community-based supportive services to care for a loved one has been largely an unreimbursed out-of-pocket expense for caregivers (National Respite Coalition, 2004). The Lifespan Respite Act, now incorporated in the Ronald Reagan Alzheimer's Breakthrough Act of 2004 in Congress, would provide competitive grants to states to make respite care available and accessible to family caregivers at minimal cost. An entire section of the Breakthrough Act, Title III, legislates assistance for caregivers. While respite care remains a national need, on July 1, 2004, California became the first state in the country to offer paid family leave, providing a model for federal legislative changes.

Geriatric and Chronic Care Management Act of 2004 (pending).

New legislation introduced in June, 2004 as a bipartisan Geriatric and Chronic Care Management Act (GCCMA) would authorize Medicare to cover geriatric assessment and care management for older adults in need of chronic disease management and care coordination (Kramer, 2004). The bill is widely supported by physician and advocacy groups for persons with chronic conditions, such as the Alzheimer's Association.

Currently case management services are available through most state Medicaid programs for home and community-based services. In addition, case management has been a basic service under the Older Americans Act since 1985 and is available on a private pay basis in many communities across the United States (Wacker, et al, 2002). The passage of the GCCMA would make case management services widely available to older adults with signifi-

cant health problems at the point of contact with their primary health care providers and complement both existing Medicaid programs and OOA programs that tend to address social needs of frail older adults.

Entitlement Barriers and Challenges

There are at least four major reasons why family caregivers are not receiving support and services from state and/or federal sources. First, caregivers may not be aware that assistance is available. Second, the program resources may not be adequate to meet demand. Third, stringent eligibility criteria for existing programs may keep utilization rates low. Finally, for personal reasons the caregivers may opt not to use a service even though they are eligible and the service is available.

Caregiver awareness and education. Transitions into a caregiving role are often very subtle and occur over a long period of time, especially when the care-recipient is an older adult with a gradual worsening chronic condition. When assuming the role, caregivers may experience ambivalence or insecurity about adopting the caregiver role (Piercy & Chapman, 2001) or simply see the responsibility as a normal part of family support and filial responsibility for dependent family members (Wicclair, 1990). In any case, most caregivers have to be taught how to find resources and access information in a long-term care system that is not easily understood.

Inadequate resources. To care for a dependent family member is to provide for that individual's overall health and social well-being needs. The number one need of caregivers is finding time for themselves in the hectic routine of caregiving (NAC & AARP, 2004). As we discussed above, several policy initiatives are proposed to provide caregivers with respite care. However, respite care is just one need in a very long list of needs that are currently under-funded areas of caregiver support. Caregivers who cannot afford out-of-pocket expenses for care are forced to do

without help until the burden becomes excessive and intolerable.

Stringent eligibility criteria.

Because there is often a paucity of support for family caregivers, agencies that do have adequate funding can generally serve only those caregivers in greatest need. This process becomes a vicious cycle of late entry into and rapid discharge from a program or service because the needs of the care-recipient quickly exceed the ability of the agency to provide beneficial care to the care-recipient or appropriate support to the caregiver. While individuals with the greatest levels of dependency are served by this approach, it could be debated about whether those in the "greatest need" have been served.

When caregivers opt out of programs and services. It is not clear why many caregivers are reluctant to take advantage of support when they are eligible and when support is available. Perhaps they have not had positive caregiver role models to learn how to reach out for assistance, or perhaps they have not had positive experiences when they did ask for assistance or information (Berg-Weger, Rubio, & Tebb, 2001). Some caregivers may simply feel that only they can provide high quality care to a loved one (Bar-David, 1999). What is known is that caregivers often wait until they are in a crisis situation to seek assistance or to attempt to change their caregiving situation (McAuley & Travis, 2000; Montgomery & Kosloski, 1995; Zarit & Leitsch, 2001).

Unmet Needs of Contemporary Caregivers

Providing caregivers with the knowledge, skills, and support they need to do their job wells is the greatest challenges in long-term care today. Unfortunately, even when intervention programs are in place, they produce few or no significant effects on expected outcomes (Cooke, McNally, Mulligan, et al., 2001). One explanation, called the floor and ceiling effects on outcome measures,

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is that a substantial number of caregivers in demonstration projects report few or no problems on measures of interest, such as burden or depression, when they begin a program. These caregivers apparently seek information in anticipation of future caregiving issues and not out of current need. When organizations target anticipatory caregiving groups and measure outcomes that are expected to change as a result of an intervention, there is no improvement of problems that the participants do not yet have (Zarit & Leitsch, 2001).

Targeting caregivers in great need of educational support and timing the delivery to coincide with teachable moments in the lives of caregivers is hard work. It is difficult to locate these caregivers if they are not already in some type of care. Typically, hard to reach caregivers also live in historically underserved areas, such as inner cities or rural environments, or may be involved in heavy care situations that really do prevent them from leaving their loved ones for any appreciable amount of time.

Much more creative and innovative efforts are needed to create programs that reach caregivers with diverse educa-

tional and support need at multiple points in their caregiving histories (Piercy & Chapman, 2001; Travis & Piercy, 2002). To this end, innovations such as teleconferencing training groups hold great promise for the future. Early evaluations suggest that teleconferencing can be just as effective as traditional on-site training, and provides a high level of satisfaction to program participants (Rosswurm, Larrabee, & Zhang, 2002). Ongoing innovations in training and support should seek to continuously raise the performance bar on caregiver education and support.

Summary and Conclusions

The regulatory model of social policy and service delivery that we have described in this paper was built on a tradition of formal procedures,

rules, control over agency resources, and relative uniformity in meeting service needs (McAuley, Teaster, & Safewright, 1999). In the case of policy to support family caregiving, paradigms that include elements of flexibility, the ability to address the needs of the individual and unique caregiving situation, personal relationships, and creative/innovative solutions appear to be more desirable (Feinberg, 2003).

We find ourselves at the beginning of the 21st century with a need to adapt a traditional regulatory model to contemporary caregiving situations, but

with little guidance about how to accomplish the task. As professional caregivers, case managers, in particular, are literally on the front lines of the growing conflict between the traditional regulatory model of social policy and service delivery and the needs of their caregiver clients. The current regulatory system approach bases decisions on the principle of the greatest good for the most people, establishes rigid adherence to rules in decision making, and distances decision makers from people and the consequences of their decisions (McAuley, et al., 1999). In contrast, caregivers need more humane and flexible social policy.

As an alternative to the current regulatory approaches, McAuley and colleagues (1999) suggest a feminist ethics perspective (Held, 1993) to social services policy that includes: (1) including all voices in decision making, (2) stressing the importance of caregiving, (3) valuing relationships, and (4) embracing complexity in decision making, and (5) encouraging the inclusion of emotion and intuition as elements of effective decision making. This type of approach, for instance, would recognize the significant contributions and needs of professional caregivers as members of the care team. While it is true that creating case management programs solely on feminist ethics of caring may be too labor intensive to be effective (McAuley, et al, 1999), incorporating some of these principles into contemporary practice may be the only way that true reform will ever be achieved.

