

Family Impact Seminars

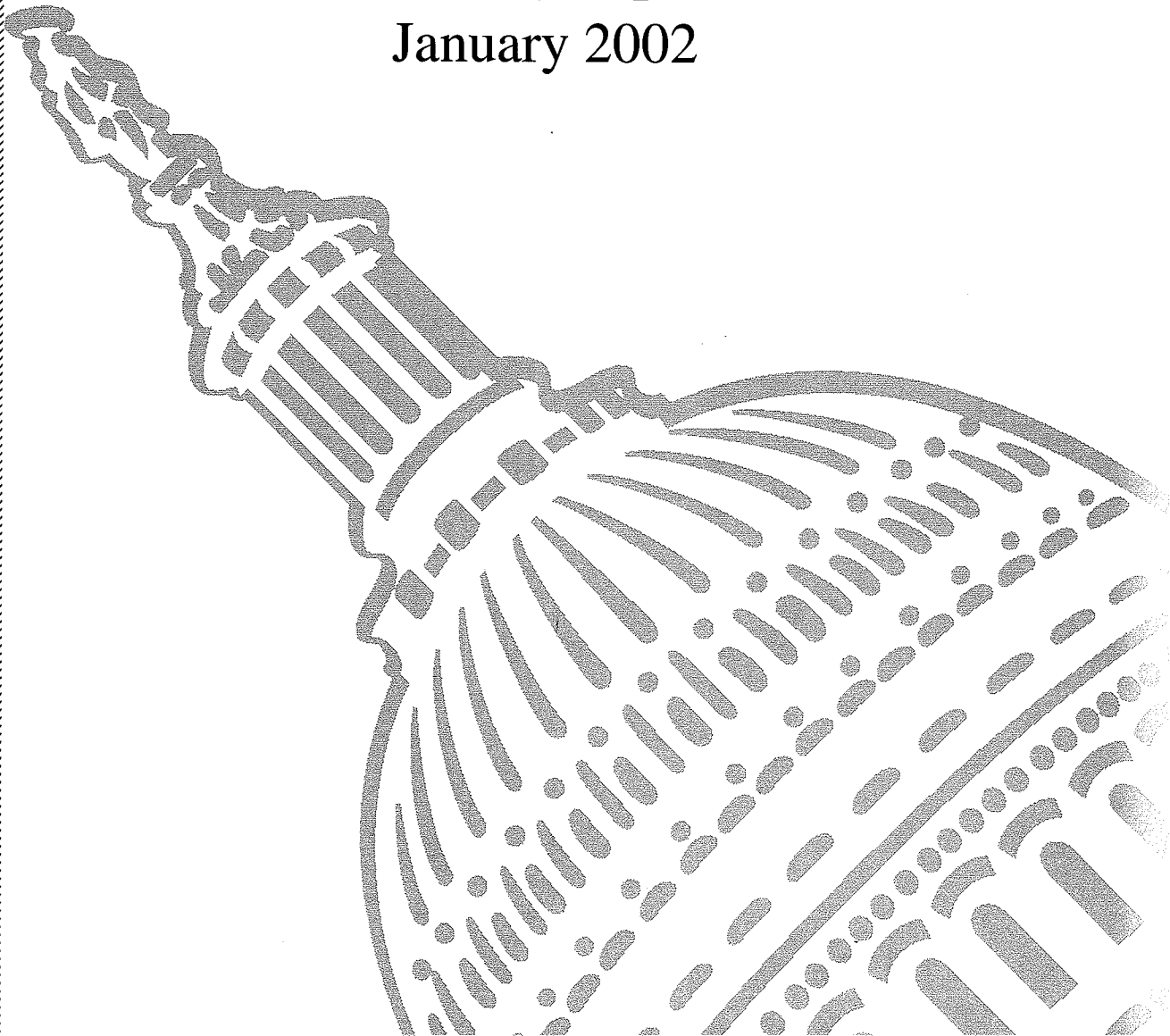


Indiana

Ensuring the Health of Long-Term Care: Policy Options

Briefing Report

January 2002



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Briefing Report
January 2002**

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Purpose, Presenters and Publications

Family Impact Seminars have been well received by federal policymakers in Washington, DC, and Indiana is one of a handful of states to sponsor such seminars for state policymakers. Family Impact Seminars provide state-of-the-art research on current family issues for state legislators and their aides, Governor's Office staff, state agency representatives, educators, and service providers. Based on a growing realization that one of the best ways to help individuals is by strengthening their families, Family Impact Seminars analyze the consequences an issue, policy or program may have for families.

The seminars provide objective nonpartisan information on current issues and do not lobby for particular policies. Seminar participants discuss policy options and identify common ground where it exists.

Ensuring the Health of Long-Term Care: Policy Options is the fourth in a continuing series designed to bring a family focus to policymaking. This fourth seminar featured the following speakers:

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Each seminar is accompanied by an in-depth briefing report that summarizes the latest research on a topic and identifies policy options from across the political spectrum. Copies may be obtained from The Center for Families at Purdue University, (765) 494-9878.

A Checklist for Assessing the Impact of Policies on Families

The first step in developing family-friendly policies is to ask the right questions:

- What can government and community institutions do to enhance the family's capacity to help itself and others?
- What effect does (or will) this program (or proposed policy) have for families? Will it help or hurt, strengthen or weaken family life?

These questions sound simple, but they can be difficult to answer.

The Family Criteria (Ad Hoc) Task Force of the Consortium of Family Organizations (COFO) developed a checklist to assess the intended and unintended consequences of policies and programs on family stability, family relationships, and family responsibilities. The checklist includes six basic principles. These principles serve as the criteria for evaluating policies and programs for sensitivity to and support of families. Each principle is accompanied by a series of family impact questions.

The principles are not rank ordered and sometimes they conflict with each other, requiring trade-offs. Cost effectiveness also must be considered. Some questions are value-neutral and others incorporate specific values. People may not always agree on these values, so sometimes the questions will require rephrasing. This tool, however, reflects a broad nonpartisan consensus, and it can be useful to people across the political spectrum.

For the questions that apply to your policy or program, use the six checklists on pages 4-7 to record the impact on family well-being.

Principle 1. Family Support and Responsibilities
Policies and programs should aim to support and supplement family functioning and provide substitute services only as a last resort.

Does the proposal or program:

- support and supplement parents' and other family members' ability to carry out their responsibilities?
- provide incentives for other persons to take over family functioning when doing so may not be necessary?
- set unrealistic expectations for families to assume financial and/or caregiving responsibilities for dependent, seriously ill, or disabled family members?
- enforce absent parents' obligations to provide financial support for their children?

Principle 2. Family Membership and Stability
Whenever possible, policies and programs should encourage and reinforce marital, parental, and family commitment and stability, especially when children are involved. Intervention in family membership and living arrangements is usually justified only to protect family members from serious harm or at the request of the family.

Does the policy or program:

- provide incentives or disincentives to marry, separate, or divorce?
- provide incentives or disincentives to give birth to, foster, or adopt children?
- strengthen marital commitment or parental obligations?
- use appropriate criteria to justify removal of a child or adult from the family?
- allocate resources to help keep the marriage or family together when this is the appropriate goal?
- recognize that major changes in family relationships such as divorce or adoption are processes that extend over time and require continuing support and attention?

Principle 3. Family Involvement and Interdependence
Policies and programs must recognize the interdependence of family relationships, the strength and persistence of family ties and obligations, and the wealth of resources that families can mobilize to help their members.

To what extent does the policy or program:

- recognize the reciprocal influence of family needs on individual needs, and the influence of individual needs on family needs?
- recognize the complexity and responsibilities involved in caring for family members with special needs (e.g., physically or mentally disabled, or chronically ill)?
- involve immediate and extended family members in working toward a solution?
- acknowledge the power and persistence of family ties, even when they are problematic or destructive?
- build on informal social support networks (such as community/neighborhood organizations, religious communities) that are essential to families' lives?
- respect family decisions about the division of labor?
- address issues of power inequity in families?
- ensure perspectives of all family members are represented?
- assess and balance the competing needs, rights, and interests of various family members?
- protect the rights and safety of families while respecting parents' rights and family integrity?

Principle 4. Family Partnership and Empowerment
Policies and programs must encourage individuals and their close family members to collaborate as partners with program professionals in delivery of services to an individual. In addition, parent and family representatives are an essential resource in policy development, program planning, and evaluation.

In what specific ways does the policy or program:

- provide full information and a range of choices to families?
- respect family autonomy and allow families to make their own decisions? On what principles is family autonomy breached and program staff allowed to intervene and make decisions?
- encourage professionals to work in collaboration with the families of their clients, patients, or students?
- take into account the family's need to coordinate the multiple services they may require and integrate well with other programs and services that the families use?
- make services easily accessible to families in terms of location, operating hours, and easy-to-use application and intake forms?
- prevent participating families from being devalued, stigmatized, or subjected to humiliating circumstances?
- involve parents and family representatives in policy and program development, implementation, and evaluation?

Principle 5. Family Diversity

Families come in many forms and configurations, and policies and programs must take into account their varying effects on different types of families. Policies and programs must acknowledge and value the diversity of family life and not discriminate against or penalize families solely for reasons of structure, roles, cultural values, or life stage.

How does the policy or program:

- affect various types of families?
- acknowledge intergenerational relationships and responsibilities among family members?
- provide good justification for targeting only certain family types, for example, only employed parents or single parents? Does it discriminate against or penalize other types of families for insufficient reason?
- identify and respect the different values, attitudes, and behavior of families from various racial, ethnic, religious, cultural, and geographic backgrounds that are relevant to program effectiveness?

