Empty Promises

Maine's Looming Elder Care Crisis

FORWARD

Like the gold miners who forged their way across this nation, opening up new frontiers, the Baby Boomers are doing the same in the field of eldercare. Our long-term care system is truly broken and the determination to stay home -- rather than face institutionalization -- has become this generation's mantra. Instead of "California or bust!," their motto is fast becoming "Home or bust!," as they opt to be number 30,000 on a waiting list for home care rather than go into a nursing home.

As a pioneer in this field myself, I have observed many well-intended efforts to care for elders result in a disarray of regulation and laws that create inadequate and constricted options for seniors. I have also been the subject of illogical regulation and enforcement that has only served to damage my clients. This paper provides an overview of how we came to be in this untenable situation – in which seniors do not have adequate supports to stay at home or to find a suitable home-like option -- as well as a roadmap for a way out of this quandary.

I would like to thank Rebekah Smith for her concise compilation of decades of research and experimentation regarding better housing and care for the elderly. As we prepare to distribute this report, I have just returned from the International Conference on Aging, Disability and Independence, which represented the current research on this topic from around the world. It substantiated and validated the research that I have been doing and that Rebekah has set forth here. Following are excerpts from some of the papers presented by leading experts from around the country:

- "A patchwork of federal, state and local policies, regulations, standards and codes…can be barriers to innovation." U.S. Dept. of Commerce, *Technology and Innovation in an Emerging Senior/Boomer Marketplace* (Dec. 2005).

- "Small community group homes appear to be emerging as the preferred mode of out-of-home care…" Dr. Matthew Janicki, *Adapting Group Homes for Dementia Care*, University of Illinois at Chicago (2006).

- "Perhaps the most detrimental effect of the traditional culture of long-term care, and the fact of institutional life that drives the movement for change the most, is how meaningless people's lives can become in the traditional nursing home. Any systemic attempts at culture change must therefore address the issue of teaching the requisite skills that insure cultural competency in the new order and thus add meaning to people's lives." Audrey S. Weiner & Judah L. Ronch, Culture Change in Long-Term Care xiv (2003).

- "We should each look at our own self in the mirror and ask a straightforward question relative to the nursing home with which we are connected: 'Would I like to spend the last days of my life in this nursing home?' If not, there is something terribly wrong with the situation." Douglas Holmes & Mildred Ramirez, *Models for Individuals with Alzheimer Disease: Beyond the Special Care Framework, reprinted in* Weiner & Ronch at 175.

This paper combines the available research with my own experience providing housing with services to seniors in hopes of stimulating a significant change in the delivery of elder care in Maine. Without such a change, we are heading for disaster.

- Joanne Miller, LSW, CMC, CSA - Administrator, ASK…for Home Care - President, Homeshare, Inc. – Member, Gov. Brennan's Small Business Advisory Council & Gov. McKernan's Human Resource Development Council

Empty Promises:
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The landscape for long-term care of elders is the throes of monumental change, both in Maine and nationally. The passage of the Americans with Disabilities Act in 1990 and the groundbreaking United States Supreme Court Olmstead decision in 1999 laid the groundwork for a new approach to elder care and housing. This clarification of the legal rights of disabled elders, in combination with an aging population of Baby Boomers who are closing in on retirement, requires us to reevaluate how we allocate our limited elder care resources. Unfortunately, the regulatory system for elder services and housing has not kept pace with these changes and continues to encourage the unnecessary and undesirable institutionalization of elders while limiting housing and care options. As a result, we face a looming crisis in elder care and housing.

This set of circumstances highlights the need for a paradigm shift in the way we think about and structure elder care. Our decisions must be tempered by the overwhelming desire of most seniors to avoid institutionalization in large nursing homes for the final years of their life in favor of receiving care in a home or community-based setting. **This briefing provides an explanation of the changes in the legal landscape of elder care that have occurred over the last fifteen years, reviews the needs and desires of elders, and suggests a promising model to combat the impending crisis here in Maine.**

I. Legal Standards for Care of Disabled Elders

A. Americans with Disabilities Act

The federal Americans with Disabilities Act ("ADA") was enacted in 1990 to establish minimum standards to protect those with disabilities from discrimination in employment and places of public accommodation. It provides the basic tenets of legal rights for disabled elders. When signed into law, the ADA "represented the most significant piece of civil rights legislation in the United States in nearly 30 years." Alexandria Stewart et al., Center for Health Care Strategies, Inc., *Beyond Olmstead and Toward Community Integration: Measuring Progress and Change* 3 (Dec. 2003). The preamble to the ADA sets forth that this country's "proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency." 42 U.S.C. § 12101(a)(8). Enacting the ADA, Congress made the significant findings that:

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- "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem,"
- "discrimination against individuals with disabilities persists in such critical areas as . . . housing, . . . institutionalization, [and] health services," and
- "individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, . . . failure to make modifications to existing facilities and practices . . . [and] segregation."

42 U.S.C. § 12101(a)(2), (3) & (5).

The ADA governs the provision of public services to disabled elders, requiring that no disabled individual "be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132. The law requires public entities to administer programs "in the most integrated setting appropriate to the needs" of disabled individuals. 28 C.F.R. § 35.130(d). Further, government programs and regulations must accommodate a person's disability unless such a modification would "fundamentally alter the nature of the service, program, or activity." 28 C.F.R. § 35.130(b)(7).

B. Olmstead v. L.C.

In 1999, the United States Supreme Court issued the landmark decision of Olmstead v. L.C., 527 U.S. 581 (1999), which held that the institutionalization of disabled individuals who could receive care in a community setting was a violation of the ADA. The Court held that it was illegal for the state of Georgia to keep mentally retarded patients institutionalized in a state-run mental health facility when treatment professionals concluded that they could be cared for appropriately in a community-based program. Olmstead, 527 U.S. at 587. Specifically, the Court held that the ADA requires states to provide community services to qualified individuals when the treating provider believes community placement is appropriate, the affected client does not oppose it, and placement in the community can be reasonably accommodated taking into account the resources available to the state and the needs of others. Olmstead, 527 U.S. at 587.

The Court rejected Georgia's arguments that insufficient funds prevented them from serving the individuals in a community-based setting. Instead, the Court found that the unjustified institutional isolation of those with disabilities is a form of discrimination and noted that "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." Olmstead, 527 U.S. at 600. Moreover, the Court determined that the ADA established that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." Olmstead, 527 U.S. at 601.

The Olmstead holding has been given context in many subsequent cases, most notably in a California case. There, the United States Justice Department concluded that California had contributed to the unnecessary isolation of disabled individuals by failing to

ensure that residents were adequately assessed for non-institutional placements; neglecting to inform residents of home-based and community-based alternatives; and failing to provide sufficient meaningful community options and support services to reasonably accommodate qualified residents. United States Department of Justice, Letter to Honorable Arnold Schwarzenegger 2 (Aug. 3, 2004).

C. New Freedom Initiative

To ensure the successful implementation of the Supreme Court's Olmstead decision, President George W. Bush launched the New Freedom Initiative in 2001 with an Executive Order highlighting the federal government's commitment to "community-based alternatives for individuals with disabilities and [recognition] that such services advance the best interests of Americans." Executive Order No. 13217, *Community-based Alternatives for Individuals with Disabilities* (June 19, 2001). The Executive Order directed federal government agencies to work with states to swiftly implement the Olmstead decision and provide services to disabled individuals in community-based settings in order to "help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life." Executive Order No. 13217.

D. State Efforts to Implement Olmstead

In response to Olmstead, the federal Department of Health and Human Services ("HHS") issued guidance suggesting that each state create a plan for its implementation of Olmstead. Such a plan would include a reliable quantification of how many people with disabilities were institutionalized and eligible for community-based services, an adequate system of data about institutionalization and eligibility, and a willingness to make improvements to data collection services when necessary. National Council on Disability, *Olmstead: Reclaiming Institutionalized Lives* (Aug. 2003) at 40 (citing HSS guidance of Jan. 14, 2000). Further, HHS noted that states needed to carefully review assessment procedures to ensure that they were adequate first, to identify institutionalized persons with disabilities who could benefit from services in a more integrated setting and second, to identify individuals in the community who are at risk of placement in an unnecessarily restrictive setting. National Council on Disability at 40 (citing HHS guidance). Moreover, HHS suggested that state plans should identify available community-based services, assess the extent to which such programs could serve individuals in the most integrated setting, identify improvements that could be made, evaluate whether such programs were sufficient to meet the needs of people who were likely to require assistance, and identify changes that would improve the availability, quality, and adequacy of such services. National Council on Disability at 40 (citing HHS guidance).