In the meantime, caregiving advocates must monitor policy agendas, legislative initiatives, and funding priorities at both state and federal levels. The process is complex and requires constant vigilance. For an example of national leadership, caregiver advocates in the United States might look to Canada, whose Prime Minister recently appointed a Minister of State (Families and Caregivers) to oversee its growing programs in their area. In the United States, groups such as the National Quality Caregiving Coalition (NQCC) of

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the Rosalynn Carter Institute for Caregiving are available to provide information and a unified voice for caregiver advocacy and policy debate. For more information visit the NQCC website at (<http://www.nqcc-rci.org/index.htm>).

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Footnotes

- 1 Executive Director and Professor, Rosalynn Carter Institute for Caregiving, Georgia Southwestern State University, 800 Wheatley Street, Americus, Georgia 31709. Phone 229.928.1234; fax 229.931.2663; email: talleyrc@rci.gsw.edu & National Quality Caregiving Coalition of the Rosalynn Carter Institute for Caregiving, 750 First Street, NE, Washington, DC. 20002. Phone 202.336.5606 www.nqcc-rci.org
- 2 Dean, College of Nursing and Health Science, George Mason University, 4400 University Drive - MSN3C4, Fairfax, Virginia 22030-4444. Phone 703.993.1918; fax 703.993.1943.

What Do We Do About Mom? Helping Clients through the Legal Maze

By Patricia Tobin, J.D. CELA

When the adult children call you for help, they look to you to help them manage the confusing issues, choices and solutions that surround long term care

Often, on your first visit, they present you with the file box of papers, the shopping bag of medication bottles, the manila envelope of unopened mail, and their most pressing questions. Often these questions can be summarized as:

“How do we meet the costs of care?” and

“How can we have adequate legal control of the patient’s finances so that we can develop and implement the care plan we need?”

To answer these questions, care managers need to be conversant on two important topics:

1. What social services programs (especially for financial assistance) exist, and how can these programs be helpful. This will be termed public benefits planning
2. What are the legal documents that clients may have created or wish to create, and how do these documents affect the implementation of the care plan. This will be termed estate planning.

I. Myths And Misconceptions

There are so many myths and misconceptions about public benefit planning and estate planning, that they have become part of the conventional wisdom. When your

clients raise this misinformation with you, here’s an easy way to respond:

Myth No. 1

“Mom has Medicare, and pays \$200/mo. for additional Medicare supplemental insurance. Why worry about Medicaid eligibility?”

Don’t count on Medicare.

Medicare covers nursing home care only in specific situations. At best, Medicare will fully cover only 20 days of nursing home care; even with a supplemental policy, full coverage is rarely provided beyond 100 days.

This restriction under Medicare results in the exclusion of many patients who suffer from Alzheimer’s or other dementing diseases, or who are admitted to the nursing home after only a brief hospital emergency room visit or directly from home.

Just one family member will need an INCOME (not just savings) of \$50,000- 85,000.00 per year to cover the cost of his or her custodial care in a nursing facility. If both spouses, or two generations need care, this is multiplied. Since few families meet this level, virtually all clients need to be aware of the Medicaid program.

Myth No. 2

“If an elderly client goes into a nursing home, won’t Medicaid take the house?”

Help families understand the difference between qualifying the elder to receive care and protecting the estate for heirs. The federal Medicaid program does NOT require that seniors “sign over” property to qualify for coverage during their life,

however, the program MAY require that reimbursement be paid after death.

Don’t recommend selling the patient’s home unless you have considered all the options. Under many circumstances, individuals can own their residences and still qualify for Medicaid coverage. Discuss your state’s rules for homeowners with your local Senior Citizens Legal Services office, a welfare department worker, or an elderlaw attorney.

Under federal Medicaid law, each state must try to recover any funds that the state paid on behalf of a Medicaid patient, if the patient owns any property at the time of death. This attempt to recover expenditures is known as a “Medicaid estate claim.”

Under certain conditions, the Medicaid agency can put a legal restriction on the sale or transfer of real estate to insure that the property will still be available at the time the patient dies. This restriction is called a “lien.”

In various states, the Medicaid agencies pursue claims and liens with differing degrees of efficiency and vigor. Their goal is to recover money, which can be paid back to the state.

If this Medicaid claim or lien imposes a serious hardship or serves to deprive someone of his or her home, the state must follow the federal exceptions and hardship rules. Often, a compromise can be worked out. Medicaid can only be reimbursed for what it actually paid out. If private insurance or Medicare, rather than Medicaid, paid for the medical services, Medicaid cannot recover that amount from the heirs.

Note, clients who are injured and recover from the person who caused the injury are subject to other claims and liens from Medicare, Medicaid, Worker’s compensation and PRIVATE health insurers and providers. (Immediately seek expert advice in those cases).

Myth No. 3

“What do you mean Medicaid imposes a penalty for giving away

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money. I heard I can give away \$10,000 or 11,000 per year with no problem?"

Tax Law and Medicaid are two different animals. Under tax law, in 2004, single people can give up to \$11,000, and married couples can give away up to \$22,000 per recipient, per year without having to report the gift to the IRS or pay gift tax. That exclusion only applies to tax law. Medicaid law requires disclosure of **all** gifts, and will penalize an applicant who gives away assets.

Transfers must be reported, and applicants who transfer assets will be disqualified to receive benefits for a certain number of months; the exact number depends on the state's formula. For example, a \$25,000 gift causes an ineligibility period. In California, in 2004, the penalty for giving away money would be approximately 5 months; in Alabama, approximately 7.

Myth No. 4

"Mom named me as the executor of her will, so I can do anything I need to manage her money."

Who really has control? An "Executor" named in a Will has absolutely NO authority to act until the maker of the Will (known as the testator) dies. If the elder created a "Living Trust" or "Durable Power of Attorney" (**DPA**) which names the spouse or adult child as trustee or Durable Power of Attorney agent (also called an "attorney-in-fact"), the family may actually have adequate authority to act on behalf of an incapacitated elder, and the family is merely, but understandably, confused about legal terms.

Unfortunately, in many cases, the elder did no lifetime estate planning and, in fact, if the elder signed nothing but a Will, the family may need to go to court to obtain authority to get information about finances to plan for Medicaid, sell or refinance property or expend funds for care.

Myth No. 5

"The hospital social worker told us we need to go to a lawyer and get a Power of Attorney for Grandpa."

The only person who can create a Durable Power of Attorney to allow access to records and assets owned by Grandpa is: Grandpa. The owner of the property is called the "Principal". The "manager" or the person who carries out the action is called the "Agent" (also known as an "Attorney-in-Fact").

If a Principal is mentally incapacitated and cannot understand what he or she is signing, a Power of Attorney cannot be validly created. The Principal must have legal capacity to execute (sign with certain formalities) the document and have a basic understanding of the directions given in the Power to the Agent.