Principle 6. Support of Vulnerable Families

Families in greatest economic and social need, as well as those determined to be most vulnerable to breakdown, should be included in government policies and programs.

Does the policy or program:

- identify and publicly support services for families in the most extreme economic or social need?
- give support to families who are most vulnerable to breakdown and have the fewest resources?
- target efforts and resources toward preventing family problems before they become serious crises or chronic situations?

A Checklist for Assessing the Impact of Policies and Programs on Families

Adapted from Ooms, T. (1995). *Taking families seriously as an essential policy tool*. Paper prepared for an expert meeting on Family Impact in Leuven, Belgium.

The first version of this checklist was published by Ooms, T., & Preister, S. (Eds., 1988). *A strategy for strengthening families: Using family criteria in policymaking and program evaluation*. Washington DC: Family Impact Seminar.

The checklist and the papers are available from Karen Bogenschneider and Jessica Mills of the Policy Institute for Family Impact Seminars at the University of Wisconsin-Madison/Extension, 120 Human Ecology, 1300 Linden Drive, Madison, WI 53706; phone (608) 263-2353; FAX (608) 262-5335; <http://sohe.wisc.edu/familyimpact>.

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Financing of Public Programs that Serve the Elderly

by Joshua Wiener, Ph.D.
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This paper examines state cost-containment strategies on long-term care, consumer directed home and community service programs for older people, and federal and state initiatives to develop a market for private long-term care insurance.

State Cost Containment Initiatives

States must address long-term care for the elderly in order to control Medicaid expenditures. Three broad strategies are used to control spending: (1) reforming the delivery system for greater efficiency; (2) utilizing outside resources to offset state expenditures; and (3) reducing Medicaid eligibility, reimbursement and services. States differ both in the extent to which they focus on each strategy, and in how far they have progressed in implementing long-term care reform.

System reform

Reorganizing the healthcare delivery system in ways that make care more efficient and effective is an important general strategy for saving money.

Expanding home and community-based services. The most wide-spread reform has been the effort to shift the delivery system away from institutional care and toward home and community-based services. Despite this policy initiative, Medicaid long-term care expenditures for the elderly are still overwhelming for nursing home care. This movement to noninstitutional services has been aided by recent court cases. The U.S. Supreme Court's 1999 *Olmstead v. L.C.* decision found that the Americans with Disabilities Act (ADA) meant unnecessary institutionalization was illegal discrimination, and created a limited right to home and community-based services.

Medicaid home care spending is very uneven, with California, Massachusetts, New York and Texas accounting for 54% of total home care expenditures for the elderly in 1997. Most states are increasingly choosing to finance their home and community-based services through the Medicaid program.

Medicaid funding strategies

•States can fund Medicaid home and community-based services through the regular Medicaid program with coverage of home health and personal care, or through home and community-based services (HCBS) waivers.

•States are increasingly choosing to expand their commitment to more tightly controlled Medicaid waivers, rather than open-ended entitlements. Under the waivers states can cover a wide range of nonmedical long-term care services, including case management, personal care services, home modification, transportation, adult day care, habilitation, rehabilitation, and respite care. States are required to target those at high risk for institutionalization, and assure the federal government that the average cost of providing services with the waiver will not exceed the average cost without the waiver. In addition, states may provide these services only to a pre-approved number of people.

•Regulatory changes implemented by the Clinton administration have made obtaining waivers routine, although states complain about the paperwork and staff time involved in obtaining them.

Cost containment strategies

•Home and community services are “sold” in almost every state primarily based on their ability to achieve cost savings. While states seek to substitute lower cost home and community-based services for more expensive nursing home care in order to save money, most research suggests that total long-term care costs are actually increased rather than decreased with this strategy (Wiener & Hanley 1992).

•Recent research about the cost-effectiveness of home and community-based care, however, is more encouraging. Some states point to low Medicaid waiver costs that are achieving cost neutrality, if not cost savings, even while serving additional people who would otherwise be institutionalized (Raetzman & Joseph 1999).

•Federal government programs such as “Date Certain” and “Nursing Home Transition” grants encourage states to identify and remedy barriers to community-based care and assist nursing home residents to relocate to the community.

•States have used a variety of ways to address the issue of cost-effectiveness of home and community-based services:

- (1) Set a maximum amount that will be spent on home and community-based services for a single individual.
- (2) Provide services to a population at higher risk of institutionalization than they did 10 years, increasing the probability of substituting home care for nursing care.
- (3) Test consumer-direct home care programs which give beneficiaries, rather than agencies, the power to hire, train, supervise and fire workers (Tilly & Wiener 2000). Because independent workers receive less supervision and fringe benefits, and sometimes lower wages than agency-directed employees, consumer-directed care is less expensive.

- (4) Explore the potential role of residential alternatives to nursing home care, such as adult foster care and assisted living, in order to offer services that are more home-like, provide greater personal autonomy, and cost less than nursing homes.

•Expanding these residential alternatives presents states with a number of very difficult issues.

- (1) How do states superimpose these new concepts of consumer-oriented, homelike residential facilities onto the large existing stock of nonmedical residential facilities?
- (2) How can these new facilities be regulated in a way that allows individuals to “age in place” without having to move to obtain needed services? Will these facilities become unlicensed nursing homes?
- (3) How can these residential options be made available to the moderate- and lower-income elderly population? A recent analysis found that most moderate- and low-income individuals age 75 and older could not afford assisted living facilities unless assets were liquidated to help pay for them (Hawes et al. 1999).

Integrate acute and long-term care services through managed care. While financing acute care is largely the province of Medicare and the federal government, long-term care is dominated by Medicaid and state governments. This separate financing system not only provides a strong incentive for both the federal government and states to shift costs, the lack of coordination in the delivery system presents difficulties to older individuals who require long-term services.

•States have four goals in integrating acute and long-term care services:

- (1) Eliminate arbitrary divisions between acute and long-term care to achieve better quality care.
- (2) Substitute lower-cost ambulatory and home-based care for more expensive hospital and nursing home care.
- (3) Reduce the number of providers to facilitate setting contract standards and monitoring performance.
- (4) Make state spending more predictable by using “per person” payments that shift financial risk from government to providers.

There are impediments to integration. Critics hold that joining acute and long-term care services could have an adverse effect on long-term care, contending that fiscal pressures could short-change long-term care by shifting funds to acute care. In addition, long-term care could become over-

A recent analysis found that most moderate- and low-income individuals age 75 and older could not afford assisted living facilities unless assets were liquidated to help pay for them.

medicalized and services less consumer-directed when the balance of power shifts from the individual client and provider to HMOs, insurance companies or other administrative entities. A final factor that slows the pace of integration initiatives is the turmoil in Medicaid and Medicare managed care efforts.

Increase private and federal resources

States are bringing additional private and federal resources into the long-term care financing system to offset state expenditures. This is done in several ways: encouraging the purchase of private long-term care insurance, strictly enforcing prohibitions against transfer of assets, and maximizing Medicare and Medicaid financing for long-term care services.

Encourage private long-term care insurance. Only 8% of the elderly have any type of long-term care insurance (Health Insurance Association of America, 2000), and by most estimates only 10 to 20% of the elderly can afford it (Wiener, Illston and Hanley, 1994). States are adopting three strategies to expand private long-term care insurance.

- (1) Eighteen states offer tax incentives to individuals or employers to purchase private long-term care insurance (Wiener et al. 2000).
- (2) Nineteen states offer, or are preparing to offer, private long-term care insurance to employees, retirees and, in some cases, parents and parents-in-law of employees (Wiener et al. 2000). All of these states are using an "employee-pay-all" financing system with no employer contribution.
- (3) Four states, Indiana included, have established "public/private partnerships" to encourage the purchase of private long-term care insurance (Wiener et al. 2000). These partnerships allow individuals who purchase a state-approved private long-term care policy to keep far more assets and still qualify for Medicaid. Individuals in nursing homes in these states, however, must still contribute all of their *income* toward the cost of care, except for a small personal needs allowance.

Enforce prohibitions against asset transfer. Media have focused attention on the middle-class and wealthy elderly who transfer, shelter and under-report assets in order to appear poor enough to qualify for Medicaid-financed nursing home care (Burwell & Crown 1995). The goal of this effort, called "Medicaid-estate planning," is to protect private wealth against the costs of long-term care. State officials seek to prevent these transfers, arguing that Medicaid should be preserved for the truly needy.

Maximize federal financing. Public funding options for the elderly include Medicare, Medicaid and state-only funded programs. Since Medicare is entirely federally funded, states have long sought to shift state and Medicaid long-term care expenditures to Medicare. This effort has been frustrated by the narrow range of nursing home and home health services covered by Medicare. However, Medicare coverage expansions during the 1990s made this cost shifting more possible.

A traditional strategy to control spending

A more conventional mechanism that states can use to control expenditures includes cuts in reimbursement rates. Medicaid payment rates for nursing facility care are a logical target. States now have almost complete freedom in setting nursing home payments rates, except for a requirement to hold public hearings. In comparison to Medicare and private pay rates, Medicaid nursing home payment rates are already fairly low in many states. Thus, nursing homes often prefer higher paying private-pay to Medicaid residents, and this can result in access problems for Medicaid beneficiaries. However, since few nursing homes can survive without Medicaid residents, the extent to which facilities can reduce access is limited.