Many states, including Maine, issued such reports. In addition, many states have undertaken efforts to empower seniors to direct their own care and services and others have attempted to shift people from nursing homes and intermediate care facilities into the community. Wendy Fox-Grage et al., National Conference of State Legislatures, *The States' Response to the Olmstead Decision: A 2003 Update* 6 (Feb. 2004).

Nevertheless, many of the action steps in such plans have been underfunded or completely unfunded. Moreover, many of the plans do not go far enough to satisfy

Olmstead's mandate. States continue to institutionalize "many individuals simply because they face multiple disabilities or disabilities for which there are no community-based State programs." United States Department of Justice, *Delivering on the Promise: Self-Evaluation to Promote Community Living for People with Disabilities* 19 (April 2002) (recounting constituent testimony) [hereinafter *Delivering on the Promise*]. Despite significant efforts by states to plan ahead, implementation of Olmstead remains "sluggish." Fox-Grage at 9.

In 2002, a United States Department of Justice evaluation noted that individuals across the country continued to be institutionalized in nursing homes unnecessarily because states lacked understanding of the ADA and the Olmstead decision. *Delivering on the Promise* at 19. A continuing lack of accessible services and facilities also exacerbated the unnecessary institutionalization of disabled individuals. *Delivering on the Promise* at 19. In 2003, the National Council on Disability ("NCD") issued a comprehensive evaluation finding that implementation of Olmstead's mandate remained incomplete. The report noted that the greatest barrier to integrating disabled individuals into the community was the lack of affordable and accessible housing. National Council on Disability at 5 (noting that individuals with disabilities do not receive a fair share of the approximately $7 billion in federal housing subsidies). **The unnecessary and illegal institutionalization of seniors remains a problem of epidemic proportions.**

The NCD report found that in 1999, 1.3 million individuals (3.7% of the country's elder population) lived in nursing homes. **About 1 million (77%) of those residents received Medicaid funding assistance.** National Council on Disability at 9. This phenomenon has contributed to the growth in state Medicaid budgets. In institutions built to accommodate 50% of its beds as Medicaid funded, the fact that 77% of residents are utilizing Medicaid assistance is problematic. **It also underscores the fact that those disabled elders who can afford to pay privately for housing and services do not choose nursing homes; yet we continue to routinely house low-income seniors in these less desirable institutions.** The NCD report revealed that individuals continued to be institutionalized because they needed skilled care but none was available in the community. National Council on Disability at 10. Many of these 1.3 million residents, even those with complex health needs, could have been provided care in the community, the report concluded. National Council on Disability at 10.

The implementation of Olmstead to free seniors of unnecessary institutionalization has been compromised for a number of reasons. In addition to poor planning and funding of elder initiatives, states have focused their implementation of Olmstead on younger individuals with disabilities and have not been pushed "to reform the poorly integrated network of services to older disabled individuals." Gema G. Hernández, *Promises to Keep: The Successful Implementation of the Olmstead Act to Care for Frail Elders*, GCM Journal, Winter 2005, at 19 (Hernández is the former Secretary of the Florida Department of Elder Affairs). Further, service providers have not developed appropriate evaluation tools to determine an elder's degree of readiness to move back into the community; instead, current assessment tools "focus on the skills and activities of daily living of a person that is still living in the community," while failing "to address some of the critical components needed to be in place for an individual that for months or years has not dealt with community living, but now is attempting to go back to that community setting." Hernández at 20. Ironically, the lack of an appropriate assessment tool has not been an issue, "because few states are seriously evaluating older nursing home residents in an attempt to comply with the Olmstead decision." Hernández at 20.

Moreover, rather than decreasing in accord with Olmstead's mandate, the number of elders on waiting lists for services has doubled in the last two years. Hernández at 20. To avoid scrutiny of these waiting lists, "some state agencies have done some cosmetic changes of no real benefit to the elders." Hernández at 20. **Other states have simply eliminated a waiting list for elders in need of community-based services in order to remove the pressure from government officials to ask for additional funding to expedite services.** Hernández at 20. **Moreover, many states illegally impose limits on the number of clients eligible for Medicaid.** Hernández at 21.

II. Maine's Response to Olmstead

Governor John Baldacci's own vision for Maine's aging elders is consistent with seniors' desire for expanded choices in services and housing. Governor Baldacci's plan advocates that elders be able to live in an environment where they "can maintain active, productive lives in their communities and those with increasing infirmities can receive affordable, responsive assisted living and long-term care." Governor John Baldacci, *Vision for Meeting Maine's Older Adult Needs*, *available at* www.maine.gov/governor/baldacci/vision/older_adults.html. The Governor recognizes that "successful aging policy needs to emerge out of a caring, inclusive, integrated, and community-building philosophy; one that appreciates the diversity of Maine's aging population and the resources that can be brought to bear in responding to an aging society." *Vision for Meeting Maine's Older Adult Needs*. The Governor also promotes a stay-at-home philosophy that supports "creative approaches to services that help older adults stay at home despite growing infirmities." *Vision for Meeting Maine's Older Adult Needs*. Unfortunately, although the Governor's policies are consistent with an improved model of elder care in Maine, his goals have not been put into practice.

In response to the Olmstead decision, Maine convened a Work Group for Community-Based Living charged with developing a vision for improving home and community-based services. Prior to that group's final report, the Maine Commission to Study Assisted Living filed a report with the Maine Legislature in 2001 that included a series of recommendations related to assisted living communities. The Commission noted the popularity of assisted living programs. **The Commission also found, however, that Maine's laws and rules regarding assisted living were confusing and cumbersome.** Commission to Study Assisted Living, *Final Report of the Commission to Study Assisted Living*, State of Maine, 120th Legis., 1st Sess. ii (Dec. 2001). Recognizing the need for reform, the Commission concluded that the State should attempt to maintain a mix of affordable housing programs that are of high quality and affordable, working with residents who can manage their own housing and services costs. Commission to Study Assisted Living at iv.

The Commission noted the operation of six publicly subsidized congregate living demonstration assisted living sites around the State for low-income residents. Commission to Study Assisted Living at 4. The Commission concluded that the financial stability of publicly subsidized assisted living programs and residential care facilities was "precarious"; the Bangor program, for example, was expected to end the year with a $60,000 budget shortfall. Commission to Study Assisted Living at ii & 6.

Likewise, the Work Group for Community-Based Living, which issued a report in 2003, recognized the need for a paradigm shift in Maine's regulation of elder housing and care. The Work Group's guiding vision of "[a]ll of us together in community with equality in rights and dignity, in pursuit of happiness and fulfillment" led it to recognize that "[s]ervices should be offered in a way that not only permits but encourages people to maintain control over their lives, including maximizing the use of voluntary services." Work Group for Community-Based Living, *Roadmap for Change* § 1 at 4 & 5 (2003). A 2001 study of disabled Mainers found that consumers felt patronized and intimidated when others made choices for them and advocated for the expansion of self-directed services. Institute for Health Policy, Edmund S. Muskie School of Public Service, *Living in the Community: Voices of Maine Consumers* 1 (July 2001).

In order to comply with Olmstead, the Work Group for Community-Based Living recommended that Maine:

- improve data collection "to measure the needs, unmet needs and the anticipated needs of persons with disabilities,"
- create and implement improved "measures that identify the needs, unmet needs, and anticipated needs of persons with disabilities," and
- "use better data to develop budget requests and provide sufficient funding to meet anticipated needs."

Work Group for Community-Based Living, § 5 at 1.

The Commission also suggested that the State:

- increase opportunities for consumer voices to be heard,
- "[e]xpand self-directed services by providing individuals and families with the power to control and direct the services delivered, including the right to recruit and select their own employees and deliver the paycheck,"
- "organize services around the person served, not for provider convenience," and
- "[d]efine 'need for services' to include the range of services necessary to support sustained community living and participation."