A family member cannot "get a Power of Attorney" for someone else, and a conscientious lawyer should not hand the family a blank document to be signed by an uncomprehending elder.

This is disappointing news to a family who, in the absence of a valid Durable Power of Attorney, may not be able to access assets in a brokerage account, refinance a home or get medical and financial information so that they can effectively appeal a denial of insurance coverage. They may need to start a more burdensome process of getting court authorization to act.

Myth No. 5

"Aunt Mary put my name on her bank account and her house, what more do I need?"

Bank, brokerage accounts and real estate are treated differently. Joint ownership alone may not give sufficient authority to act. Since banks generally allow access to all persons named on the account, families typically expect that such flexibility will apply to all property.

Banking laws specifically allow one of the joint owners to exercise control. But, for most other assets, especially real estate, joint ownership means ALL owners must act together.

If one owner lacks mental capacity, and has made no estate plan to allow a substitute to participate in a transaction, (see below concerning DPA and Living Trust) typically the transaction cannot be completed.

Myth No. 6

"I had to sign this Living Will at the Hospital."

Don't be intimidated. Under the federal Patient Self-Determination Act, hospitals nationwide are required to advise patients of their right to refuse treatment and their right to execute a document known as a "Durable Power of Attorney For Health Care" or a "Living Will" or an "Advance (Health) Directive". These documents allow someone else to make health care decisions, if the patient is too sick to make the decisions personally.

Frequently, patients come away with the impression that they are required to sign such a form. In fact, the hospitals are required to advise their patients of their rights, but patients are not required to do ANYTHING about advance directives.

II. A Pocket Guide to Public Benefits

To meet the clients' needs for public benefits planning, you must know what the various programs provide:

Social Security: This is a check received monthly. This benefit is available to retired workers, disabled workers or certain dependents of those workers. The Old Age Survivors and Disability Insurance Program (OASDI) (which pays to disabled or retired wage earners or their survivors) is not based on financial need.

Social Security is the best and most comprehensive disability and life insurance policy young wage earners will ever own, be sure to refer families to the Social Security Administration or adequately screen for eligibility for every family with whom you work.

Supplemental Security Income (SSI): This benefit consists of a check from the Social Security Administration. It is normally received on the first

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of the month. The SSI program is **based on financial need**. The amount payable is based on the recipient's living situation.

In some states, the recipient automatically gets Medicaid and can qualify for chore worker services at home. In some states, the recipient can receive food stamps. In other states, often with higher benefit rates, recipients get a state supplemental payment known as SSP and are not permitted to receive food stamps.

Medicaid: (Comparable programs are known by other names, in other states, such as Arizona Long Term Care System (ALTCS) in Arizona, Medi-Cal in California, MassHealth in Massachusetts.)

This medical coverage benefit is based on financial need. Medicaid is a program, which provides medical care to people with limited assets and low incomes.

General Rules

Clients do not receive cash from Medicaid. However, Medicaid can be used as health insurance to cover the costs of physicians, hospitals, prescriptions, and skilled nursing facility care. Clients use their cards to obtain covered services

from a participating doctor or provider. The provider then bills the Medicaid program for services.

Providers usually are paid less than the usual and customary rate for services, and only basic or generic items are covered. In limited circumstances, a related program can be used to cover the cost of private health insurance premiums or Medicare premiums or co-pays.

Caregivers for elders often seek assistance under the Medicaid program when the patient requires twenty-four hour per day "custodial care." "Custodial care" means providing assistance with the activities of daily living (ADL's) such as dressing, eating, grooming, getting to the bathroom and bathing.

The Medicaid program is the largest source of funding for patients who receive nursing facility care. In some states, such as New York, Medicaid provides significant funding for home based long term care.

While Medicaid is a federal program, within certain guidelines, the states are permitted to vary the eligibility and coverage rules for Medicaid.

Under federal Medicaid rules, if one member of a couple requires placement in a Medicaid covered long term care facility, and the other spouse can live outside of a nursing home, that married couple is subject to less restrictive eligibility rules, known as "spousal impoverishment rules".

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EVER WONDER WHAT THOSE LETTERS MEAN AFTER THE SOCIAL SECURITY (SSA) NUMBER?

Looking at these 30 Categories of suffixes gives you some idea of how broadly SSA coverage reaches. It is the most cost effective disability and life insurance policy any young adult can EVER buy!!

CODE	IDENTIFICATION
A	Wage Earner (Retirement)
B	Wife
B1	Husband
B2	Young Wife
C1-C9	Child - Includes disabled or student child
D	Aged Widow
D1	Widower
D6	Surviving Divorced Wife
E	Widowed Mother
E1	Surviving Divorced Mother
E4	Widowed Father
E5	Surviving Divorced Father
F1	Father
F2	Mother
F3	Stepfather
F4	Stepmother
F5	Adopting Father
F6	Adopting Mother
G	Claimant of Lump-Sum Death Benefits
HA	Wage earner (disability)
HB	Wife of disabled wage earner
HB1	Husband of disabled wage earner
HC	Child of disabled wage earner
J1	Primary Prouty entitled to deemed HIB
M	Uninsured - Premium Health Insurance Benefits (Part A)
M1	Uninsured - Qualified for but refused HIB
T	Uninsured - Entitled to HIB under deemed or renal provisions
W	Disabled Widow
W1	Disabled Widower
W6	Disabled Surviving Divorced Wife

Be aware that most group and private disability insurance policies (probably including your own policy—if you are a small business owner, you DO have disability insurance, right?) provide for an OFFSET of Social Security Disability Insurance benefits.

This means that if a client has been receiving private disability benefits of \$2500 per month, and will start to receive \$1300 in monthly Social Security disability benefits, the disability payment will be reduced to \$1200 when Social Security starts.

The client will get a total of \$2500 per month, not \$3700. Prepare your client for this, because there may be a recoupment of overpaid private benefits or a debt for a BIG repayment!!

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Spousal Impoverishment Rules

These “spousal impoverishment rules” allow the “WELL” spouse at home to keep assets and preserve income at levels far in excess of the usual limits for income and property. However, the “ILL” spouse in the institution is typically subject to asset rules which are comparable to the rules for an unmarried public benefits recipient.

Resources for state specific rules

The programs can vary widely from state to state. See your own state’s information. The following references can help you and your clients learn more about your specific state programs for in-home care and medical coverage, and benefit programs in general.

National Association of Protection and Advocacy Systems, Inc

www.napas.org

900 Second Street, NE, Suite 211
Washington, D.C. 20002

Phone: 202-408-9514

Fax: 202-408-9520

Eldercare Locator 1-800-677-1116.