The Role of Consumers in Controlling Services

This study examines the experiences of public programs that serve older persons in eight states in order to assess the policy implications of consumer-directed home and community services for this population. These programs give beneficiaries, rather than agencies, the power to hire, train, supervise and fire workers. Both the quantitative research and most stakeholders interviewed for this study, indicate that many older beneficiaries want to and can manage their services, although significant issues exist when considering the management ability of those with cognitive impairments. Although quality of services remains a contentious issue, limited research results point to better—or at least no worse—quality of life for beneficiaries when they direct their services. Consumer-directed care has some disadvantages for workers, including fewer fringe benefits. State agencies, with few exceptions, have not provided extensive consumer or worker support, or aggressively regulated quality of care.

Implications for programs serving older people

The extent to which clients control their services is a key issue in the design of home and community services programs. Consumer involvement in managing publicly funded Medicaid and state-funded programs currently runs the gamut from very little to virtually complete control over services. States use two broad models of consumer control in their programs—agency-directed and consumer-directed services. Advocates for younger adults with disabilities insist that consumers should be able to direct individual workers rather than having to rely on home care agencies. There is some controversy among advocates for older people, however, about whether that population should control their home and community services in this way.

Agency-directed model. The agency-directed model provides consumers with little direct control. States contract with home care agencies that are responsible for hiring and firing home care workers, directing services, monitoring quality of care, disciplining workers if necessary, and paying workers and applicable payroll taxes. The agency-directed model assumes that professional expertise matters a good deal more than the opinions of consumers. At its extreme, a “medical model” is imposed and individuals with disabilities are considered to be “sick,” as opposed to simply needing compensatory services (Parsons 1951). Beneficiaries can express preferences for services or workers in this model, but have no formal controls over them.

Although quality of services remains a contentious issue, limited research results point to better—or at least no worse—quality of life for beneficiaries when they direct their services.

A key policy question is whether programs serving older persons should provide them the opportunity to manage home and community services and, if so, under what conditions.

Consumer-directed model. The other end of the management continuum is represented in the consumer-directed model offered by some Medicaid and state-funded programs. Beneficiaries assume the responsibility for decisions about their services, including recruiting, training, hiring, directing, and firing their workers (NCOA 1996).

There are several types of consumer-directed programs (Mahoney and Simon-Rusinowitz 1997). In most programs, consumers take on all worker management tasks with the exception of paying the worker. Some state-funded consumer-directed programs provide cash payments to beneficiaries, who then shop and pay for services that fit their needs and budgets. Medicaid-funded programs, however, must abide by the federal rule that prohibits Medicaid beneficiaries from receiving their benefits in cash (Flanagan and Green 1997).

A growing number of states are incorporating consumer direction into their home care programs for older people, and some groups representing older people are strongly advocating that consumer-direction principles be built into home and community services programs. Thus, a key policy question is whether programs serving older persons should provide them the opportunity to manage home and community services and, if so, under what conditions.

Adding to this debate, this analysis compares publicly funded agency and consumer-directed services in relation to several issues: whether older persons want to and are capable of managing services, the quality of those services, and the effects of consumer direction on workers. A major focus of this effort was on state policy decisions and program design.

Research methods

Data collection for the comparative analysis was undertaken through an extensive literature search and interviews with government officials and key stakeholders in eight states with coexisting agency and consumer-directed models. This strategy satisfied the goal of gathering the views and opinions of those who had experience with consumer-directed programs that served significant numbers of older people as well obtaining information about the structure of the programs. The study authors identified relevant literature through a comprehensive search of published and unpublished literature using major bibliographic databases. Only four quantitative studies of consumers' willingness to manage services and two studies that compared beneficiary or worker outcomes under the two methods were found.

Several surveys of home care programs offering consumer-direction opportunities that were conducted in the mid-1990s or later (Flanagan and Green 1997; Scala and Mayberry 1997; National Association of State Units on Aging 1998; U.S. General Accounting Office 1999) were examined to identify potential case study states. To qualify for inclusion in the study, states had to provide both agency- and consumer-directed services to older adults with disabilities, have at least 2,000 beneficiaries, and have at least two years of experience with consumer direction. These criteria yielded study states with relatively large, mature programs that permitted comparisons between the two models. States that met the selection criteria and were included were

California, Colorado, Kansas, Maine, Michigan, Oregon, Washington and Wisconsin.

For each state, the study authors interviewed the state program officials responsible for home and community services programs, state Medicaid or State Unit on Aging officials, and representatives of key stakeholder groups who had the most knowledge of consumer-directed programs. These included advocates for younger people with disabilities, advocates for older beneficiaries, unions and home care agency associations. Contact information for program officials and representatives of key stakeholders was gathered from surveys of consumer-directed programs and from Web sites on independent living and home care agencies. Additionally, each program official or key stakeholder interviewed was asked to suggest other stakeholders who were considered knowledgeable about the state's home- and community-based services system.

While program officials and representatives for younger people with disabilities in every state agreed to be interviewed, stakeholders representing the older population were interviewed in only half of the states because program officials and other stakeholders could not identify a knowledgeable person to interview. Home care agency representatives agreed to be interviewed in every state except Michigan, and union representatives were identified in six states. Thirty-three sets of interviews were conducted with government officials and key stakeholders:

- eight with government officials
- eight with advocates for younger people with disabilities
- four with advocates for older people
- seven with home care agency association staff
- six with union officials

When more than one agency official participated in an interview, their responses were considered as one. Respondents were guaranteed anonymity to encourage candor. Open-ended, structured interview protocols were developed that addressed program structure and policy issues related to consumer direction for older persons.

Program description

The eight case study states had to make a number of program design decisions about financing, eligibility, cost containment, and quality assurance in order to establish their programs. Generally, states relied on a combination of Medicaid and state funds to finance their programs, with Medicaid home- and community-based services playing an important role in financing the services. The programs measured a person's inability to perform daily activities to determine functional eligibility for benefits, and access to most programs was means-tested, with eligibility being limited to the low-income population. Expenditures were controlled by limiting the number of people served or the hours of service covered. In some cases there was a cap on the cost of services that an individual could receive. Most programs allowed beneficiaries to hire family members other than spouses, and quality assurance involved minimal monitoring of beneficiaries.

Key policy issues

Four key policy issues were identified:

The bottom line is that older beneficiaries do not comprise a homogeneous group and should therefore be provided with a choice of management models.

Preference for consumer direction. While survey and interview results indicate that older people are less likely to want consumer direction than younger people, a significant minority of older people do prefer consumer direction. Providing the consumer-direction option will require a substantial restructuring of current home and community services programs in most states. Programs should have the flexibility to allow beneficiaries to manage their own services when they want to, while providing agency services to those who do not want to manage or are incapable of management. The bottom line is that older beneficiaries do not comprise a homogeneous group and should therefore be provided with a choice of management models.

The effect of cognitive impairment on directing services. Although some older beneficiaries want to and currently do direct their own services, a significant number of stakeholders raised questions about their capacity to do so, citing the prevalence of cognitive impairment among the older population. Despite these concerns, every study state allowed the cognitively impaired to participate in consumer-directed programs through reliance on surrogates to make care decisions for the consumers when necessary. This is a reasonable accommodation for the cognitively impaired, but it should be recognized that decisions made by surrogates are unlikely to be a perfect representation of the choices that the consumer would have made if not impaired. Surrogate decisions will sometimes reflect their own preferences, schedules and interests. And, despite raising questions about cognitive impairment, most states do relatively little to help clients cope with management tasks. The exception to this is that states used fiscal agents to pay workers and withhold applicable taxes, substantially reducing the paperwork clients must complete.

Quality of care and monitoring services. The most contentious issue surrounding consumer-directed programs relates to whether the quality of care is adequate and how services should be monitored. Consumer-directed services often lack the standard quality assurance structures, such as training of paraprofessionals and professional supervision. Limited quantitative research on the cognitively intact population and interviews with stakeholders suggest that consumer-directed services are no worse than agency-directed care, and may be better because the service is more tailored to the preferences of the client. Stakeholders did express a higher degree of concern over the quality of care provided the cognitively impaired because of their vulnerability to abuse.

Despite the expressed concerns about quality of services, most states have taken relatively minimalist approaches to monitoring quality, identifying problems through complaints and case manager interaction with clients. Although most of the services provided in consumer-directed programs are unskilled, the lack of training requirements and monitoring is striking during a time when proposals for increased regulation of nursing facilities are commonplace. Consumer advocates and policymakers have placed greater priority on maintaining flexibility and consumer choice in the home and

community services setting, perhaps fearing that increased regulation will replicate an “oppressive” nursing home setting.

Consumer-directed programs rely on the client’s ability to fire unsatisfactory workers and hire replacements in order to assure quality. The current labor shortage makes recruitment difficult for all long-term care services, and may threaten quality by undermining the willingness of clients to fire sub-standard workers. This may increase the need for more formal quality assurance mechanisms.

Worker environment and compensation. Independent workers appear to fare better than agency workers in their work environment, although home care and union representatives question this finding. Independent workers, however, do less well financially than agency workers. Part of the attraction for states to employ the consumer-directed model is its lower per-person cost. Although workers’ hourly wage rates in the study states appeared to be about the same in both models, the lower payment rates for consumer-directed care are due to the absence of administrative overhead in part, and also because workers receive less in the way of health, vacation and other fringe benefits.