Work Group for Community-Based Living, § 1 at 12-15.

With regard to regulation of elder housing, the Commission recommended that the State:

- "[b]reak the link between housing and services so that individuals do not feel they have to give up their choice of providers in order to keep their residence,"
- "[b]reak the link between a residential setting and the level of services available so that, rather than moving from one setting to another setting a person can stay in one place and receive appropriately adjusted levels of service,"

- "[d]efine 'most integrated setting' and track whether the people served are receiving services in the most integrated setting appropriate to their needs and preferences," and
- "make sure that all people not served in the most integrated setting appropriate to their needs and preferences are provided that option within a reasonable period of time."

Work Group for Community-Based Living, § 1 at 18. The Work Group also touted consumer-directed options as expanding the workforce "because consumers often hire relatives, neighbors and friends who would normally not enter the direct care field." Work Group for Community-Based Living, § 7 at 5. The Work Group noted the success of voucher programs that allow direct reimbursement to the consumer for personal care attendant services. Voucher programs have a 93% satisfaction rate and allow individuals to maintain control over hiring and firing their own personal assistants. Work Group for Community-Based Living, § 4 at 5. The Work Group concluded that "[s]ervices should be offered in a way that not only permits but encourages people to maintain control over their lives, including maximizing the use of voluntary services." Work Group for Community-Based Living, § 8 at 5.

Further, the Work Group emphasized that service delivery should be designed to meet the individual's needs and that the design and delivery of services should be integrated. A change in outlook as well as regulation was recommended to link services to a person not a setting so that an individual could "live where he or she prefers, and not have to move when his or her need for services changes." Work Group for Community-Based Living, § 4 at 5 & § 8 at 5. Instead of having to move when his service needs change, "the individual stays put (if that is his or her choice) and the services are increased or reduced as necessary." Work Group for Community-Based Living, § 4 at 5 & § 8 at 6.

Although seniors prefer small and inclusive housing options, the Work Group found that large group settings were the only options available to many people. Work Group for Community-Based Living, § 8 at 4. Over 80% of the 5300 licensed beds in Maine residential care facilities were in facilities with over 10 residents. Work Group for Community-Based Living, § 8 at 4. **Focus group participants who lived in residential care facilities reported isolation, helplessness, and displacement.** Work Group for Community-Based Living, § 8 at 4. Residents reported that they no longer had any personal belongings, they had no opportunities to practice basic life skills like shopping or cooking, and they felt stigmatized from their communities. Work Group for Community-Based Living, § 8 at 4.

Nevertheless, despite the recommendations of the Working Group and the good intentions of State policymakers, aging Mainers continue to face a dearth of options for care and services, with the result that many are forced into unnecessary institutionalization and isolation.

III. The Rise of Assisted Living Facilities

Despite the effort that has been put into evaluating the needs and desires of aging seniors, government policy continues to stagnate and thwart seniors from realizing the outcomes they seek. Because community-based care remains elusive for most seniors and they seek to avoid institutionalization, the vast majority continue to rely on unpaid family,

friends, and neighbors for informal care. **Amazingly, more than 90% of disabled elders living in the community get their everyday care from unpaid family caregivers.** National Council on Disability at 9. **One study found that over 27 million individuals provided uncompensated care in 1997, for a value of $196 billion in services.** Andrew I. Batavia, *The Right to Personal Assistance Services: "Most Integrated Setting Appropriate" Requirements and the Independent Living Model of Long-Term Care,* 27 Am. J.L. & Med. 17, 18 (2001). Despite proposals that informal caregivers be provided support as well as a refundable tax credit to offset the cost of providing such services, no such policies have been implemented. Commission on Affordable Housing and Health Facility Needs for Seniors in the 21st Century, *A Quiet Crisis in America*, *Recommendations* 40 (2002) (submitted to Committee on Appropriations, United States Senate, and Committee on Appropriations, United States House of Representatives). Instead, this invisible majority works tirelessly to care for this country's elders without financial assistance or public recognition.

In conjunction with desiring self-determination and consumer-directed models of care, "[m]ost people desperately want to avoid going to a nursing home." Barbara Basler, *Suing the World to Get Out*, AARP Bulletin 3 (June 2004). Nevertheless, our country's long-term care system "has a built-in bias towards nursing homes." *Suing the World to Get Out* at 4. Only recently has "the federal government allowed states to begin to develop alternative care for the old and the disabled." *Suing the World to Get Out* at 4. This bias toward institutional care is counter-productive since studies have made clear that home and community services are generally less expensive than nursing home care. *Suing the World to Get Out* at 3. **For the cost of 2 beds a day in a nursing facility, 5 elders would be fully supported in their communities.** *See, e.g., Suing the World to Get Out* at 4. Our current system is also contrary to seniors' wishes; as one analyst reported, **"People would rather be No. 30,000 on a list for community care than go into a nursing home."** *Suing the World to Get Out* at 4.

In conjunction with this surge in interest in community and home-based care, nursing home occupancy rates dropped from 92.3% in 1987 to 85.6% in 2003. Robert Mollica & Heather Johnson-Lamarche, National Academy for State Health Policy, *State Residential Care and Assisted Living Policy: 2004* (Mar. 2005) at 1-39. **This precipitous decline in nursing home occupancy rates causes concern about state Medicaid budgets.** As private pay elders choose assisted living options over nursing homes, the proportion of nursing home residents who are covered by Medicaid increases. This increased reliance on Medicaid payments creates pressure for Medicaid payment rates to increase in order to replace the revenue formerly generated by private pay residents. Mollica & Johnson-Lamarche at 1-39. In addition, excess nursing home capacity creates a high likelihood that Medicaid nursing home expenditures will rise if Medicaid beneficiaries do not have access to sufficient home based services and must enter nursing homes at greater Medicaid expense. Mollica & Johnson-Lamarche at 1-39.

A. Defining Characteristics of Assisted Living

An alternative to nursing homes, "assisted living" facilities have become an increasingly popular long-term care option among seniors over the last decade. United States General Accounting Office, *Assisted Living: Examples of State Efforts to Improve Consumer Protections* (GAO-04-684) 3 (April 2004) [hereinafter *Examples of State Efforts to Improve Consumer Protections*]. Assisted living facilities are generally settings that

"provide a level of care between independent living and nursing homes for persons who need assistance with one or more [activities of daily living], such as bathing or dressing." *Examples of State Efforts to Improve Consumer Protections* at 3. Assisted living homes are also sometimes referred to as personal care homes, boarding homes, residential care facilities, adult homes, and homes for the aged. *Examples of State Efforts to Improve Consumer Protections* at 4.

Most assisted living facilities provide housing, meals, housekeeping, laundry, supervision, medication administration, and assistance with some activities of daily living. *Examples of State Efforts to Improve Consumer Protections* at 4. The assisted living model is dynamic and provides a wide range of services. Usually included are 24 hour supervision, 3 meals a day in a group dining room, and a range of services promoting quality of life and independence include personal care, health care, social services, and exercise and education. The philosophy of an assisted living facility may be described as fostering a home-like environment that maximizes residents' independence, autonomy, and dignity while minimizing residents' need to move when their need for services increase. AARP Public Policy Institute, *An Overview of Assisted Living: 2004* 2 (2004), Contrary to institutional settings, which often have two to four individuals sharing a room and eight to ten residents sharing bathing facilities, assisted living facilities typically offer residents greater privacy and control over their daily activities. Mollica & Johnson-Lamarche at 1-15.

Although use of the term "assisted living" is widespread and many states now utilize the concept in regulation, there are considerable variations among states in how the term is defined. Historically, states have licensed residential care as either adult foster care or family care (typically serving five or fewer residents in the provider's home) or group residential care (typically serving six or more residents in a variety of settings ranging from commercial apartment buildings to nursing homes). Mollica & Johnson-Lamarche at 1-7. Today, all types of residential care are generally referred to as assisted living. In 2004, states reported 36,451 licensed residential facilities with 937,601 beds. Mollica & Johnson-Lamarche at 1-2. The average size of an assisted living facility is 23 units with 30 beds and 24 residents. National Center for Assisted Living, *Assisted Living: Independence, Choice and Dignity* 4 (2001).