Area Agency on Aging <http://www.n4a.org/links.cfm>

Social Security/SSI www.ssa.gov 1-800-772-1213

Medicare www.medicare.gov

Veteran’s Administration
www.va.gov

Veteran’s Legal Service Project
www.nvlsp.org

Medicare: This benefit is available only to individuals who are eligible to receive Social Security retirement or disability benefits, or in limited situations, have kidney failure. It is not available to those who receive Social Security as a dependent or survivor, unless they have another link to eligibility. Medicare does not

cover the cost of custodial long-term care in a skilled nursing facility.

Medicare is a completely different program from Medicaid, and it is **not** based on financial need. People with Medicare coverage receive only a small white paper card with a red, white and blue border, which says, “Health Insurance Claim Number” on it. It should indicate whether the person is qualified for both Part A (hospitalization) and Part B (medical) insurance. At present, this card will not cover most outpatient prescriptions.

However, see the pilot program (website listed above) for covering certain expensive medicines for cancer, Multiple Sclerosis and other chronic illnesses on an outpatient basis.

The new Medicare prescription program is scheduled to be implemented in January 2006. In general, to benefit from the program, you have to sign up with a particular plan provider. That provider offers a list of covered drugs, and only those drugs will be covered. Different providers may offer different covered lists. Dually eligible Medicare/Medicaid clients will face confusing and complicated procedures to have their medications covered.

Temporary Aid to Needy Families [formerly known as Aid to Families with Dependent Children (AFDC) and known by other names in various states]: This is a cash grant program, which pays benefits to dependent children and their caretakers. If the parent or parents are deceased, disabled, absent or unemployed, a very low income-low asset child will qualify. The client will usually have a “worker.” It may be necessary to have the client obtain confirmation from the worker of the exact nature of the specific program, as coverage under this program varies. Normally, however, a TANF parent or child receives a monthly cash grant payment, automatic eligibility for Medicaid, and food stamps.

This can be a critical benefit for grandparents who are raising their grandchildren. Often Medicaid, food

stamps, vocational training, child care, child support enforcement and kinship or grandparents adoption and foster care payments are tied to this program.

In Home Support Services

(IHSS): This is a program to provide “chore workers” or aides to provide personal care services to aged or disabled people in their own homes. It is available only to financially needy individuals. IHSS can provide homemaker services to disabled individuals to enable them to remain in their homes and avoid the need for institutionalization. Benefits are not available for full-time 24-hour a day care, however, depending on the availability of services, current budget funding, and the disability of the individual, significant home care services can be provided.

It is known by different names outside of New York and California and is often tied to the Program for All-Inclusive Care of the Elderly (PACE) and “home or community-based (waivered)” Medicaid.

Veteran’s Benefits: Veterans may be eligible for health care, cash benefits or home care services known as “Aid and Attendant” services. “Veteran’s Pension” is one type of cash grant available to low income, disabled or aged veterans (or their widow(ers)).

The other major veteran’s cash benefit is called “Veteran’s Compensation.” This is available to veterans of any age who have a “service-connected” injury. The amount of compensation depends on the disability “rating” of the veteran. The veteran is rated as 10 to 100 percent disabled. For a 50% or greater service-connected veteran, the compensation can provide a very substantial monthly payment and health benefits. The finding of disability, especially for post traumatic stress disorder, can be made decades after the service.

Every veteran (or veteran’s widow (er)) on your caseload should be referred to apply for linkage at a Veteran’s Administration Hospital. It can take months or (even) years before the intake is completed, but for

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some veterans it will provide substantial help at low or no cost and usually transportation can be arranged or provided.

III. Estate Planning Basics

Clients are often influenced by aggressive marketing by financial planners and, yes, even lawyers. (Author's note: the author is a lawyer) Clients are often led to believe that simply signing a Trust will make them eligible for Medicaid.

While they are highly touted as the solution to so many problems, in reality, Living Trusts do not create eligibility. In general, Trusts and Powers of Attorney are useful in Medicaid planning only because they allow property to be managed, sold or spent when the owner is unable to handle his or her finances. Trusts managed by adult children for their parents require ongoing administration, and Trustees may have unexpected obligations to their siblings or other beneficiaries.

Special kinds of trusts can be used to make it easier to become eligible or remain eligible for Medicaid, but they are generally useful only in special cases, and only when they can be created and maintained carefully enough to continually meet the exceptions to the general program rules of the public benefit program.

In some cases, it is necessary to plan for the needs of two generations: a parent who is facing the need for long term care; and a (usually adult) child who is disabled and may need to remain qualified for public benefits.

Two generation planning can help to maximize the value of any assets which would be available to the child after the parent(s) die(s), by preserving any needs based public benefits for which the child may be eligible.

An example of a situation that would benefit from two generation planning is the family where the 45 year old mentally disabled child lives

with the 75 year old mother and the 80 year old father. The child receives SSI benefits and Medicaid, and one parent now needs nursing home care.

In special circumstances, such as two generation planning, a special needs trust can be created by the parent (called a settlor or trustor) to provide a reserve fund for the child, and still allow one of the parents to qualify for Medicaid nursing home benefits. Upon the death, or disability of both parents, the property can be managed by a trustee of the special needs trust for the benefit of the surviving child (called a beneficiary).

HOW DO YOU KNOW YOUR LAWYER KNOWS ELDERLAW?

1. What is the difference between a Board and Care facility (also known as Adult Foster Care or Residential Facility for the Elderly or other names) and a Nursing Facility?
2. What is your state's name for the Medicaid program, and what is the difference between that program and Medicare?
3. Have you ever represented anyone in a conservatorship or adult guardianship matter?
4. If a client was diagnosed with Alzheimer's disease one year ago and now wants to transfer her home to her daughter, can the lawyer spot at least 4 of these 6 issues:
 - a. Transfer penalties
 - b. Medicaid (Medi-Cal)
 - c. Capital Gains Tax
 - d. Fiduciary duties
 - e. Estate Tax
 - f. Legal and Personal Decision Making Capacity

The following summaries can help you to help your client to distinguish the various estate planning documents, which they may seek to create or perhaps have already created.

Durable Power of Attorney for Finances (DPA): The principal (i.e. the person who owns the property) writes or signs a document, which appoints someone (the agent or "Attorney in Fact") to manage the finances. This document directs how the Principal wants the property managed. This Power of Attorney can become effective when the Principal becomes mentally incapacitated or at a time when the Principal no longer wants to manage the property. The document will be effective when the Principal is incapacitated **ONLY** if it is termed "Durable".

Durable Power of Attorney for Health Care (DPAHC): The "maker" of the Power (known as the Principal) names someone to consent to (or refuse) health care treatment. This can include consent to invasive tests, the release of medical records and even the use or withdrawal of life sustaining treatment. This power is effective only if the Principal is mentally unable to decide. (NOTE: a Living Will is a formal statement of your wishes concerning the use or discontinuance of life sustaining treatments; it is not used in California, but in other states this is sometimes used interchangeably with the DPAHC.)