It is important to consider that a significant portion of independent workers—as many as half in some study states—are family members. In California the vast majority of independent workers were known by the consumer before they became paid caregivers. The issues of management, training, quality assurance and payment levels take on a very different cast if the independent worker is a family member or friend. This may account for some of the states’ relatively *laissez-faire* approach to quality assurance, as well as for some of the positive results on quality.

Conclusions

The protective or paternalistic nature of most home and community services programs for older people is challenged by consumer-directed home care advocates who assert that clients want to and are capable of managing their own care. The situation becomes more complicated for those who are cognitively impaired, although surrogate decision-makers can allow participation even for them. States may want to consider whether a more activist approach toward providing supports, such as worker registries and monitoring client satisfaction, is warranted.

Initiatives to Jump-start the Market for Private Long-term Care Insurance

Various strategies at federal and state levels are designed to encourage the purchase of long-term care policies: individual tax incentives, tax incentives for employer contributions, state and federal “role models,” and public-private partnerships that relax Medicaid requirements. These initiatives have produced only modest gains with the effect being more symbolic than substantive. These initiatives raise a number of fundamental policy issues that must be addressed before progress can be made.

Should the government encourage private long-term care insurance?

Should the government fund long-term care via direct spending in federal benefit programs?

Which strategy is most effective/efficient?

Long-term care is a major source of catastrophic out-of-pocket costs for the disabled elderly, with nursing home care exceeding \$50,000 in 1997.

Long-term care is overwhelmingly financed through public programs and out-of-pocket payments (Frolik & Kaplan 1999). People with disabilities may find that neither Medicare nor their private health insurance cover nursing home and home care to any significant extent, and have to rely instead on their own resources and Medicaid. Long-term care is a major source of catastrophic out-of-pocket costs for the disabled elderly, with nursing home care exceeding \$50,000 in 1997 (Wiener 1999). This financial strain on individuals and their families, as well as both federal and state governments, is expected to escalate as it is anticipated that Medicaid long-term care expenditures for the elderly will roughly double between 2000 and 2020 (U.S. Congressional Budget Office 1999).

Private long-term care insurance currently plays only a small role in financing care for the older population, accounting for only about 2.5% of national long-term care expenditures in 2000 (U.S. Congressional Budget Office 1999).

In order to induce more people to purchase long-term care policies by lowering premium costs, policymakers have considered or enacted three strategies of governmental intervention:

Provide individuals with tax incentives to encourage purchase. These incentives have become law at both federal and state levels, although only modestly reducing the net price of private long-term care insurance policies. Insurance advocates argue that these tax incentives signal purchasers that the government believes such policies are a worthwhile product.

At the federal level the Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides certain federal tax benefits for "qualified" private long-term care insurance premiums, but only under certain circumstances. Most observers believe that these tax incentives are not large enough to lead to major increases in sales, noting that only about half of the older people pay federal income tax (1998 Green Book) and that few itemize their deductions. HIPAA clarified that payment of long-term care insurance is a medical expense, but it is only tax deductible when the taxpayer has out-of-pocket medical expenses that exceed 7.5 percent of adjusted gross income. Advocates agree that changes to federal tax incentives are necessary to substantially increase sales, arguing that the entire premium should be tax deductible and not subject to the 7.5% adjusted gross income requirement. Other suggestions include allowing employers to offer long-term care insurance on their cafeteria plans and flexible spending accounts, and allowing individuals to draw from their retirement accounts to pay premiums without encountering a penalty for the withdrawal.

A number of states have enacted tax incentives over the last few years to encourage the purchase of long-term care insurance. Eighteen states provided tax deductions or credits to purchasers in 1999, and tax incentive legislation was introduced in another 18 states during the 1999 legislative sessions.

These tax incentives are likely to have only a minimal impact because of relatively low state tax rates, which make a deduction or credit less attractive. In some cases a taxpayer must choose between the federal or state incentive and, although state tax incentives are available to a broader population than HIPAA, they are quite modest in reducing the cost of insurance.

Encourage employer-based private long-term care insurance through tax incentives and offering of coverage by federal and state governments. These initiatives that encourage the purchase of insurance at a younger age offer several advantages over policies that older people purchase individually, although the employer-sponsored market remains very small.

Premiums for young policyholders are, first of all, less expensive because premium earnings have time to build before benefit pay outs (Weiner et al 1994; Crown et al 1992; Rivlin & Wiener 1998). Secondly, group policies take advantage of economies of scale in marketing and administrative expenses, and allow negotiation of lower prices (and thus, lower premiums). Finally, because benefit managers of these employer-based programs have a stronger negotiating position than individuals, the quality of long-term care insurance plans might improve.

Tax incentives to encourage employer contributions into these programs have been provided by both the federal government and some state governments. Possible contributions, however, have been overwhelmed by the financial problems of under-funded employer-sponsored acute health insurance benefits for retired employees. A large number of employers have cut back on retiree acute benefits, made retirees pay a larger part of the cost, or have dropped the coverage altogether. In this environment it seems unlikely that employers will want to contribute to a new, potentially expensive insurance plan that will primarily benefit retirees years after they have left the company. It is conceivable, however, that they may be more willing to offer private long-term care insurance on an employee pay-all basis to help compensate for decreases in acute care coverage.

This employee pay-all basis has been embraced by the federal and 19 state governments—a strategy that, it is hoped, will set a “good example” for other employers and bring visibility to the issue.

Waive Medicaid asset-depletion requirements so that purchasers of long-term care policies can retain some of their assets and still qualify for Medicaid. Under these public-private partnerships, a few states (Connecticut, New York, Indiana and California) provide higher levels of protected assets to individuals who purchase state-approved private long-term care policies. Unlike employer-paid plans and tax incentives that aim to reduce the net cost of insurance, these partnerships seek to increase the amount of benefits per dollar spent by combining insurance with more liberal Medicaid financial

eligibility standards (McCall et al. 1991; Meiners 1993; Meiners & Goss 1994; Meiners & McKay 1990; Meiners 1998).

A key observation that supports this public-private approach is that the long-term care products that cover shorter periods of nursing home and home care rather than lifetime benefits are less expensive and more affordable than policies with longer periods of coverage. Outside of this program, individuals who buy policies that cover two years of nursing home care could lose all of their assets if the in-care period extended to five years, despite the purchase of insurance. Thus, under these initiatives, lifetime asset protection can be obtained without having to buy lifetime benefits. And since many of those who use nursing home care do not stay for long periods, policies of relatively short coverage (i.e., one to two years) provide "full" coverage for about half of all users (Kemper & Murtaugh 1991).

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These partnerships have not had a major impact on the financing of long-term care. Only 52,560 policies were in force in the four states as of Sept. 30, 1999, compared to over seven million older people living in these states (U.S. Bureau of the Census). From the consumer point of view, three reasons can be identified to help explain the low participation rate: (1) the policies are still expensive; (2) asset protection is not a driving force for the purchase of insurance; and (3) easier access to Medicaid is not perceived as desirable. The insurance industry continues to see the partnership as an opportunity to increase the size of the private long-term care insurance market, but has offered only lukewarm support despite initially advocating the partnership. The number of policies sold has been disappointing (Korb et al. 1998), and the long-term care partnership is unattractive because it requires reversing basic sales strategies and lacks portability of Medicaid benefits from one state to another.

Conclusion

Since the collapse of proposals for comprehensive health care reform in 1994, and for a Medicaid block grant in 1996, long-term care reform proposals have focused on private insurance. The emphasis on private solutions to long-term care is reinforced by the unwillingness of Congress to spend the large sums of public money necessary to substantially address the many problems. There is, however, a fundamental problem with this strategy: Despite more than a decade of double-digit sales growth, private long-term care insurance remains a small niche product, with affordability being the principal barrier to purchase (Wiener et al. 1994). Also playing a role are lack of knowledge about the risks of needing long-term care, misinformation about Medicare coverage, and competing priorities.

A number of incentives have been implemented to "jump-start" the market for private long-term care insurance, but they are modest and are likely to have only minimal effect on the number of people carrying policies. The HIPAA tax deduction bears a low value because only about half of the elderly population pay federal taxes; marginal tax rates are low for the vast majority, and few have enough out-of-pocket medical expenses to qualify for deductions. State tax incentives average \$100 or less, and virtually no state officials interviewed thought that the incentives were having a major impact. Very few

employers are contributing toward the cost of premiums, and take-up rates for state employer-sponsored long-term care insurance for employees and retirees are low. The number of partnership policies remains small and represents only a modest portion of the market, although sales are increasing.

Overall, these initiatives have not significantly changed market dynamics, and raise the following policy questions:

- Money spent or revenue lost in support of promoting these initiatives is not available for tax credits for informal caregivers or persons with severe disabilities, or for direct funding of services through Medicaid Medicare, the Older Americans Act, or the Social Services Block Grant. How hard should policymakers work to make private long-term care insurance a major source of financing?
- Proposals to promote private long-term care insurance depend on tax incentives, which inevitably raise issues of equity and efficiency. Should the federal tax code be used to subsidize private long-term care insurance?
- Demand for long-term care and its financial pressures are sure to increase as the population ages. Americans must have realistic expectations about the ability of private sector initiatives to improve the situation. Private insurance can do more, but at best will finance only a small proportion of long-term care expenses. Thus the public policy question becomes: What should we do about the large majority of disabled older individuals who have no private care insurance?

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Wiener, J. M., D. G. Stevenson & J. Kasten. (2000) *State Cost Containment Initiatives for Long-Term Care Services for Older People*. CRS Report for Congress.