More assisted living residents are female than male, most are between 75 and 85 years of age, and most are mobile but need assistance with two activities of daily living. *Examples of State Efforts to Improve Consumer Protections* at 2. Ninety-three percent of residents need or accept help with meal preparation and housework while 86% need or accept help with their daily medication. *Examples of State Efforts to Improve Consumer Protections* at 2 & n.5. Although national research suggests an average monthly cost of $2,100 to $2,900 for assisted living services, AARP Public Policy Institute at 12, a survey of assisted living facilities in the mid-coast area of Maine reveals an average monthly charge of $4,335 for a private room and $4,042 for a semi-private room, with only two homes providing services for less than $2,250. Further, charges ranged as high as $6,420.

B. Lack of Access to Assisted Living Services

Although assisted living services are a viable option for some seniors to avoid nursing home institutionalization, it is not a solution to the impending crisis because they are costly and often inaccessible to seniors. Two-thirds of assisted living placements are

paid for without governmental support. *Examples of State Efforts to Improve Consumer Protections* at 5-6. According to one study, only 8% of assisted living residents rely on family funding and 14% utilize Supplemental Security Income. National Center for Assisted Living at 5. Less than 10% of those age 65 and older have a private long-term care insurance policy. AARP Public Policy Institute at 12-13. The difficulty in funding assisted living services makes this option inaccessible for most seniors:

> The high cost and lack of public funds have serious implications for older persons. Assisted living residents often have to sell their assets, spend their savings, or get help from family members to pay for their stay. Many moderate or low-income older persons who cannot afford assisted living either live at home without needed services or go to a residential supportive services setting that provides a lower level of services and privacy. Residents who pay privately and then run out of money may have to move to a nursing home, where Medicaid is an entitlement, if they cannot obtain Medicaid coverage for assisted living.

AARP Public Policy Institute at 14.

Further, assisted living services in most states continue to be regulated via an outdated medical model of care rather than a holistic social model. Moreover, government regulation continues to limit the range of choices for seniors.

1. Medicaid Continues the Irrational Policy of Covering Room and Board Only in Institutional Settings

For those seniors who require financial assistance, existing federal programs are heavily skewed toward more institutional settings such as nursing homes. Medicare provides relatively little help for long-term care since it only covers short, post-hospital rehabilitative stays. Philip D. Sloane & Sheryl Zimmerman, *Long–Term Care Options: How nursing homes and assisted living facilities measure up*, ElderCare Vol. 4, Issue 4 at 6. Medicaid also does not routinely cover assisted living services. **Ironically, although Medicaid is the single largest payer of long-term care in the nation, financing 40% of all long-term care spending of $150 billion in 1998, it remains heavily tilted toward the most expensive forms of institutionalized care and continues to cover nursing home care but not assisted living as a covered service.** Batavia at 23. **Further, Medicaid covers the cost of room and board only in institutions, such as nursing homes and hospitals, but not for non-institutional settings.** Mollica & Johnson-Lamarche at 1-43.

States can, however, access Medicaid funds for recipients in residential care through a Medicaid state plan or a Home and Community-Based Services ("HCBS") Section 1915(c) waiver. Mollica & Johnson-Lamarche at 1-41.[2] Thirty-six states utilize a Medicaid waiver and six additional states use a state Medicaid plan to fund residential care facility services. Mollica & Johnson-Lamarche at 1-41. The HCBS waiver program is intended to "alter the institutional bias of the Medicaid program, providing real choices and opportunities to control their lives for individuals who wish to live in the community." Batavia at 24; *see also* Mollica & Johnson-Lamarche at 1-42.

[2] States may also fund residential care through a Section 1115 demonstration program or a Section 1915(b) managed care initiative, but these options are not frequently utilized.

2. HCBS Waivers Have Significant Limitations

With a HCBS waiver, a state can provide services for Medicaid recipients that are not covered by a state's Medicaid plan, such as personal care, home delivered meals, adult day care, personal emergency response systems, respite care, and other services that are required to keep a person from being institutionalized. Mollica & Johnson-Lamarche at 1-42. Such a waiver also allows states to provide waiver recipients a greater amount, duration, and scope of services than are provided under the state plan. Mollica & Johnson-Lamarche at 1-42. States apply for a specified number of waiver slots and allow individuals qualified for home and community-based services up to the number of waiver slots available to choose this option. Batavia at 24. In contrast to the regular Medicaid program, however, states may have waiting lists for waiver services. Mollica & Johnson-Lamarche at 1-42.[3] Further, state expenditures under a waiver must be the same or less than they would have been without a waiver. Batavia at 24. Finally, even under a waiver, room and board in a residential care facility may not be covered with Medicaid funds even though room and board in nursing homes is a covered Medicaid service. Mollica & Johnson-Lamarche at 1-43.

Despite states' efforts to offer assisted living options to some low-income seniors, the number of beneficiaries who receive Medicaid funds for residential care services is "considerably lower than might be expected" because of limits on the number of people served under HCBS waivers. Mollica & Johnson-Lamarche at 1-45. In addition, to be eligible for waiver services, an individual must meet the state's criteria for needing the level of care provided in an institution, such as a nursing home, and be able to receive care in the community at a cost generally not exceeding the cost of institutional care. *Examples of State Efforts to Improve Consumer Protections* at 7. Moreover, waiver programs are vulnerable to state budget deficits because they can be cut at any time. Mollica & Johnson-Lamarche at 1-46.

Even facing these obstacles, participation in the HCBS waiver program has increased significantly since the mid-1980s and expenditures have risen from $0.7 billion in 1988 to $4.6 billion in 1995. Batavia at 25. From 1992 through 2002, the number of waivers increased by almost 70% and the number of beneficiaries tripled to almost 700,000 (55% of whom were elderly). *Examples of State Efforts to Improve Consumer Protections* at *Highlights* 1. By 2004, 41 states were serving 121,000 residential care residents with Medicaid funds. Mollica & Johnson-Lamarche at 1-3.

Nevertheless, Medicaid expenditures for the elderly continue to be heavily skewed toward nursing facilities, with 84.1% of 1995 Medicaid long-term care dollars going to nursing home care and only 10.3% going to home care. National Council on Disability at 9. About 33% of annual Medicaid expenditures are for long-term care, and Medicaid pays for about 64% of all nursing home expenditures each year. Mollica & Johnson-Lamarche at 1-38. Medicaid spending for institutional care in nursing homes and intermediate care facilities rose from $35.4 billion in 1993 to $56.1 billion in 2003. Mollica & Johnson-Lamarche at 1-39. One estimate of total Medicaid spending on long-term care in 2001

[3] Waiting lists for waiver services are often long. Mollica & Johnson-Lamarche at 1-58. If a waiver slot is not available, a Medicaid recipient must enter a nursing home at a higher cost. Mollica & Johnson-Lamarche at 1-58. States that fund waiver services and nursing homes from a pooled appropriation or who allow funding to "follow the person" who transfers have more flexibility. Mollica & Johnson-Lamarche at 1-58.

reached $75 billion. United States General Accounting Office, *Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened* (GAO-03-576) 3 (June 2003) [hereinafter *Federal Oversight*].

C. State Regulation of Assisted Living Facilities

As interest in assisted living has risen, states have made some attempts to update their regulation of residential care, with some states providing a stronger freedom of choice philosophy than others. Most states incorporated a distinctive "philosophy of care" into their regulation of assisted living services, a philosophy that emphasizes residents' choice, independence, and dignity. AARP Public Policy Institute at 1-2. States employ a variety of models of regulation of assisted living facilities. Because assuring that residents retain autonomy is a central concept in the assisted living philosophy, fifteen states have regulations that outline a process or approach to negotiating disagreements about residents' autonomy and risk taking. Mollica & Johnson-Lamarche at 1-14. Four states license assisted living as a service while others license assisted living as a physical location in which services are provided. Mollica & Johnson-Lamarche at 1-8.

Most states do not allow individuals who need skilled care to be served in residential care facilities; only a few states do not allow individuals who meet their minimum nursing home levels of care criteria to be served in residential care facility settings. Mollica & Johnson-Lamarche at 1-19. Many states allow residential care facilities to serve residents with a continuum of needs. Mollica & Johnson-Lamarche at 1-20.