Living Trust: The Trust is like a contract, which is created to allow management, distribution and expenditures of property manager by the owner of the property or by a substitute manager appointed by the owner. This "contract" is similar to a corporation because, by a written document a special framework is created which can continue to own property, after the owners die or are otherwise no longer involved in management. The instructions in the Trust document direct how the trust will operate. State law and tax laws also direct what the trustee is allowed to do.

When the owners of the property, known as the Settlers or Trustees,

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hold the property in this special framework, someone else, a Trustee, can manage the property for the benefit of the Settlers or for the benefit of others named by the Settlers, such as children or charities. When the Settlers die, the trustee can usually distribute the property to the children, or other heirs, without going through the court process, known as probate. A trust can also be used by married couples to avoid estate taxes on death.

Will: A will appoints an executor and directs the executor how to distribute property to friends and family after death. It gives no authority over property during the owner's life. An executor cannot

manage property if the person who makes the will and signs it (known as the testator) is ill, nor make health care decisions. Wills can be superseded by joint tenancy and other beneficiary designations.

Special Needs Trusts: These are trusts which generally include restrictive language and are designed to closely follow the requirements of public benefit rules. When it is properly funded and administered, a special needs trust may be used to hold a "nest egg" or reserve fund for a beneficiary as an exception to the general rule that the public benefits recipient is not permitted to have access to assets in excess of the program limit, which for most purposes is \$2000. It is helpful

to think of such a trust as a process, not a document. Such sophisticated planning must be handled very carefully and requires expertise

in both estate planning and public benefits areas.

A care manager who is familiar with both estate planning and public benefit issues will be better able to assist the family to provide the best available and affordable care and answer the question of "What do we do about Mom".

Patricia Tobin is an attorney licensed to practice in New York and California. She graduated from Cornell Law School. She specializes in Estate Planning, Elder Law and legal planning for those who need to provide for a disabled family member. She writes articles on Elder Law and teaches Continuing Legal Education classes for lawyers and other professionals. She was elected to the Board of the National Academy of Elder Law Attorneys in May of 1994. She is certified as an Elder Law Attorney by the National Elder Law Foundation and is a Fellow of the National Academy of Elder Law Attorneys.

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Alzheimer's Disease and Public Policy

By Karen S Kauffman, PhD, CRNP, BC
and Michele Douglas is the

The rapid rate of increase of Alzheimer's disease in America is astounding. Today, an estimated 4.5 million people have Alzheimer's disease. This number has more than doubled since 1980 and will continue to grow to 11.3 million to 16 million by 2050 (Herbert, Scherr, Bienias, Bennett, and Evans, 2003). Nationwide, Alzheimer's disease has become the 8th leading cause of death among all races, both sexes, and all ages (CDC, 2004). In Maryland, nearly 85,000 people had Alzheimer's disease in 2000. By 2030, this number is expected to increase to nearly 195,000 (Alzheimer's Association, Maryland State Public Policy Committee, 2003.)

Currently, national direct and indirect annual costs of care for individuals with Alzheimer's disease are at least \$100 billion and will also increase exponentially (Ernst and Hay, 1994.) Within a societal context of increasing competition for finite resources, advocates for people with Alzheimer's disease face tremendous challenges to assure access to and quality of care. An effective and efficient public policy agenda is one important strategy to address these challenges.

From the perspective of Maryland's Public Policy Committee of the Alzheimer's Association, the following paper will define public policy, describe how public policy is set, and discuss how public policy shapes quality of care as it relates to

assisted living and to access to care as it relates to Medicaid eligibility. The significant role of geriatric care managers in setting and implementing a public policy agenda will be described.

Public Policy

Public policy is defined as the laws, rules and regulations, procedures and budgetary actions enacted by government bodies. Through advocacy and education, the Maryland Public Policy Committee of the Alzheimer's Association works on behalf of people with Alzheimer's disease and related dementias, and with their families and caregivers to positively affect state public policy. The Committee (comprised of professional and lay experts in the

Currently, national direct and indirect annual costs of care for individuals with Alzheimer's disease are at least \$100 billion and will also increase exponentially

fields of Alzheimer's disease and public policy) establishes, oversees, and advocates for the organization's public policy agenda.

Effectively influencing public policy on a legislative, regulatory or budgetary issue, can be achieved using a variety of methods. These methods include educating elected and appointed officials, educating and organizing the public to advocate their support or opposition to a particular issue, directly lobbying

elected officials, working with partner organizations and groups of people such as caregivers that have a similar interest in the outcome of an issue, and developing coalitions of organizations that share a common interest, mission or philosophy.

The role of a geriatric care manager in advocacy, both individually and systemically, is vital. As experts in the field, geriatric care managers have the ability to draw on their real world experience to educate policymakers and the long-term care industry about successes, unmet needs (including resources, necessary system changes) and the effect of current policies on their clients' everyday lives across the spectrum of care. Through education and advocacy, geriatric care managers are significant players in helping to shape the body of long-term care public policy to provide better care for the growing aging population.

Quality of Care - Assisted Living

Recent research from the *Maryland - Assisted Living Study (MD-AL)*, conducted by the Johns

Hopkins University Division of Geriatric and Neuropsychiatry, demonstrates the significant presence of dementia in people living in assisted living (Rosenblatt, A., Samus, Q. M., Steele, C. D., Baker, A. S., Harper, M. G., Brandt, J., Rabins, P. V., and Lyketsos, C. G. (2004). Using a stratified

random sampling of assisted living facilities of all types and sizes throughout the state, the study found 80% of the residents had dementia or a psychiatric disorder (such as mood, anxiety or psychotic disorder) and 14% had both dementia and a noncognitive psychiatric disorder. The overall prevalence of dementia was 68%. Findings from this study can provide policymakers with a greater understanding of the

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prevalence of dementia in today's assisted living and the concomitant issues to be addressed.

Maryland first began regulating assisted living under a single point of oversight within the Department of Health and Mental Hygiene in 1999. State regulations that have been promulgated over time are currently in the process of being wholly reviewed in light of the evolving nature of assisted living facilities in the state and the composition and needs of the residents. Issues to be addressed in the state's regulatory review process that impact the care and safety of residents with Alzheimer's disease and related dementia (such as licensure, awake overnight staff, and dementia-specific training for managers and direct care staff) have also been debated at the national level. The Report of the National Assisted Living Workgroup (2003) provides guidance to states to improve policies, including regulations and practices affecting the assisted living industry.

States can play an important role in abating harm and improving quality of care for residents by licensing and monitoring assisted living. Assisted living facilities in Maryland are currently licensed to provide up to three levels of care; level three being the highest care need. Given the sheer number and types of assisted living facilities and variety of services offered, the National Assisted Living Workgroup (2003) rightly concluded that, "Quality assurance begins with licensing..."

In the review of its assisted living regulations, Maryland faces the difficult task of ensuring that there are adequate standards and oversight.

Lack of resources, both staff and budget, continue to plague the state's oversight system. Although the state is required to survey each facility annually, only 2% of mandated surveys have been completed in the past few fiscal years.