Wiener, J. M., & J. Tilly. (2001) *Consumer-Directed Home and Community Services: Policy Issues*. Occasional Paper Number 44, The Urban Institute.

Wiener, J. M., J. Tilly, & S. M. Goldenson. Federal and State Initiatives to Jump Start the Market for Private Long-Term Care Insurance. *Elder Law Journal*, in press 2000.

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The Aging of America: Issues in Long-term Care

**by P. Willging, Ph.D.
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Even for those steeped in gerontology, the statistics reflecting the phenomenon we call “the aging of America” are nothing short of awe-inspiring. With the American population as a whole slated to grow by a third over the next few decades, the population over 85 will grow by an astounding 400 percent. And that, of course, is the population most in need of long-term care, with over 20 percent already residing in nursing facilities. Many of us are aware of the fact that, by the year 2050, 20 percent of all Americans will be over the age of 65. How many realize that, at the same time, five out of every 100 Americans will be over 85 (up from less than 1/10th of 1 percent as recently as 30 years ago)?

Don't Let the Numbers Fool You

There are four basic types of long-term housing and care for seniors. For want of common definitions, we can call them categories A, B, C and D. Category A (referred to by some as “independent living” or “active adult”; by others as “age-restricted” or “age-qualified”) is essentially real estate. Amenities may exist (golf courses, swimming pools, gardens and walking paths), but there are usually no services provided. Category B, often referred to as “congregate living” or “congregate care,” offers services—usually unrelated to frailty or health status—including housekeeping, transportation or common meals.

Only with the delivery of healthcare services do we begin to see the attributes that distinguish categories C and D, commonly referred to as assisted living and nursing facilities. The distinctions, particularly between categories A and B on the one hand and C and D on the other, are critical. They differ not only with respect to the very basic dissimilarities in their service packages, but in terms of the age and preferences of their customers as well. Differences in health status are obvious, as is the correlation of health status with age. Age differential at admission between categories A/B and C/D is significant.

Customers for categories A and B are looking for changes in lifestyle; those in categories C and D for help in the basic activities of daily living. Big difference. And that, in turn, stimulates the biggest difference of all—the actual decision-maker. Because the final decision-maker for selecting either assisting living or nursing home care is not the resident, but the resident's family. On the other hand, it is the resident who makes the choice for independent living or congregate care.

These are very basic demographic realities which only very recently became obvious to assisted living operators. Many assisted living operators made two basic mistakes: They lumped all the elderly into one category and failed to see the crucial distinctions within the senior populations. And, to a very considerable extent, they focused on the wrong customer. The end result was a saturation of services for the C/D category.

Let's look first at the failure to distinguish among the elderly. By viewing the elderly as a homogeneous group consisting of all seniors over the age of 65, assisted living failed to see the "pig in the python." A term common in the jargon of demographers, the "pig in the python" is a way of characterizing the movement through time of the large growth in the American population following the close of World War Two. These are the so-called "baby boomers." Assuming they were swallowed whole by our apocryphal python in 1945, they would not, given average ages at admission, be beating on the doors of assisted living communities until the year 2030 (at the earliest). True, given the pent-up demand for this new product line, the market was reasonably large in the 1990s and could absorb the initial new capacity. But nowhere near as large as those looking at an undifferentiated seniors population might (and, in reality, did) assume. The real growth in seniors housing and care, at least in the foreseeable future, will be (and was) in categories A/B, not in C/D.

And, unlike categories A/B where growth will occur in the Sunbelt, the growth in categories C/D will occur in the hometowns of the residents' children. Sunrise, a very successful assisted living company, has made a practice of selecting sites for new development, not in communities with large populations of seniors making at least \$25,000 per year, but in communities of adult children making \$75,000 per year. Sunrise, unlike many contemporaries, understood early who the customer was. It is the kids, not the parents, who make the choice (just like nursing homes) for assisted living. And Sunrise has not, as a result, experienced the downturn so characteristic of the rest of the industry.

So, what about demographics? Important? Absolutely! But only if carefully analyzed. Like so many social phenomena, demography makes for complicated social science. But, as a social phenomenon, demographics can be a useful tool for predicting the nexus between population characteristics and customer markets. But the devil is in the details, and failure to distinguish among those details can make for a very mischievous brew.

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The Restructuring of Long-term Care

In the late 1980s and early 1990s the concept of “aging in place” became the mantra for those who would argue the overriding value of home and community-based long-term care services. To “age in place” was a wonderful concept! There was no need to be “institutionalized,” no need to suffer under the psychological burden of “transfer trauma.” You could simply remain in your own home, your own “place,” as it were.

At its root, the concept has real appeal and has driven much of the restructuring of long-term care over the past two decades. Americans do wish to remain in their own homes as long as practically possible. That is a very legitimate and understandable desire. Accomplishing that goal without bringing harm to the recipient of services is the real issue.

There is the potential for harm—and more than minimal harm—that can surface on a number of fronts. “Aging in place” can become a quality-of-care problem; it can become a marketing issue; it can occasion operational difficulties; and it can, ultimately, raise legal concerns.

In reality, it is the long-term care customer’s condition that will determine need; need that will determine service; service that will define setting. If a provider can accommodate to any condition, adjust to any need occasioned by that condition, and provide all services responsive to that need—then it makes little difference whether that provider is licensed as home care, assisted living, adult day care or nursing facility.

Therein lies the dilemma. How many providers can really do that? Early in its current life cycle, many in assisted living made that promise to their customers, a promise many also found they had to break. Indeed, average turnover in assisted living facilities approximates 50 percent per year. And the setting in which most outgoing residents are placed is the nursing facility—not really what those customers had in mind when reviewing the assisted living facility’s brochures. I’m reading one now: “Whatever their requirements, now or in the future, we will offer our residents the necessary care and services. As residents’ needs or conditions change over time, their Care Plans change accordingly.” Pretty direct, yet unlikely to be fulfilled. Because, as we noted before, those changes in condition will occasion changes in need, which will require changes in service.

Confronted with a change in condition which might precipitate needs and services more typically associated with a nursing facility, an assisted living community really has only three options available: 1) do nothing; 2) attempt to provide nursing services; or 3) discharge the resident. Most facilities opt for number three. But a distressingly large number choose options one or two.

Number one is a recipe for disaster (a disaster which, in all likelihood, will entail tort litigation). Number two would appear the most desirable, at least from the customer’s point of view, but it is an option fraught with financial pitfalls. Jim Moore, one of assisted living’s most respected consultants, refers to this approach as the “one million dollar wake up call.” Adding just 60

minutes of assistance per day for just 40 percent of the typical community's residents will cause an additional \$123,000 in expenses. If unable to cover those additional expenses with higher prices, traditional valuation methodologies will show a decrease in the value of that community to the tune of \$1.4 million.

Coming to Terms with Quality in Long-term Care

Quality care in America's nursing homes has, beyond a doubt, become the most contentious issue in contemporary long-term care. The issue has polarized the political process, created an environment working at cross-purposes with the very goal of enhancing quality, and threatened the underpinnings of an entire industry. And, most surprisingly, it has done so with all participants to the debate espousing essentially the same goals. It has divided those who should be allies. Clearly, something is wrong here.

The industry, for its part, must accept the reality of the problem. It must openly admit to the presence of poor providers and accept responsibility for working to eradicate their practices and, if necessary, to eradicate the providers themselves. Few in the industry are unaware of the "bad apples." But equally few are willing to say so publicly.

The problem is that accepting the reality of "poor performance" and being able to define it in a commonly acceptable fashion are two separate issues altogether. Therein, perhaps, lies the reluctance of even good providers to publicly accept the reality of their less-benign brethren. It is here that government must play a role. If the provider community chooses, after years of official silence, to take on the responsibility of working to rid itself of those who give all a bad name, then there must be some assurance that the definition of poor care is understood and accepted by all.

The issue of measurement is critical to the entire debate. Absent some common understanding of how we measure quality, how can we expect to join forces both to improve it as well as fund it? Avedis Donabedian, in his seminal work on quality assessment, posited three measures of quality:

- structure (the resources available to provide care),
- process (the adherence to procedures) and
- outcomes (the actual condition achieved by the patient).

Our system of measurement is still oriented primarily toward structure and process and less toward outcomes. But that approach has two major disadvantages, as has been eloquently pointed out by Rosalie and Bob Kane in a recent publication co-authored with Dick Ladd, *The Heart of Long-term Care*:

"(1) The majority of the regulations are based not on empirical evidence of what activities are associated with better outcomes but on professional judgments, which quickly approach dogma. (2) Strict statements about what should be done for whom become rapidly restrictive at a time when long-term care dearly needs innovation and creativity. Especially because so little has been proven about how to

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deliver the best care (and there is every likelihood that more than one way is available to achieve this end), it is premature to ossify the process.”

Yet ossify the process we have, and we have accompanied it with an enforcement system which has worked counter to the very goals the process was designed to foster. Punishment is a most appropriate reaction to those who have abused and neglected their patients. However, for those who have inadvertently acted contrary to “professional judgments,” punishment (absent adverse outcomes) is totally inappropriate. For it will create the very atmosphere in our nursing facilities which all should abhor, an atmosphere attractive only to those whose interests are in mercenary return rather than professional fulfillment. One of the most difficult labor markets in recent memory is a direct result of the atmosphere of fear engendered by a system whose end result can only work to the detriment of patient care. Buildings do not provide care. People provide care. And, when 25 percent fewer candidates sit for licensure exams as long-term care administrators, are we seeing the handwriting on the wall?