In 2004, the AARP summarized the largest assisted living studies that had been conducted in the United States. Researchers noted that the ability to age in place depends largely on the facility's discharge policies as set by the provider. AARP Public Policy Institute at 10. Many states require assisted living facilities to discharge residents who have certain medical needs or conditions. AARP Public Policy Institute at 11. Some states take a waiver approach to discharge, allowing a residence to apply for a resident-specific waiver to keep a resident after he or she develops a condition that would normally require discharge. AARP Public Policy Institute at 11. Other states allow a resident to remain in assisted living if the resident, the resident's physician, and the facility all agree in writing that they can continue to meet the resident's needs safely. AARP Public Policy Institute at 11.

IV. The Looming Crisis

> It is ironic that at a moment of relative affluence, there is little civic dialogue about a societal approach to long-term care and the culture(s) that inform it. Despite pressing problems inherent in all facets of long-term care, we are in the lull before the storm. We are missing the opportunity for structural reform. . . . There is no agreed-upon civic agenda, yet such an agenda is essential to reform a system that appears to be both unsustainable and inhumane in its current form.

Monsignor Charles J. Fahey, *Culture Change in Long-Term Care Facilities: Changing the Facility or Changing the System?, reprinted in* Audrey S. Weiner & Judah L. Ronch, Culture Change in Long-Term Care 47 (2003).

Despite the explosion in interest in assisted living services, the country faces a looming crisis in trying to meet the long-term care needs of aging seniors. Assisted living, even with current limitations in access and affordability, cannot possibly meet the growing need for long-term care. If the growth in assisted living were based on the increase in the 75 and older population alone, ignoring all other factors, the number of assisted living beds would nearly double over the next 25 years, from 987,000 in 2000 to 1,900,000 in 2030. AARP Public Policy Institute at 21.

A 2002 report delivered to Congress by the Commission on Affordable Housing and Health Facility Needs for Seniors in the 21st Century foresaw a crisis arriving in the coming decades. **In 2002, 12.4% of Americans were 65 years old or older; by 2020, this figure will approach 20%, and 44% of those seniors will be aged 75 or older.** Commission on Affordable Housing and Health Facility Needs for Seniors in the 21st Century, *A Quiet Crisis is Looming for America's Seniors*, *Executive Summary* 1 & 3 (June 2002) [hereinafter Commission on Affordable Housing]. About 16% of people over age 65 currently require assistance with an activity of daily living such as bathing, dressing, or feeding oneself or an instrumental activity of daily living such as a household chore, handling money, or shopping. Batavia at 17. **As the numbers of elderly and working-age people who need long-term care grows, the demand for services is expanding rapidly.** Batavia at 18.

All seniors in America, "whether rich, poor, or somewhere in the middle, face many barriers to an old age in which very basic human desires for physical safety, appropriate health care, and maximal independence are met." Commission on Affordable Housing, *Executive Summary* at 1. **In view of the unprecedented growth in the proportion of the population who are seniors, the United States "has both a moral obligation and a financial imperative to establish a more rational long-term care system."** Commission on Affordable Housing, *Executive Summary* at 2. In short, the report stated, "[t]he simple fact is that this country lacks a national policy that addresses humanely and cost-effectively the needs and preferences of seniors who have diminished abilities to care for themselves." Commission on Affordable Housing, *Executive Summary* at 2. The most striking problem the Commission uncovered was the disconnection between senior housing and health care, noting that most seniors get their housing from one source and their health care from another. Commission on Affordable Housing, *Executive Summary* at 5.

The Commission found that currently 20% of seniors have significant long-term care needs and that elders across the income spectrum are at risk of institutionalization due to declining health and the absence or loss of support and timely interventions. Commission on Affordable Housing, *Executive Summary* at 3. **The Commission concluded that current elder care programs were "an accumulation of unrelated decisions and unintended consequences."** Commission on Affordable Housing, *Executive Summary* at 3. Particularly with regard to government funding, the Commission concluded that Medicaid funding was an imperfect system for reimbursement of nursing homes and merely a skeleton of payment for home and community-based care. Commission on Affordable Housing, *Executive Summary* at 3. It is projected that inflation-adjusted expenditures for long-term care will double from 1993 to 2018. Batavia at 17.

A. The Fundamental Disconnect Between Elder Housing and Services

Considering this fundamental disconnect, the Commission discovered that government regulation not only prohibited the integration and coordination of senior housing and medical care, but also led to premature institutionalization as a more costly but practical option. Commission on Affordable Housing, *Executive Summary* at 5 & 10. Ironically, committed investment in affordable senior housing has declined over the past three decades. Commission on Affordable Housing, *Executive Summary* at 10. Yet the resolution of this disconnect, which will require considerable time, effort, and commitment, must be achieved before Baby Boomers reach retirement age. Commission on Affordable Housing, *Part II* at 2.

The Commission emphasized that a key message conveyed by elders they surveyed was that "the importance of their homes to seniors' dignity and well being cannot be overstated. A senior cannot be healthy or maintain quality of life without a decent home." Commission on Affordable Housing, *Recommendations* at 2. The Commission noted its belief that "seniors should have opportunities to choose the services they use, where and how they receive services, and where they live." Commission on Affordable Housing, *Recommendations* at 3.[4]

The Commission stressed the "alarming" rate of loss of affordable senior housing and foretold of a "housing crisis" on the horizon. Commission on Affordable Housing, *Recommendations* at 4 & 11. The Commission exhorted that an immediate and substantial effort at increasing the public and private production of senior housing was essential to meeting the needs of America's increasing numbers of seniors. Commission on Affordable Housing, *Recommendations* at 11. In particular, the Commission recommended an increase in the annual production of all types of assisted living facilities. Commission on Affordable Housing, *Recommendations* at 12. Despite the growing need for elder housing, the national growth rate in licensed residential care facilities was basically flat between 2002 and 2004, and the number of beds rose by only 3%. Mollica & Johnson-Lamarche at 1-2.

B. The Need for Person-Based Services

The Commission also reported that the resources devoted to home and community-based services pale in comparison to those devoted to facilities-based care. Commission on Affordable Housing, *Executive Summary* at 10. Further, the Commission emphasized the need for an increase in appropriate home and community-based services in rural areas and urged Congress to adopt a flexible rural waiver demonstration program that would authorize targeted funds to states and their rural communities. Commission on Affordable Housing, *Recommendations* at 18. With particular regard to long-term care, the

[4] After speaking to seniors across the country, the Commission determined five principles to guide senior care in the coming decades. The first was to preserve the existing housing stock, units of which were being lost faster than they were being gained. Commission on Affordable Housing, *Executive Summary* at 7. The second was to expand successful housing production, rental assistance programs, home and community-based services, and supportive housing models. Commission on Affordable, *Executive Summary* at 7. The third was to link shelter and services to promote and encourage aging in place. Commission on Affordable Housing, *Executive Summary* at 8. Specifically, the Commission urged that "[i]n the area of long-term care services, public programs must move away from institutionally based models of service delivery." Commission on Affordable Housing, *Executive Summary* at 8. The fourth was to reform existing federal financing programs in order to maximize flexibility and increase housing production and health and service coverage. Commission on Affordable Housing, *Executive Summary* at 9. The final guiding principle of the Commission was the need to create and explore new housing and service programs, models, and demonstrations. Commission on Affordable Housing, *Executive Summary* at 9.

Commission noted that "it is critical that public programs look beyond institutionally based models of service delivery" in order to deliver services in the locations seniors prefer, usually private homes, apartments, or assisted living units. Commission on Affordable Housing, *Recommendations* at 19-20. The Commission urged states to expand home-based care under HCBS Medicaid waivers. **The Commission recognized that "[h]ome and community-based services under Medicaid are an empty promise if people who meet the eligibility criteria cannot afford to stay in their own homes."** Commission on Affordable Housing, *Recommendations* at 31.

The Commission also addressed the inequalities of the Medicaid program's payment of room and board costs only for nursing facilities but not for non-institutional settings, noting that many seniors cannot meet room and board costs at an assisted living or other non-institutional setting. Commission on Affordable Housing, *Recommendations* at 32. The Commission felt that Medicaid guidelines should be restructured to level the playing field between nursing facilities and other residential options. Commission on Affordable Housing, *Recommendations* at 32.