In its January 2004 report on Maryland's Assisted Living Program, the Department of Health and Mental Hygiene's Office on Health Care Quality states, "Because there are no routine inspections, there is little continuity or even assurance that a provider who barely met standards last year meets minimal requirements this year." This stands in stark

Policymakers play a critical role in allocating resources and setting policies that ultimately have a significant impact on the quality of care in assisted living facilities.

contrast to the National Assisted Living Workgroup's (2003) recommendation that, "Each state shall have adequate survey staff to enforce its assisted living regulations..." Advocates and providers are increasingly concerned about the impact of declining resources on the safety and quality in assisted living.

Currently, Maryland does not require assisted living facilities to have awake overnight staff. The issue of whether or not to require awake overnight staff is under debate in Maryland. The National Assisted Living Workgroup recommends that states require awake overnight staff in assisted living facilities to provide oversight and meet scheduled and unscheduled needs of residents. Sundowning, a phenomenon common for people with Alzheimer's disease, often results in increased wandering, restlessness, confusion and agitation through nighttime. As the numbers of

residents with Alzheimer's disease and related dementia have significantly increased in assisted living, awake overnight staff is vital to respond to emergencies, ensure safety and meet the needs of the residents.

The body of knowledge regarding dementia quality of care and training has increased dramatically in recent years. According to the *MD-AL Study* (Rosenblatt et al, 2004), direct care staff was unable to correctly identify Alzheimer's in 22% of residents with the disease. Certified nurse aides in another recent study showed a 75% improvement in applied

knowledge after taking basic dementia training (Doerr Foundation Research Study, 2000). Specific training to increase staff ability to identify dementia, understand and manage common behaviors associated with dementia including wandering, agitation and depres-

sion among others can result in improved health and quality of life for residents and an improved work environment for staff. Caregivers and providers alike note the importance of ongoing staff training for both job satisfaction and in quality of care. (American Association of Homes and Services for the Aging, 1999 and 2002)

Policymakers play a critical role in allocating resources and setting policies that ultimately have a significant impact on the quality of care in assisted living facilities. Therefore, ensuring that policymakers understand the scope and complexity of the needs of residents with Alzheimer's disease and related dementia and shape state laws and regulations to address those needs throughout varied assisted living settings is an important challenge for families, caregivers, advocates and providers.

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Access to Care - Medicaid eligibility

Access to appropriate and quality care is complicated by the long-term and progressive nature of Alzheimer Disease, leading to need for total and round-the-clock care that is often provided in nursing homes. According to Harrington, Carrillo, Wellin, & Burdin (2003), nearly 24 thousand Marylanders resided in the state's 229 nursing homes in 2002. Based on the estimates from the National Nursing Home Survey (1985), at least half of these residents have AD. Of the total number of Marylanders residing in nursing homes, 62% received care reimbursed by Medicaid. For each of these residents, Medicaid spent on an average \$4874 per month. Over the past few years, the annual rate of growth for Medicaid in Maryland has been nearly 9%. It is expected that this rate will continue if not increase.

To become eligible for Medicaid, older adults must meet both financial and medical eligibility criteria. Due to the high costs of long-term care, older adults with AD often spend down quickly to less than \$2500 in assets and become financially eligible. To be deemed medically eligible, the same adults must need a level of care that requires full-time (24-hour) supervision by a licensed nurse (RN or LPN). In other words, Medicaid eligibility reflects the need for nursing home care (nursing facility services).

To control the growth of long-term care costs and to develop alternatives to expensive institutional care, Maryland's Department of Health and Mental Hygiene (DHMH), in collaboration with the Department of Disabilities (DOD) and the Department of Aging (DOA), is proposing to create a new Medicaid waiver program, CommunityChoice, to manage services for older adults and people with disabilities. The program would be mandatory managed care for

a cohort 70,000 Marylanders who are dually eligible for Medicaid and Medicare. This cohort population is comprised of people already living in the community (~40,000), in nursing homes or chronic hospitals (~22,000), and in the community on Medicaid waivers (~8000) (<http://www.dhmh.state.md.us/mma/longtermcare/>. Accessed 09.16.04)

The CommunityChoice program proposes to offer a comprehensive set of care services, including primary, acute, long-term care, and mental health, with the goal to integrate Medicare funding and services for dual eligibles. It also intends to support the State's *Olmstead* objectives and expand the array of services available in the community to people who need long term care.

Community Care Organizations (CCOs) would be the vehicle to offer and manage the CommunityChoice program. CCOs would receive a Medicaid capitation payment to coordinate and pay for health services provided by a network of providers, such as care coordinators, personal care assistants, nurses, physical therapists, etc.

The objective of CommunityChoice is to slow the growth of long-term care costs by substituting lower cost community care for more expensive nursing home care, reducing hospitalizations, and coordinating care. Care in the home would be the least expensive and would be considered first by the CCO

care coordinator. An individual would be moved into higher levels of care services when the level of care needs rise. Nursing home care, the most expensive, would be considered the last resort.

The Alzheimer's Association and other Maryland organizations advocating for older adults raise important policy and implementation issues with this proposal. For example,

To become eligible for Medicaid, older adults must meet both financial and medical eligibility criteria. Due to the high costs of long-term care, older adults with AD often spend down quickly to less than \$2500 in assets and become financially eligible.

given that CommunityChoice would be mandatory for all dual eligibles, and that Medicaid medical eligibility (needing 24-hour care supervised by a licensed nurse) would have already been determined, is it possible that complex care equivalent to nursing home care be provided in the community and at a lesser cost? What control or self-determination will participants have when planning for their own care? What services will be covered under the program? How are

standards of care set, measured, and monitored? How will continuity of care be defined, measured, and monitored? How many nursing home residents will be transitioned to the community? What safeguards will be in place to ensure quality of care and timely transfers to the appropriate level of care? Will capitation rates be risk-adjusted for patients with complex progressive diseases, such as Alzheimer's disease, to remove the financial barrier for CCOs to provide quality care in the most appropriate

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Alzheimer's Disease and Public Policy

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setting? How will provider networks be determined to be adequate? Will the program be implemented before adequate provider networks, including necessary specialists, are in place?

While other states have implemented managed care for some of their Medicaid dually eligibles, Maryland's program would be mandatory throughout the state. State policymakers – both Administrative and legislative – and advocates will play a critical role in shaping and implementing this first-of-its-kind program. The Alzheimer's Association is deeply involved in the various policy discussions. Working with other Maryland advocates for seniors and people with disabilities, as well as providers throughout the long-term care spectrum, the Alzheimer's Association is engaged in on-going stakeholder meetings with the Department of Health and Mental Hygiene (DHMH), holding meetings with legislators, and testifying at hearings and briefings before the Maryland General Assembly to provide input into the program design. The Alzheimer's Association is also working with its expert Med-Sci Board (a medical scientific advisory group comprised of Alzheimer's disease researchers and expert practitioners in Maryland) to develop recommendations for DHMH to use in measuring CCOs' clinical outcomes for patients with dementia. It is anticipated that the process of developing the detailed program, including regulations, will take over a year. During that time, there will be numerous opportunities to advocate for the needs of people needing long-term care. Geriatric care managers have a unique perspective that will help shape this new mandatory managed care system of providing long-term care to vulnerable older adults.