Assisted living shares with nursing homes the problematic reliance on a labor force which is scarce, under-trained and volatile. Contributing to the competitive price advantage enjoyed by assisted living is the somewhat more robust nature of its clientele. They are not as frail and present fewer co-morbidities. But they require staff attention, nonetheless. And we skimp on staff at our own peril. Staffing becomes even more critical as a building (with its residents) ages. While cross-training of staff, with an eye on the “universal worker,” is one approach to dealing with the issue, that approach can only partially alleviate the problem. A more permanent solution will be more difficult to come by.

The Long-Term Care Imperative: Baby Boomers and Beyond

There is an issue lurking in the wings that, if not successfully addressed, might lead us 20 to 30 years hence to refer to these as the good old days: long-term care financing. We’re not talking about reimbursement, which is the method and amount of payment for an individual long-term care service, but financing, which is the system and resources assigned by society to cover the totality of long-term care costs.

The system in place today is actually a strange amalgam of public and private resources, and is as much an accident of history as it is a cohesive and comprehensive method of financial support. Its predominant feature is a welfare program (Medicaid) that was never envisioned as the primary funding mechanism for long-term care. It assumed that role because of a feature called “spend down,” which provided nursing home services to those whose costs for healthcare impoverished them to the extent that they became financially eligible for the benefit. In so doing, of course, it also perverted the long-term care continuum by steering these newly impoverished Americans toward the institutional setting that most would prefer not to utilize.

Inappropriate as Medicaid might be as society's primary long-term care financing mechanism, it, too, is experiencing fiscal pressures sufficiently serious to call its continued viability into question. Medicaid is jointly financed by the federal and state governments. For most states, in fact, Medicaid is the fastest growing budget component. There are serious questions about whether states can continue to bear the burden of Medicaid's long-term care responsibilities, especially as those responsibilities squeeze other claimants on state funds (for example, corrections facilities, infrastructure and education). Vibrant state economies have been the rule, rather than the exception, over the past seven years, and the Medicaid squeeze on state budgets has been bearable. When those seven years of feast are supplanted by famine, however (and economic good times are cyclical), can the states keep up? And if they can't, will long-term care be among the first programs on the chopping bloc?

The Future of LTC Delivery and Financing

A number of programs have been developed and tested over the past 30 years in an attempt to better structure the financing and delivery of care, particularly long-term care, for America's seniors. Most of them focused on the need to better coordinate and integrate the services provided. They did so through one of two basic, but very dissimilar, approaches: case management (the brokerage model) or the direct provision of services (the consolidated model).

Brokerage approaches have had only limited success. One reason for that is thought to be the difficulty of identifying high-risk patients for whom home and community-based services would be most cost-effective. Another is their failure to integrate funding sources

Consolidated models, such as Evercare, Social Health Maintenance Organizations (S/HMOs) and Programs of All-Inclusive Care for the Elderly (PACE), have done a better job of targeting recipients and integrating funding. And their results have been more promising. But they, too, have their limitations and challenges. Evercare, for example, is a nursing home-based approach to care integration, which manages acute care financing and care delivery for residents. It is appropriately focused on case management and the use of geriatric specialists (resulting in a significant decline in hospital admissions). But, since its clientele already reside in nursing facilities and the program assumes no responsibility for custodial care, the program is limited in terms of its applicability to a broader population and is not likely to be a significant solution to the problems of long-term care delivery and financing.

S/HMOs don't have that flaw. They were established in 1982 as part of a demonstration to bring both service providers and funding streams (Medicare and Medicaid) together. Unlike Evercare, however, their services are not oriented toward the institutionalized recipient of care. Indeed, their problem is the converse. In setting a limit on annual expenditures for any of its clientele, the S/HMO cannot financially cover the typical long-term stay in a nursing facility and, therefore, effectively denies the benefit. It is true that

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S/HMOs (incorporated into the Medicare+Choice program in the Balanced Budget Act of 1997) have shown dramatic reductions in admissions to nursing facilities (by as much as 29 percent, when compared with non-S/HMO programs). But their financial limitations make them, like Evercare, unlikely solutions to the problems of long-term care.

Their limitations notwithstanding, Evercare and S/HMOs have served us well. One can look at PACE not as a stark contrast to them, but as an evolution from them. In PACE (as is also true of S/HMOs) the concept of integrating the services needed by the client into a comprehensive package of care is facilitated by capitating payments to the programs. In this respect, PACE is clearly the more advanced of the two programs. By focusing on seniors eligible for both Medicare and Medicaid, it receives a single capitated payment from both programs. The dysfunctional compartmentalization of the elderly occasioned by separate funding streams (and separate management of that funding) is not a problem for PACE eligibles. This integration of financing gives PACE the flexibility to provide services that are needed, not just those that are reimbursable. Nor does it have the financial or programmatic limits of S/HMOs and Evercare, which limited their applicability to long-term custodial care.

The PACE program's focus on interdisciplinary assessment, care planning and intervention (delivering services deemed necessary for the client, not just those enumerated in obscure regulations) has resulted in even more dramatic reductions in nursing facility use than even those experienced by S/HMOs. While PACE clients become so only when certified by the state as being nursing-facility eligible, there are PACE programs with actual admissions to facilities as low as 5 to 10 percent. Early detection and early intervention (with the service most appropriate to the client's needs) have resulted in a dramatic reduction in the use of facility-based care. Indeed, the program's successes led Congress in 1997 to establish PACE as a permanent provider type under Medicare, with authorization for 60 such programs across the country.

Yet even PACE has its problems that, despite its documented successes, have kept it from becoming the major player it might yet become in the long-term care arena. Enrollees in most of the 20-some PACE programs number only in the hundreds. The smallest, that associated with my university, has less than 100. (I'm not sure I could sleep nights were I managing a capitated program in which the risks of potentially high-cost enrollees needed to be spread over such a small number of "lives.")

The small number of enrollees is just one of the three major problems facing the PACE program. Failure to effectively address those problems might lead the program to be perpetually relegated to what even one of its staunchest proponents refers to as "boutique long-term care."

PACE has also experienced difficulties in recruiting primary care physicians. Appropriately trained and motivated physicians are an indispensable part of the PACE equation. While certification in geriatrics is not a requirement for

physician involvement in PACE, an understanding of the principles of geriatric care is, including an appreciation for working within the interdisciplinary team.

The third major challenge facing PACE is developmental in nature. Bringing up a PACE site takes time and money. Programs have consumed from three to five years in the development phase, with about \$1.5 million in capital expenditures prior to enrolling the first client. Thus, one of the PACE challenges will be to partner with other providers, with the development phase focused on repositioning existing facilities rather than creating them from scratch.

For all their problems, programs such as PACE might well carry the seeds of a potentially successful approach to reversing the inadequacies of current long-term care financing and delivery. PACE creates cohesion where there was fragmentation, awareness where there was confusion, access where there were barriers. PACE shows the value of a coordinated, interdisciplinary approach to providing services to patients with diverse needs. PACE has shown the value of holistic medicine, the hallmark of geriatric care. And PACE changes the focus of both funding and delivery toward the recipient of service and away from the provider of that service.

PACE exhibits high levels of customer satisfaction, marked by low rates of dis-enrollment. PACE reduces both nursing facility and hospital utilization, with a hospital length-of-stay of 4.9 days (compared with the Medicare average of 7.6) and drops the average of 7.6 medications per resident in the typical nursing facility to 5.5 for the PACE population.

Perhaps the greatest lesson to be learned from PACE is to treat the client as the focus. Treat the entire client as the focus. Withstand the urge to force the recipient of care into forms comfortable to the practitioner, the bureaucrat, the financier. Make the term "holistic" something more than jargon. Make the patient more object than subject of our attentions. Make his or her needs, not ours, the ultimate goal of our endeavors. Then we just might have a system that works.

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Making Assisted Living Facilities More Affordable

Of all the issues confronting the burgeoning assisted living industry, the question of affordability takes center stage. Why, it is asked, should those with less resources be steered toward nursing homes when equally appropriate care is available in assisted living? Shouldn't public funds be available to subsidize assisted living, just as it is available for the support of skilled nursing? Indeed, wouldn't both government (the primary payer of nursing home care) and the customer benefit from this less expensive and more accommodating approach to the delivery of long-term care services?

Unfortunately, it's not that simple. First of all, assisted living isn't necessarily that much less expensive than comparable nursing home care. When compar-

ing apples and apples (i.e., recipients of long-term care services with the same levels of frailty and co-morbidities), the cost savings between nursing facilities and assisted living all but disappear. (My mother's case is a prime example: At her level of need, the cost of care in a nursing facility would likely be less than what she is paying now in assisted living.)

Some might further contend that the role of the Medicaid safety net should not be as readily available for services which are largely "social" in nature, but should be reserved for those more serious healthcare needs reflected in the care provided a nursing home resident. And finally, the skeptics would argue, since when does the public owe me something just because I want it? I might prefer to get around town in a BMW, but does society really owe me more than good public transportation?

When looking at the issues of affordability one has to begin with the two aspects of a community's operations that determine the price needed to cover that community's costs. These are development activities (which include financing and construction) and facility operations. These two areas generate the costs of a project, and it is only by reducing those costs can one can make the product more affordable.