As an example, the Commission suggested that payments for services and housing costs could follow a senior regardless of the setting in which he or she chose to receive care. Commission on Affordable Housing, *Recommendations* at 32. Further, including a shelter deduction in determining Medicaid financial eligibility for HCBS waivers would make home-based services more accessible to low-income seniors. Commission on Affordable Housing, *Recommendations* at 32. Such a provision would help homeowners as well as renters preserve their ability to remain at home while getting the services they need to lead healthy, safe lives. Commission on Affordable Housing, *Recommendations* at 32.

In conclusion, the Commission reported its view that the looming crisis is "a community crisis, a State problem, and a national concern – without a simple answer, without a single solution." Commission on Affordable Housing, Conclusion at 2. **The Commission stressed that the country must "embrace consumer choice and tailor programs to fit individual needs. Americans must think residential, not institutional."** Commission on Affordable Housing, Conclusion at 2.

V. The Social v. Medical Model of Long-Term Care

Despite the growing demand for less restrictive care models, the vast majority of funded long-term care services in this country are provided under the "medical model," in which health care workers provide services under the supervision of medical professionals and which favors institutional over residential care. Batavia at 18. Historically, our seniors' health care options consisted of hospitals or family care at home with little in between. The medical model of care, employed in hospitals and nursing homes, segregates patients by how ill they are and how much care they require. The medical model of long-term care is comprised of care ordered by physicians, planned primarily by licensed nurses, and delivered by certified nursing assistants and other professional staff. Sloane & Zimmerman at 4. It is clear that health care providers have a vested interest in ensuring that the medical model continues to predominate long-term care funding. Batavia at 40.

A growing grassroots movement spearheaded by care providers seeks "to develop new, more resident-centered models." Sloane & Zimmerman at 5. These person-based models

envision "small, decentralized facilities; involvement of nursing assistants in all aspects of decision-making and care planning; offering more choices to residents . . . ; and individualized approaches to bathing and other activities of daily living." Sloane & Zimmerman at 6. **Services grounded in the medical model are often perceived as discriminatory because such services are usually provided in institutions.** Batavia at 40. Moreover, a medically modeled system flies in the face of the notion of aging in place since an individual's medical needs may change daily or weekly, and the current system requires them to move in response to each change. Further, the medical model focuses on administrative details rather than adopting a holistic approach to meet seniors' needs.

Advocates for the elderly and disabled, however, often prefer a more independent living model. In contrast to the medical model, the social model of care measures the quality of care by asking residents and families if they are satisfied.[5] It also provides a broader focus on health. Important indicators of successful health care are the number of illnesses and hospitalizations, skin integrity, weight, rashes, appetite, infections, pain level, and general well-being. As some advocates have noted, rules intended to prevent abuse and neglect, while necessary, unintentionally "foster the idea that compliance with those regulations is the equivalent of quality." William H. Thomas, *Evolution of Eden*, *reprinted in* Weiner & Ronch at 151. As a result, "[o]ver time the steady application of such rules erodes internal, unspoken, unwritten, heartfelt ideals. While they are clearly meant as minimum standards, official approval is offered in equal measure to those who merely comply with published standards and those who soar above them." Thomas, *reprinted in* Weiner & Ronch at 151.

The social model eschews labeling seniors with an arbitrary level of care and instead promotes loving kindness, community, caring touch, supervision and some personal care assistance with professional oversight. The social model of care does not categorize needs by a transient level of care but rather focuses on allowing individuals to age in place to the maximum extent possible. It focuses more on the cognitive ability of the person and the level of personal care needs.

The medical model of care sets aside an arbitrary number of Medicaid beds and leaves those not eligible for Medicaid to fend for themselves. Some nursing homes in Maine and elsewhere require residents to pay privately for three years before they will allow them to occupy a bed paid for by Medicaid. Yet those who are able to pay privately for three years are certainly not those most in need of a Medicaid bed, and many elderly couldn't afford to pay for even one month of nursing home care privately. A social model of care would utilize other resources like housing assistance, Social Security, and rent subsidies to support the cost of housing.

The medical model continues to support the construction of large facilities even though elderly people resoundingly report a desire to live in smaller homes with more community-like settings. A social model, on the other hand, responds to the desires of elders and recognizes that elderly individuals, especially those with dementia, function better in small settings. *See, e.g.,* Elizabeth Oliner, *Finding the Right Care for Aging*

[5] Maine's Commission to Study Assisted Living considered whether a medical or social model of long-term care should prevail but was unable to reach a conclusion, although it acknowledged that consumer perception of the quality and value of an assisted living program and its ability to obtain various funding sources is impacted by the decision whether to employ a social or medical model. Commission to Study Assisted Living, *Executive Summary* at v.

Parents: When Smaller is Better, Washingtonian On-Line (2001). Smaller settings allow those with dementia, for example, to interface with fewer staff members, to acclimate to smaller areas, to navigate smaller distances, to enjoy quieter and more intimate surroundings, and to maintain normal and consistent routines.

The social model of care also provides incentives for family and community members who provide essential care for elderly relatives and neighbors. A social model of care might allow a family member who lives with and cares for an elderly relative for a specified period of time the ability to take ownership of the family homestead without penalizing the elderly relative's eligibility for assistance. Caregivers are also provided support through training and respite.

A social model of care also separates housing needs from medical services. Under Minnesota's innovative housing with services model, a variety of facilities have emerged, from small two-resident homes to large apartment complexes. **The simplicity of Minnesota's system, which requires each facility to register as an assisted living facility and allows for care to be provided by a home health agency, gives consumers real choice and opportunity.**

VI. A Housing with Services Model for Maine

For 19 years, seniors living in mid-coast Maine have benefited from a living option that met their needs and desires while being grounded in a social model of care. Created by Joanne Miller, a social worker and care manager who has spent decades caring for the elderly, the Homesteads allow elders to create a "home" while sharing the costs of home health care. Homestead residents live in one of two small community houses, maintaining their own private bedroom and bathroom while sharing eating and living areas. Residents contract with a home health agency, usually ASK…For Home Care, which allows them to share the costs of health care.

The Homesteads are committed to enhancing the lives of senior citizens while ensuring that they achieve their maximum level of independence and self-actualization in as home-like a setting as possible. The Homesteads thrive because staff believe that elders have as much to offer them as they as providers have to offer elders.

The Homesteads employ the social model to provide client-focused care. Staff are highly trained and validated in settings that allow their work to be an expression of who they are. They are well paid with good benefits; they are supported and encouraged to be dedicated to their work as well as their family and community. Residents, in turn, thrive under the care of staff who genuinely enjoy their work. The household becomes a community, caring for each other and meeting each other's social and emotional needs. Many of the problems associated with dementia and disability are mitigated by maximizing each resident's potential with healthy diets, exercise, meaningful activity and community involvement, further reducing the costs of care. Families and volunteers are actively engaged, another cost-saving benefit. **In fact, the Homestead model embodies the mandates of the ADA and Olmstead as well as the recommendations of the New Freedom Initiative and the Work Group for Community-Based Living: it allows elders to live in the least restrictive setting possible while providing them the services they need where they live.**

There are rarely vacancies at the Homesteads and residents report high levels of satisfaction with their community-based living arrangements. Congregate meals are shared and holidays and birthdays are celebrated by residents living as family. Remarkably, the Homesteads have been financially successful despite receiving no governmental subsidies. Although the Homesteads previously accepted Medicaid patients, they no longer do so due to the state's refusal to allow residents to share the cost of having around the clock care available.

The setting of the Homesteads is very different from a nursing home. As one home health aide employed at the Homesteads attested of the residents: "This is their home. It's a special place, different than a nursing home. We take them at all levels, and they can die right here. They may come when fully independent, then later be completely bed-ridden. They don't even have to move to another room." Sheila Greenlaw, *A High Calling*, Home Health Aid Digest 1 (Sept.-Oct. 2003). This home health aide had worked for several years in a nursing home in Maine's mid-coast, and she finds the contrast between the settings to be great. At the Homesteads, "we can take time to reminisce, to do an activity, even to lotion the client. We have the time to do all that." Greenlaw at 1.