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Karen S Kauffman, PhD, CRNP, BC, a gerontological nurse practitioner is President of Life Passages Care Consultants, Inc in Baltimore, MD. Dr Kauffman is Associate Professor and Program Director in Community/Public Health Nursing at the University of Maryland School of Nursing. She is a member of the Board of Directors of the Alzheimers Association of Greater Maryland and chairs this organization's State Public Policy Committee.

Michele Douglas is the State Public Policy Director for the Alzheimer's Association in Maryland and Chair of the Maryland Senior Citizens' Action Network. As a policy expert, Ms Douglas has advocated for Maryland vulnerable populations on numerous health policy issues during the past 15 years. During this time, she has successfully led efforts in Maryland to pass and defeat legislation, and to enact regulations. [She specifically said that her degree isn't applicable and doesn't want a degree/credentials listed.]

Promises to Keep: The Successful Implementation of the Olmstead Act to Care for Frail Elders

By *Gema G. Hernández, D.P.A., Former Secretary Florida Department of Elder Affairs*

Abstract: This article analyzes the implications of the Olmstead Act and the impact that the implementation the Act has on the deinstitutionalization of individuals with disabilities regardless of age. It shows how states have frequently displayed predictable responses that focus on cosmetic changes, but not in providing appropriate funding to support the deinstitutionalization of frail individuals at a “reasonable pace”. While the Olmstead Act is not limited to Medicaid beneficiaries or to services financed by Medicaid, the attention has been placed on Medicaid recipients as a way to tap into Medicaid funding and not to increase funding to critical areas. Two important points are presented; first, frail elders have not utilized the Olmstead Act as a mechanism to obtain community based services and to force state government to divert dollars from Nursing Home funding to community based care. Elders have failed to understand that the Olmstead Act also applies to them and therefore have failed to leverage a stronger position in support of the Older Americans Act program, Community based waivers for frail elders, and Nursing Home Diversion programs. Second, five years after the US Supreme Court determined in Olmstead that waiting lists for waiver services must move at a reasonable pace, waiting lists for services for elders are not being properly kept, eliminating the only objective measure the court can use to determine compliance with the orders.

Promises to keep: The successful implementation of the Olmstead Act

In July, 1999, the Supreme Court issued the Olmstead v. L.C. decision. While this decision has tremendous importance for elders and individuals with disabilities, our older population has not taken advantage of the opportunities that the Olmstead Act present to them to improve access to community based care, preventing premature institutionalization and in some cases allowing frail elders living in nursing homes to go back to the community they love.

Now, five years after the Supreme Court Olmstead decision, few states are in compliance with the Act, especially as it pertains to elders with physical and mental disabilities. However, because the Olmstead decision interpreted Title II of the Americans with Disabilities Act (ADA) and its implementing regulation, elders

and caregivers of elderly individuals have assumed the Olmstead decision applies to younger individuals with disabilities. Therefore, they have not pushed to reform the poorly integrated network of services to older disabled individuals. The Olmstead Act requires that States administer their services, programs, and activities “in the most integrated setting appropriate to the needs of qualified individuals with disabilities” with no exclusion based on age. The Olmstead decision never intended to exclude elders from the freedom and options that the act mandates be available and the fact that a great many elders are dealing with physical, mental and emotional disabilities make them eligible to be covered under the mandates of the Olmstead Act. This important information has not reached elders nor their caregivers and care managers who continue to ask for more funding, not realizing that the Olmstead law is on their side. Particularly, the Olmstead Act is there in the case of frail elders

already residing in nursing homes but able to function outside if appropriate services are given to them.

In interpreting the Olmstead Case, the Supreme Court recognizes that an unjustified institutional isolation of persons with disabilities is a form of discrimination. This discrimination is reflected in two evident judgments : 1) “Institutional placements of people with disabilities who can live in, and benefit from, community

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The Olmstead Act requires that States administer their services, programs, and activities “in the most integrated setting appropriate to the needs of qualified individuals with disabilities” with no exclusion based on age.

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settings perpetuates the unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life"; and 2) "confinement in an institution severely diminishes everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." (Olmstead Act, 119 S.Ct. 2176, 2179, 2187). The Olmstead decision affects first, all persons in institutions and segregated settings regardless of age, and second, all individuals with disabilities who are at risk of institutionalization, including people with disabilities, regardless of age on waiting lists to receive community based services and supports.

Olmstead provides elders residing in Nursing Homes the option to be evaluated, and if deemed ready, be given the opportunity to move back to their communities with services in place to support such a move. While the intent of the Act is clear, organizations serving elders have not even developed the appropriate evaluation tools to assess the degree of readiness an elder needs to have to move back to the community. The assessment instruments that are in place focus on the skills and activities of daily living of a person that is still living in the community, but the existing assessment instruments fail to address some of the critical components needed to be in place for an individual that for months or years has not dealt with community living, but now is attempting to go back to that community setting. The lack of appropriate assessment tools has not

become an issue because few states are seriously evaluating older nursing home residents in an attempt to comply with the Olmstead decision. The numbers of elders that have never been evaluated to determine their degree of readiness to move them from nursing homes to the least restricted environments constitute a failure on the part of state agencies in implementing the Olmstead Act. Moving an elder to a least restrictive environment can include in some cases the

Not having a long waiting list for services, or better yet, not having a waiting list at all, removes the pressure from the heads of the state and federal agencies to ask for additional funding.

individual's own home

The failure to implement Olmstead can be seen in the lack of adequate funds given by government organizations to support community based programs for elders. Failure could also be seen in the inability of State agencies to eliminate statewide waiting lists. On the other hand, younger individuals with disabilities have seen some significant funding increases, not to the degree needed, but to a higher degree than before 1999. These increases in funding have attracted agencies that have traditionally provided services exclusively to elders who now have seen the financial advantage to expand services to a much younger clientele. In some cases these agencies have eliminated the word elder or senior from their mission statement and instead they have concentrated the mission of the agency on the degree of disability or impediment in the activities of daily living a person has. These new words in their mission statement allow these agencies to expand their client base to individuals with disabilities while not

necessarily expanding the number of employees available to provide services to the new client population. As a matter of fact, because the agencies have not added new personnel, and funding for elders has not increased in proportion to the need, the number of elders waiting for services has doubled in the last two years.