In the development area one can look for cheaper land, or even have it donated by a philanthropic organization. One can look to tax-subsidized financing, perhaps by using tax credits available to those building low-income housing. One can engage in value-engineering, a euphemism in the building trade for lower cost materials or fewer amenities. But none of these options will have an appreciable impact on the ultimate cost to the consumer. Development costs, when amortized over the life of the assisted living community, are relatively insignificant when compared to the more critical of the cost factors: operations.

The challenge is even more daunting in the operations area. The bulk of operational costs are for manpower. Since assisted living is already competitive with nursing facilities in how much (or, more appropriately, how little) it pays staff, shaving salaries is a recipe for higher turnover. And reducing personnel is a recipe for the scandals attendant to inadequate care.

In a nutshell, it's nigh on impossible to make assisted living affordable. Mom pays what mom pays because that's what it costs to provide the service she demands. Reduce the cost, and the product that has attracted her (and hundreds of thousands like her) will be commensurately diminished. That's not what the proponents of affordability have in mind.

What affordability really gets down to, therefore, is subsidization. If you can't reduce the costs, get someone else (other than the consumer) to pay for them. In reality, even some of the development options listed above are nothing more than subsidization: Donated land is a subsidy. Tax-favored financing is a subsidy.

The only hope for affordability on the operations side is subsidization. In this case, subsidization occurs through public financing programs such as public housing vouchers or Medicaid waivers. There's nothing wrong with that as long as we're clear on the fact that we really aren't making assisted living affordable. We're simply using tax dollars to help pay for it on behalf of individuals who can't afford to pay for it on their own.

While that form of subsidization may actually be appropriate for those on the lowest rungs of the nation's economic ladder, what about those in the middle? I'm not talking about those households with disposable incomes exceeding \$25,000 (some 22% of American households headed by someone over the age of 75). Nor the 34% of such households with incomes under \$10,000, many of which will be eligible for public financing. The real issue of affordability continues to stand for the remaining 4.3 million households, which are neither fish nor fowl.

The news, however, is less discouraging than we might think. The \$25,000 benchmark exists more in the minds of those developing proposals for new assisted living properties than it does in the actions of those residing in those properties. In two recent studies conducted for the National Investment Center for the Seniors Housing and Care Industries (NIC), it was discovered that, the \$25,000 benchmark notwithstanding, two-thirds of assisted living residents didn't have those types of disposable income. They had less. In some cases, considerably less.

How did they afford the price of care? Two ways. One, they were also subsidized—in this case, by their adult children. Many American children, often disinclined to substitute their own resources for Medicaid dollars when it comes to nursing home care for their parents, are more than willing to pay for that care when provided in an assisted living community. The second method of paying for assisted living by those without the disposable income necessary to afford it is by “spending down.” Borrowed from terminology common to Medicaid eligibility determinations, spend down simply means that fixed assets (e.g., one's house) are transformed into disposable income.

Between 1984 and 1999, the median net worth among households headed by persons aged 65 or older increased by 69 percent. Seventy-three percent of households headed by someone over 75 own a residence with a median value of \$80,000. Over 90 percent have non-financial assets (other than real estate) with a median value of \$79,000. By the mid-1990s, America's seniors showed every willingness to “spend down” some of that net worth to purchase assisted living services.

Subsidization and spending down, taken together, explain the underlying weaknesses in the \$25,000 benchmark. Obviously, assisted living is eminently more affordable to “middle class” seniors than previously assumed. While its price might have been higher than conventional wisdom thought affordable, its perceived value is clearly not. What seniors see in assisted living is an environment for the delivery of long-term care services that they find desirable, and worthy of liquidating their assets to purchase. They have been joined in those transactions by their children.

What seniors see in assisted living is an environment for the delivery of long-term care services that they find desirable, and worthy of liquidating their assets to purchase.

That more seniors have not taken advantage of a service many of their peers have found so attractive is perhaps less a function of affordability than it is of understanding. Other studies undertaken by NIC have shown an incredible lack of familiarity, both by seniors as well as their children, with the assisted living product. That issue is perhaps where we should begin to direct our attention.

This article is compiled from a series of columns:

- Willging P. (2000) Aging in place: coming home to roost?, *Caring for the Ages* 2(2).
- Willging P. (2000) Assisted living: day of reckoning?, *Caring for the Ages* 1(7).
- Willging P. (2000) Coming to terms with quality in long-term care, *Caring for the Ages* 1(5).
- Willging P. (2001) Demographics: don't let the numbers fool you, *Caring for the Ages* 2(7).
- Willging P. (2000) How to make ALFs more affordable, *Caring for the Ages* 2(1).
- Willging P. (2000) The future of LTC delivery and financing: order out of chaos?, *Caring for the Ages* 1(9).
- Willging P. (2000) The long-term care imperative: baby boomers and beyond, *Caring for the Ages* 1(6).

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Increasing Quality of Life for Parkinson's and Alzheimer's Patients

**by Nancy E. Edwards Ph.D., RNC
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As the older population increases there is a corresponding rise in individuals who are most vulnerable to and most affected by chronic conditions. These conditions are the major cause of illness, disability and death in the United States, and are overtaking infectious diseases such as influenza and pneumonia as the primary health problems facing America. Over 100 million Americans of all ages suffer from chronic health conditions (Hoffman, Rice and Sung 1996). In 1995 the cost of medical care for Americans with chronic conditions was \$470 billion. Almost 160 million people will be affected by 2040, at a cost estimated to be as high as \$864 billion (Robert Wood Johnson Foundation 1996).

Chronic conditions are those defined as illnesses or impairments that cannot be cured. Some of the most prevalent, such as sinusitis or hay fever, are not disabling. Others, such as heart disease and arthritis, can cause significant limitations in an individual's ability to perform the basic activities of daily living (ADL), and may require personal, social or rehabilitative care over a prolonged period of time. The most common chronic conditions for those age 75 and older (regardless of gender) are arthritis, hypertension, hearing impairments, heart disease and cataracts.

Added to this escalating equation are the rising demands on healthcare utilization and caregiving that result from the proportional increase in progressive neurological conditions such as Alzheimer's and Parkinson's disease, Multiple Sclerosis and Amyotrophic Lateral Sclerosis (ALS). This paper examines the impact of Parkinson's and Alzheimer's disease on the emotional and physical health of the affected population and their caregivers.

Illustration #1: In-home Care and Parkinson's Disease

According to a 1998 report from the National Institute of Neurological Disorders, an estimated 50,000 Americans are diagnosed with Parkinson's every year. Because Parkinson's disease is a chronic illness, the majority of

Parkinson's disease, like other chronic conditions, affects not only the individual, but the entire family.

patients are cared for in their homes by a spouse, family member or other caregiver. Thus, Parkinson's disease, like other chronic conditions, affects not only the individual, but the entire family. Family members typically have not anticipated that they will need to assume the role of spousal or parent care-taker, and are often ill-equipped to manage the emotional and physical demands that come with that role (Wallhagen & Brod 1997).

The unpredictable trajectory of Parkinson's disease challenges the perceived amount of choice and control individuals and families have over their future. The caregiver often must assume more responsibilities in caregiving duties as well as in managing the household. The success with which families or significant others cope with chronic illness may affect how the patients manage their conditions. Successful management by the caregiver is thought to lead to a decrease in the downward slope of the disease's progression.

If, however, caregivers are unable to continue providing the needed care because of increased burden, the result is expensive care in an extended care facility (Chenier 1997). Holicky advocates that caring for caregivers should be viewed as a method of preventing a decline in their health (Edwards & Ruettiger). When caregiver health declines and requires healthcare intervention, there is an increased overall cost of care to the family. *Effective strategies for reducing healthcare costs can be achieved by (1) realizing that the caregiver is the intermediary between the patient and the healthcare system and (2) finding ways to reduce caregiver burden.*

Caregiver burden

Caregiver burden is defined by Zarit, Todd & Zarit (1986) as the extent to which caregivers perceive their health, social life and financial status to be suffering because of their caregiving experience. Caregivers often feel overwhelmed by additional tasks: At times they must carry both their own responsibilities and those that a spouse or significant other is no longer able to perform. The increasing number of commitments may have both personal and relational costs. Stressors include the physical demands of caregiving, conflict over competing roles, difficult or annoying care-receiver behaviors, loss of companionship, and a lack of support (Williams 1994).

Increased caregiver burden in Parkinson's disease families is associated with a significant decrease in management of the disease (Edward & Ruettiger). Consequences of this increase in caregiver burden may include:

- Caregivers become so involved in caregiving that they neglect their own physical and mental well-being (Chenier 1997) and may, therefore, create an "additional" patient (Parks & Pilisuk 1991; Williams 1994).
- Social support has long been regarded as a powerful mediator or buffer for stressful situations (including caregiving); a perceived lack of support from family or friends may cause caregivers to feel lonely or isolated (Borneman 1998).

- Abuse or neglect of the care recipient may result.
- Declining physical and emotional health of the caregiver can impact the care patient who must be institutionalized.

Since an increase in burden results in a decrease in management and increased institutionalization, the professional's role in decreasing caregiver burden is important to both the family and in reduced patient care expenses. Relief of this burden and, thus, more successful management of the disease may need to become the focus of nursing intervention.