At the Homesteads, the staff collects a "life story" for each resident by spending a great deal of time asking questions, learning as much as possible about the client and gleaning facts that reveal the client's emotions and needs. Greenlaw at 1. That life story is a major factor in devising and customizing a care plan for the client. Greenlaw at 1.

The unique quality of care, provided in the setting that its residents desire, is most clearly evident in the voices of those most intimately affected by it:

- From the family of a resident: "We want to extend a sincere thank you to all who had a hand in the care of Joyce during her three year stay at your facility. We feel that she received excellent care and know that she was not always an easy person to care for."

- From the family member of a resident to the nurse: "I am very grateful to you for the time you spent with me explaining Ellen's condition. We were all most impressed by the care and love that you give to your guests!"

- From the daughter of a resident: "We couldn't have done it without you and your truly fine staff. When we called you in August it had been clear for a while that we needed significant, qualified, trustworthy, reliable help for Mom. As she was coming out of rehab in August on mid-coast Maine we found that few local services could provide the 24/7 help we needed. You and ASK, however, were prepared to do whatever it took to get this care truly cared for: 24/7, reliably, responsibly, and with sensitivity. Not only were you sensitive to the needs of a frail and very independent lady, but also to her family. Your staff was well trained, hard working, respectful and fun. [The nurses] were helpful checking in every couple of weeks and handling prescription filling and setting up Mom's medications in predispensed amounts so they were easy for either of us or the ASK staff to give her. And you stayed in touch with both Mom and me, with an openness and willingness to suggestion options and alternatives for us to consider and a real understanding of what the elderly go through and experience – an eye opener and a comfort for those

of us (young and elderly) who haven't previously experienced this phase of life first hand. . . . P.S. This is our ASK performance evaluation: A+!"

- From the family of a couple who spent their final years at the Homestead: "Thank you so much for helping us provide Harold and Rena a warm and caring 'home away from home' during the last few years. They never wanted to go to a nursing home, and we promised to do everything we could to see that they didn't. You and the 'Homesteads' helped us to keep that promise, and for that we will always be grateful!"

- From the family of a resident: "Thank you for providing expert and personal care to our mother during her stay at The Homestead. She had been in three nursing homes prior to coming to your establishment. The Homestead stands head and shoulders above those facilities. Mom thought a great deal of the caregivers and cooks, always commenting on the wonderful care and the delicious meals she received. While she was not with you long she had come to call the Homestead home. . . . The Homestead should be very proud of the service it provides to the community and should be extremely proud of its employees. We would recommend your services to anyone who wants the best of care for aging relatives and friends."

- From the daughter of a resident: "Most of all thank you for the wonderful care my mother got during her years at The Homestead! It was not just like a real home – it was home, one full of sunshine, laughter and above all, kind, caring and expert staff. They made her last years a joy and her last days comfortable and dignified."

- From the family member of a resident: "It was a great comfort to know that Dad's last year was spent in a loving family environment. He was always talking about how he was 'fussed over.'"

- From a family member of a resident: "Your concept of HomeShare and carrying it through very successfully is truly an asset to the surrounding communities."

- From the daughter of a resident: "I feel so thankful to live here in this area and have such wonderful care for our elderly. They have been the pillars of our communities, churches and organizations helping us to grow. Now in their elderly years they should be treated very special. Thank you again for having such lovely accommodations for our older folks and giving them such tender, loving care!"

Despite the ability of the Homesteads to meet their residents varying and changing needs with quality and expert care, within a housing model that allows residents to feel "at home," the State of Maine has consistently sought to alter their system of care. The Homesteads have withstood a variety of unsuccessful enforcement actions by the State as well as illogical rule changes while continuing to provide excellent care to its residents. Although the Homesteads have succeeded in spite of the State's enforcement actions, it has resulted in the loss of thousands of dollars in legal fees and distraction from the Homesteads' main business of providing a home for elders. Other providers have faced the same obstacles.

For example, State administrators have reduced the ability of seniors in southern Maine to obtain personal care in their homes through its actions against In Home Senior Services, one of the oldest providers of personal care services for elders, by discontinuing their State contracts due to an oversight. When a regulation was passed requiring such agencies to verify that all new employees did not have an annotation in the State C.N.A. registry, regardless of whether they were C.N.A.s or not, In Home Senior Services readily complied. The regulation did not state, and In Home Senior Services did not contemplate, that agencies were expected to retroactively review the C.N.A. register for annotations related to all employees hired prior to the law's passage. When a routine audit in 2004 revealed that an employee hired prior to the regulation's passage had an annotation on the C.N.A. directory, In Home Senior Services immediately let the employee go. Despite the fact that there had been no complaints against the employee and the agency's successful implementation of its contract for 9 years, the State terminated its contract with In Home Senior Services and forced the agency to repay funds already remitted under the contract for work already performed. Prior to the State's illogical action against In Home Senior Services, it had 55 employees. It now has 15.

Further, MaineCare residents in southern Maine are now often without personal care services since most providers in the area will not accept the one or two hour shifts that In Home Senior Services did. As a result of the State's actions, it is even more unlikely that seniors previously served by In Home Senior Services will continue to be able to receive services at home despite Olmstead's mandate that states further rather than thwart efforts of seniors to forgo institutionalization.

Moreover, in the recent case of Goudreau v. Maine Department of Health and Human Services, DHS ordered a provider of housing with services to displace all of his residents and fined him $18,500 for failing to obtain a license to provide assisted living services. The Maine Superior Court found that the Department of Health and Human Services had violated the rights of a service provider by imposing sanctions pursuant to a statute that did not set a maximum possible penalty. Goudreau v. Maine Department of Health and Human Services, Maine Superior Court, Docket No. CV-04-226 (April 20, 2005). Despite DHHS's arguments to the contrary, such a maximum was required in order to assure that DHHS did not arbitrarily assert its power to impose a penalty on unlicensed long-term care facilities. In the case of the Homesteads, in the State's most recent action against them, the penalty the State assessed was over $70,000 when the State finally dismissed its claims.

As epitomized by the sagas of these providers, State policymakers must work aggressively to bring Maine's regulatory system into alignment with the growing needs, changing desires, and legal rights of Maine's seniors.

VII. Statutory Changes Needed in Maine

In response to Olmstead, Maine policymakers streamlined the licensing categories for housing but did little to facilitate a broader range of living options. Maine law currently licenses congregate elder housing providers in three categories: assisted living programs (individuals living in private apartments but obtaining services), residential care facilities (individuals living in private or semi-private bedrooms with a common living and dining area), and private non-medical institutions (a type of residential care facilities that receives

MaineCare funds). 22 M.R.S.A. § 7851 & 10-149 Department of Health and Human Services regulations § 113. Each category of housing is divided into levels of licensing based on the number of residents. Among the problems with this model are its continued unnecessary institutionalization of disabled seniors, its failure to provide a meaningful range of choices, and its disallowance of self-determination and consumer-directed care for seniors.

A more promising, and successful, approach to regulation is that taken by the state of Minnesota, which has been a leader in this arena. Following Olmstead, Minnesota began to revise its policies regarding elder care and assisted living. When it found that it was developing a set of regulations that essentially placed nursing home restrictions on senior housing with services settings, it scrapped the entire set of draft regulations and instead developed the Housing-with-Services Contract Act. Making a "conscious decision to avoid a detailed, prescriptive approach," drafters acknowledged that housing with services settings were proliferating "precisely because of consumers' strong preference for home-like environments over highly regulated, institutional nursing homes." Minnesota Health and Housing Alliance, *Assisted Living* 12 & 14 (2005), *available at* www.mhha.com. Thus, "[i]nstead of institutional standards, a more flexible and consumer-driven approach toward quality assurance was needed in these settings." Minnesota Health and Housing Alliance at 14.