To make sure this long waiting list does not attract the attention of the media and be challenged in court as a violation of the Olmstead Act some state agencies have done some cosmetic changes with no real benefit to the elders. Cosmetic change is the terminology used when identifying the frail older individuals waiting for services. State and federal agencies are changing the terminology from words like number of clients on waiting lists to number of assessed clients on the priority list. The

sad comment is that the majority of these elders have not been assessed by a professional but by their own statement of need during the first phone contact with the agency. This phone self assessment process is the latest protocol being tested in Florida and is another cosmetic change. This step is designed to eliminate the professional assessor while putting culturally distinct clients and clients with limited English proficiency at a serious disadvantage. If the phone self assessment is finally instituted, it will result in more individuals becoming ineligible for services and by default will reduce the waiting list and the need for more funding.

The fact that the word waiting list is being eliminated altogether to identify those frail elders waiting for services avoids giving the impression that the state has a long waiting list or a waiting list at all. Not having a long waiting list for services, or better yet, not having a waiting list at all, removes the pressure from the heads of the state and federal agencies to ask for additional funding. Therefore, if there is no

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significant number of elders waiting for services and the period of wait is reasonable, the public will not challenge the agency's budget request to Congress or to the state legislators. If the agencies show no need to divert more elders back to the community because there are no names of elders in nursing homes classified as "ready" or if the agencies show few names of frail individuals waiting for services, technically speaking the agency is meeting its obligation under the Olmstead Act.

One issue that needs clarification is whether or not the elder suffering from Alzheimer's is covered under the mental disability portion of the act. If they are, as I think they should be, the states are also failing in this category. The Court indicated that one way states can show they are meeting their obligations under the ADA and the Olmstead decisions is to develop a "comprehensive, effectively working plan for placing qualified people with mental disabilities in less restrictive settings" (Olmstead at 2179). Based on this, almost all states are in the process of developing or have already developed such plans for younger disabled populations, but almost no states have developed a plan for elders suffering from Alzheimer's or other cognitive impediments.

It is important for elders and their caregivers to know that while the Centers for Medicare and Medicaid Services (CMS) plans have reviewed relevant Federal Medicaid regulations, policies and previous guidance to assure that they are compatible with the requirements of the ADA and Olmstead decision and are focused on the needs of persons with disabilities, CMS has not done the same to ensure that Medicaid waivers are consistent with the needs of elders with disabilities. Medicaid is an important financial

resource to assist States in meeting the Olmstead mandate. However, the scope of the ADA and the Olmstead decision is not limited to Medicaid beneficiaries or to services financed by the Medicaid program. The ADA and the Olmstead decision apply to all qualified individuals with disabilities regardless of age. This is a very important point that should not be forgotten particularly now when the Medicaid programs are going to be the target of administrative and policy reviews in the next year.

Care managers and caregivers should be aware of the components of the Olmstead Act and how those components impact frail elders so they can successfully argue on behalf of their clients and older family members. The following are key components of the Olmstead Act:

- If an older person's application for community based service is denied, the individual has the right to re-apply (Social Security Act 1902 (a) (3)). Agencies must have Due Process procedures in place for those clients that are denied services. Sometimes denying services involves refusing to take the client's name because of the long waiting list or could involve telling the client the agency is not accepting applications or referrals at this time.
- Older disabled persons are covered under the Freedom of Choice. Freedom of Choice means that a Medicaid client can choose between receiving services in the community or in an institutional setting. If an elder meets the institutional care requirement, that elder has the right to select where he or she will receive that care. Furthermore, states cannot impose limits on the number of Medicaid eligible clients they are able to serve. Twenty five states are facing lawsuits for imposing limits in the number of slots available to Medicaid eligible individuals (Social Security 1902(a)(3)). Elders and caregivers continue to accept the limits states are imposing without disputing the legality of such caps.
- Olmstead gives frail elders the right to evaluate if the state is

operating the Medicaid program to their best interest. Some states have even been sued for failure to operate their Medicaid program in the best interest of recipients as required by Social Security 1902(a) (19). An example is the case of a Medicaid program that contracts only with agencies that have no bilingual personnel even though 35% of the recipients do not speak English; or a Medicaid program that excludes competition for a variety of services including but not limited to care management; or a Medicaid program that allows self referral of clients to other units of the agency that has done the original assessment whether or not that is the most appropriate agency to provide such services.

- Once the client's application is approved, or, in the case of Florida, once the client is assessed and his or her name is placed on the assessed priority list formerly known as the waiting list, placing that client's name on that list definitely violates the Social Security rules. Federal courts have ruled that Social Security Act 1902 (a)(8) bars states from wait listing individuals for entitled Medicaid services. Services should be delivered in a timely fashion. A waiting list or a priority assessed client list that is not moving and is keeping elders for months with no in home services is not considered delivering services in a timely fashion.
- A variation of the above violation involves agencies that have placed Elders that are Medicaid eligible in other funded program categories that offer fewer options and fewer services to the frail elders. Agencies that use this method to balance their own agency's budget by moving elders in and out of different program categories are in violation of the Olmstead Act and the Social Security Act. Elders and care managers need to realize that the authorization for services should not be less than what the client requires. This involves the type of services, frequency of the services, the intensity and duration of services. Designing a care plan

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that only shows the services the agency offers or limits the frequency of services to the available budget is again in violation of the Olmstead Act.

- Access to services, all type of services should exist in all geographical locations. Social Security 1902 (a) (10) states that Medicaid services need to be available in a comparable basis to all eligible individuals. Offering a waiver in one part of the state and not in another is in violation of this rule. This involves Medicaid waiver programs like Consumer Directed Care, PACE, Nursing Home Diversion and Assisted Living facilities. Waivers should be available in all geographical areas of the state if the state possesses such a waiver program.
- Advocates should evaluate if the particular state has placed more restrictive financial eligibility criteria to frail elders than to individuals with disabilities. If this is the case, this is also a violation of the Social Security regulations which mandates the same eligibility criteria for all clients. In some states younger disabled individuals can qualify for Medicaid services if their income does not exceed 133% of the federal poverty line while the older disabled individuals need to spend down until he or she reaches 100% of the federal poverty line. This represents 33% of disparity in their income.

Conclusion:

At the time of this article the Centers for Medicare and Medicaid and the Administration on Aging are providing seed funding to create one stop centers where individuals with disabilities and elders will come together to receive services. While the idea of merging this to uniquely distinct populations could present

some benefit from a federal budget stand point, it could be a disservice to both populations because even though the degree of impediment could be similar, the fact that they represent different cohorts with different values, expectations and historical background could detract from serving their needs. This type of integration without proper funding is in direct contradiction to the intent and the spirit of the Olmstead Act.

Gema G Hernandez, D.P.A. is the former Secretary of the Florida Department of Elder Affairs and a former professor at NSU. During Dr Hernandez' tenure as Secretary, the first 21 elder residents of nursing homes in the state were able to move back to a community setting after being in a nursing home an average of 5 years. Dr Hernandez was a caregiver for her parents for 18 years and during this time she learned to challenge the service delivery system to comply with the Medicaid regulations. At the time of her departure she has accomplished a long list of initiatives on behalf of elders and caregivers.

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