The Professional's Role

The rehabilitation nursing role of counselor, educator and supporter contains these components:

- Support the family in caring for the Parkinson's patient in the home by assisting them to determine what role and what level of caregiving they may assume. Caregivers must be able to identify a realistic level of support they can give without experiencing unnecessary guilt (Kuyper 1998).
- Focus on both caregiver and patient. Educate both parties about the symptoms associated with Parkinson's and the expected trajectory of the disease. Informing both the patient and caregiver about intervention methods to control symptoms as they arise can affect the health of both.
- Promote active participation with support and exercise groups for both caregiver and patient. These groups offer continuing education and socialization opportunities, and allow for the expression of frustrations that can decrease the burdens and frustrations encountered in the caregiver/patient relationship.
- Examine the changing components of the relationship by assessing communication, workload distribution and lifestyle satisfaction, thus identifying potential problem areas that could benefit from counseling.
- Explore the advantages and disadvantages of home assistance or respite care with the caregiver and patient.

Illustration #2: Alzheimer's Disease and Nutrition

Alzheimer's disease may reach epidemic proportions by the middle of this century, increasing by 350 percent unless effective methods for prevention and treatment are developed (Medscape 2000). Approximately 4 million Americans have Alzheimer's disease (AD), affecting 1 in 10 people over 65 and nearly half of those 85 and older (Hingley & Ruggeri 1998), and it is the fourth leading cause of death. Without a cure or prevention in the foreseeable

future, efforts toward improving the quality of life for AD individuals must be undertaken.

AD begins with mild cognitive deficiencies such as forgetfulness and gradually worsens, manifesting in difficulties with orientation, loss of independence, disruptive behavior and disordered eating behavior. Weight loss is common in AD patients, leading to reduced muscle mass and a loss of functional independence that typically results in an increased risk of infections, skin irritation ulcerations and falls. These factors combine to produce a decreased quality of life and an increased likelihood of hospitalization for AD patients.

More recently, studies in different nursing homes reveal that, in general, the staff believe animal programs to be beneficial without significantly adding to the workload.

Weight loss in AD is not a new phenomenon; Alois Alzheimer first observed it in 1907. More recently, numerous studies have systematically observed lower weights for hospitalized dementia patients, particularly those with AD, than those of control subjects in good health (Morgan & Hullin 1982). Energy malnutrition, wasting and low body weight are found in approximately half of the demented older adults (Donaldson, Carpeter, Toth, Goran, Newhouse & Poehlman 1996). A two-year longitudinal study following 362 individuals with AD and 317 healthy controls found that almost twice as many AD individuals experienced a weight loss of 5 percent or more (White, Pieper & Schmader 1997).

The impact of weight loss on mortality has also been studied. White, Pieper and Schmader (1998) found that weight loss is associated with the severity and progression of disease. When controlled for age and stage of AD, weight loss is a predictor of mortality; weight gain significantly decreases mortality and slows progression. Thus, it is important to study useful clinical interventions that encourage food intake, offsetting malnutrition and weight loss.

Animal-assisted therapy

Environment is an important influence in managing difficult behaviors associated with AD. The more vulnerable the individual, the more likely it is that he or she will be influenced by environment (Lawton 1975). Although using animals to assist human therapeutic activities has a long history, its extensive, documented and organized use is relatively new (Beck 1985, 2000; Beck & Katcher 1984, 1996; Beck & Meyers 1996). Yet it has been widely observed that interactions with animals can positively influence and improve morale.

One of the first therapeutic explorations of using animals for institutionalized adults involved introducing a cat "mascot" into each ward of a nursing home (Brickel 1979). Some negative aspects, such as concerns about fleas and allergies, were reported, but the overall impression was that the cats improved patient responsiveness, offering them pleasure and enhancing the general milieu of the treatment setting. More recently, studies in different nursing homes reveal that, in general, the staff believe animal programs to be beneficial without significantly adding to the workload (Cole & Gawlinski 1995; Crowley-Robinson & Blackshaw 1998; Kranz & Schaaf 1989).

Many nursing homes today offer residential animals or animal visitation as part of their recreation programs (Beck & Katcher 1996), with most using dogs, cats and rabbits to improve patient social interaction (Beck & Katcher 1996; Bustad 1980; Draper, Gerber & Layng 1990; Fick 1993; Perelle & Graville 1993). Bird feeders in a nursing home setting improved both self-reported and nurse ratings for control, happiness and activity (Banziger & Roush 1983).

There is little indication that animal programs are particularly dangerous and, while there are risks associated with any animal contact, there are few reports of adverse effects (Shantz 1990; Walter-Toews 1993). Nevertheless, value to the patients must be demonstrated in order to justify any risk associated with animal contact; and one of the most common criticisms of animal-facilitated therapy is that they are not goal-oriented with a clear evaluation of goals (Beck 2000; Beck & Katcher 1984; Draper, Gerber & Layng 1990; Hundley 1991).

Health benefits

It is now generally accepted that natural surroundings and contact with nature is good for people (Ulrich 1993); viewing nature scenes dominated by green vegetation is less stressful than viewing urban scenes devoid of vegetation (Ulrich 1979).

Fish tanks offer a way to introduce “nature” into the home or therapeutic setting. Subjects who observed fish tanks under laboratory conditions experienced significant decreases in blood pressure (Katcher, Friedmann, Beck & Lynch 1983). Other studies have shown that people who contemplated an aquarium underwent dental surgery with reduced stress (Katcher, Segal & Beck 1984). One of the first studies on the uses of fish tanks for older adults was conducted in public-subsidized housing. Residents who received aquariums were assessed to be more relaxed and to have improved overall satisfaction with their leisure than those who received services but no aquarium (Riddick 1985).

An analysis of nutritional intake

Researchers examined how fish aquariums influenced nutritional intake for AD residents in three specialized Alzheimer’s units located in extended-care facilities in Indiana. The influence was analyzed by comparing the nutritional intake for the baseline period with the treatment period. All three facilities experienced a significant increase in nutritional intake when residents were exposed to aquariums.

This baseline intake was then compared to the six-week, post-treatment intake, revealing another significant increase in all three facilities. Combined data from the three facilities showed that, not only did the aquariums increase nutritional intake during the treatment period, nutritional intake for the six-week, post-treatment period was significantly higher than the treatment period.

Another positive benefit of the increased nutritional intake was an approximately 25 percent decrease in the use of supplements, yielding a significant savings in healthcare costs.

Analyzed individually, the majority of subjects (87 percent) showed an increase in dietary intake, with only 9.7 percent having no change or a decrease in their dietary intake. Nutritional intake was also analyzed by meal, yielding a significant increase between baseline intake and treatment that remained for all meals, and for the six-week post-treatment period.

Several observations suggest why people ate more in the presence of aquariums. Individuals with a history of pacing and wandering sat during mealtimes for longer periods observing the aquarium, leading to increased nutritional intake. Lethargic individuals were more attentive and awake in the presence of aquariums, and increased their nutritional intake. These effects lasted throughout the study period.

Another positive benefit of the increased nutritional intake was an approximately 25 percent decrease in the use of supplements, yielding a significant savings in healthcare costs. Typically, supplements such as Ensure, Sustacal, Glucerna or Carnation Instant Breakfast were routinely given to patients when less than 50 percent of the meal was consumed and, in many cases, wasted when only a small portion was consumed.

Nutritional problems, especially unexplained weight loss in individuals with AD, are of great concern since they are an indicator of protein-energy malnutrition in the older adult and predictive of mortality (White et al 1998). This study demonstrated a non-invasive and non-chemical intervention that resulted in increased dietary intake. Only eight subjects demonstrated no increase or a decrease in nutritional intake. Overall, the study subjects showed a 21.1 percent increase in nutrition when treatment was initiated and a 27.1 percent increase through the post-test period.

Implications for AD individuals and caregivers

Numerous, positive implications exist for increasing nutritional intake in individuals with Alzheimer's. Increased nutritional intake can delay muscle wasting which can, in turn, delay functional dependence and loss of autonomy. Additionally, the increase in intake can help prevent skin infections, decubitus ulcers, sepsis, and help decrease the incidence of falls. Quality of life improves for the Alzheimer's individual, and caregiver burden is reduced (Sandman, Adolfson, Nygren, Hallmans & Winbald 1987).

Several additional benefits accompany the reduced need for supplemental nutrition. Eating food, with its variety of textures and tastes, helps stimulate the sensory system. Facilities or home caregivers need not endure the cost of preparing and serving meals that are not eaten or substitute prepared supplements that maintain nutrition. In summary, more food consumed during mealtime brings increased nutritional value and sensory sensations, and decreases expenses attributed to wasted food and supplemented nutrition.

In the past, animal-assisted therapies with AD individuals have focused on the use of dogs, cats and rabbits but, because the AD individual can act inappropriately without warning, these programs have required direct supervision to prevent animal injuries. Specifically designed automated aquariums

can be safely used and require little staff attention, but had not previously been studied with AD individuals. The tanks used in this study provided a safe environment for the animals and are still intact several years after completion of the study. This study demonstrated that the aquariums held the AD individuals' interest, increased nutritional intake at mealtimes and decreased the use of supplements, yielding these positive effects for 87 percent of the individuals studied. There may be additional positive effects not measured in this study. It did appear that the aquariums facilitated interaction between AD individuals and visitors as a focus point for communication. Furthermore, this study demonstrates that the influence of animals can be quantitatively measured, showing more than anecdotal results.

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Edwards, N. E. & A. M. Beck (2001) *The influence of animal-assisted therapy on nutritional intake in individuals with Alzheimer's Disease*, under review.

Edwards, N. E. & K. M. Ruettiger *The influence of caregiver burden on the extent to which individuals with Parkinson's disease manage their condition: Implications for rehabilitation nursing*, under review.

National Academy on an Aging Society newsletter (1999).

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