In Minnesota, drafters decided that a contract approach would work best because it would be flexible enough to meet the needs of very different types of communities and consumers and it would allow providers to be innovative and creative in meeting those needs; it would build on existing laws and requirements and avoid the creation of new and unnecessary regulatory systems since providers already operate in a highly regulatory environment; it would build on existing contract law as well as other State regulatory requirements without creating a new licensing system; and it would be consumer-driven as well as consumer-friendly. Minnesota Health and Housing Alliance at 14. The Minnesota experience, discussed below, highlights the problem of placing nursing home regulations on assisted living facilities: they result in assisted living facilities that look just like nursing homes. The result is an autonomous model of elder care, based on the outdated medical model that is not reflective of elders' desires.

The guiding principle for the drafters of Minnesota's Act was the fact that consumers and providers both identified choice as a value that should be given dominance. Choice had the multiple dimensions of:

- Recognizing that people have a right to make choices for themselves.
- Assuming that people are competent to make their own choices and those who may not be competent should receive assistance.
- Recognizing the rights of consumers to be educated and informed, including clear information on the provider's policies and procedures and the services they are purchasing.
- Consciously accepting that choices entail risks and that consumers will sometimes make decisions that others perceive as "bad choices."

Minnesota Health and Housing Alliance at 14-15.

The end result was a State law that licenses only two categories of elder housing, housing with services and Medicaid waiver homes. Minnesota's law emphasizes elders' desire for independence, autonomy, flexibility, and individualized services. The law presumes that elders are competent unless shown otherwise; in contrast is traditional nursing home regulation that presumes that elders are incompetent. This revolutionary approach has met with great success and has been heralded by seniors and their advocates as providing protection for them while acknowledging their strong desire to remain as independent as possible. Importantly, it also reflects a respect for the Supreme Court's mandate that states provide the least restrictive setting for seniors to age in place.

VII. Conclusion: Maine Must Act.

Maine's response to elders' growing need for housing and care must be community-based with family members playing a major role. With the current generation of Baby Boomers reaching their 50's, the need for elder housing, health care, and personal care is expanding exponentially and will overwhelm our aging nursing home residences unless a paradigm shift is achieved in how we think about and structure elder housing and care. We must respond to the desires of seniors while forging a financially sound system. **Instead of allowing for flexibility and options for seniors, the Maine licensing system establishes a standardized approach that is unworkable as well as illegal, given the mandate of Olmstead.** Maine lawmakers should build on the learning of Minnesota in responding to aging Mainers' desire for a more consumer-driven model of elder care that provides meaningful choices. Choices for seniors should be expanded to allow for more community-based options, including facilitating alternatives for elderly Mainers to stay at home with the help of a home health care agency, family member, or neighbor.

A simplified system that allows a variety of choices for seniors by any providers who are registered with the State and who provide services based on a contract with their elder customers would be optimal. Toward that end, a pilot project should be considered in the counties of mid-coast Maine to explore alternative housing and services configurations. In particular, attention should be paid to the ability of programs in the pilot project to provide housing and care at a significantly lower cost than the current models of care required by the State in residential care facilities and nursing homes.

On a practical level, cost considerations and the legal mandate of Olmstead require a rethinking of our elder care systems. By failing to fully implement Olmstead, the State risks loss of federal Medicaid dollars and exposes itself to lawsuits for its systemic violation of the ADA.

A moral imperative also requires a reconsideration of the current system, which stymies choices for seniors and does not respect and care for elders the way they deserve. The way in which we as a society treat our elders today is the way in which we can expect to be treated when we are elders. In short, "[c]ulture change will occur only if there is a strong and coherent agreement among the principal stakeholders that frail people and those who care for them should be treated with respect." Fahey, *reprinted in* Weiner & Ronch at 50.

EXECUTIVE SUMMARY

As the landscape for long-term care in our nation has shifted dramatically in the past decade due to changes in elders' desires and new Supreme Court precedent on the Americans with Disabilities Act ("ADA"), Maine's regulatory system for elder services and housing has not kept pace. Maine seniors continue to face a dearth of options when seeking services and housing as they age. This policy brief serves to explain the coalescence of circumstances that requires Maine to forge substantial changes in our elder care policies. Some key points are highlighted in this executive summary.

National research reveals a problem of epidemic proportions:

- In 2002, 12.4% of Americans were 65 years old or older; by 2020, this figure will approach 20%, and 44% of those seniors will be aged 75 or older. As the numbers of elderly who need long-term care grows, the demand for services is expanding rapidly.
- Amazingly, more than 90% of disabled elders living in the community get their everyday care from unpaid family caregivers. Over 27 million individuals provided uncompensated care in 1997, for a value of $196 billion in services.
- Despite the vast amount of unpaid care our elders receive, the unnecessary and illegal institutionalization of seniors remains a serious and pervasive problem.
- Assisted living homes, which provide a level of care between independence and nursing homes, have grown increasingly popular. They are not accessible to the vast majority of elders, however, due to cost.

Medicaid policies perpetuate the unnecessary and illegal institutionalization of our nation's elders:

- Ironically, although Medicaid is the single largest payer of long-term care in the nation, financing 40% of all long-term care spending of $150 billion in 1998, it remains heavily tilted toward the most expensive forms of institutionalized care.
- Medicaid continues the illogical policy of covering the costs of room and board in a nursing home but in no other setting.
- About 1 million (77%) nursing home residents received Medicaid funding assistance in 1999. Thus, institutions that are often financially feasible only if Medicaid funding is limited to 50% of residents face enormous financial pressures on the institutions as well as Medicaid budgets.
- For the cost of 2 beds a day in a nursing facility, 5 elders would be fully supported in their communities. "People would rather be No. 30,000 on a list for community care than go into a nursing home." Barbara Basler, *Suing the World to Get Out*, AARP Bulletin 3 (June 2004).
- Although Medicaid-funded home and community-based services are available in some states, the national Commission on Affordable Housing recognized that "[h]ome and community-based services under Medicaid are an empty promise if people who meet the eligibility criteria cannot afford to stay in their own homes." Commission on Affordable Housing and Health Facility Needs for Seniors in the 21st Century, *A Quiet Crisis in America*, *Recommendations* 40 (2002).

Other government policies also thwart efforts to enforce seniors' legal rights:

- In 1999, the United States Supreme Court issued the landmark decision of Olmstead v. L.C., 527 U.S. 581 (1999), which held that the institutionalization of disabled individuals who could receive care in a community setting was a violation of the ADA. Implementation of Olmstead continues to be sluggish and haphazard.

- Despite the effort that has been put into evaluating the needs and desires of aging seniors, government policy continues to stagnate and thwart seniors from realizing the outcomes they seek.
- The national Commission on Affordable Housing concluded that current elder care programs are "an accumulation of unrelated decisions and unintended consequences."
- Noting the fundamental disconnect between elder services and housing, the Commission on Affordable Housing discovered that government regulation not only prohibited the integration and coordination of senior housing and medical care, but also led to premature institutionalization.
- In response to Supreme Court mandates that states may not compile waiting lists for services, some states have simply eliminated waiting lists for elders in need of community-based services in order to remove the pressure from government officials to ask for additional funding to expedite services. Other states illegally impose limits on the number of clients eligible for Medicaid.

Our philosophy of elder care must be altered:

- In view of the unprecedented growth in the proportion of the population who are seniors, the United States "has both a moral obligation and a financial imperative to establish a more rational long-term care system." Commission on Affordable Housing.
- The United States must "embrace consumer choice and tailor programs to fit individual needs. Americans must think residential, not institutional." Commission on Affordable Housing.
- The looming crisis is "a community crisis, a State problem, and a national concern – without a simple answer, without a single solution." Commission on Affordable Housing.
- A social model of care, which provides more independence and individualization of care, should be employed to expand choices and opportunities for seniors.
- Minnesota, leading the way on this issue, has created a sensible and simplified system of regulation of elder care that should serve as a model for other states.

In Maine, change is desperately needed:

- The Work Group for Community-Based Living concluded that Maine's laws and rules regarding assisted living were confusing and cumbersome.
- Maine focus group participants who lived in residential care facilities reported isolation, helplessness, and displacement.
- Although Governor Baldacci's policies are consistent with an improved model of elder care, his goals are not reflected in Maine's policies.
- Maine seniors lack options when faced with the need for housing and services and this problem will continue to grow exponentially.

Cost considerations, legal requirements, and a moral imperative to respect our aging seniors require national and state policymakers to rethink our systems of elder housing and services.