

2013

UNDER THE RADAR: AN EXAMINATION OF THE UNMET NEEDS OF MAINE'S AGING POPULATION.

A primer for Maine policymakers..



Volume 1

**Food Insecurity
Family Caregivers
Housing
Elder Abuse
Developmental Disabilities & Dementia**

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Introduction

The Maine Gerontological Society (MGS) is a Maine nonprofit association committed to helping develop the field of gerontology to ensure that Maine people are able to age well and have access to the aging network services and supports in their community of choice. The MGS is comprised of organizations and individual members who are educators, healthcare professionals, students of all ages, and older adults who are dedicated to being a constructive voice of aging in Maine. As part of the mission of the organization, we are offering the document, *Under the Radar: An Examination of the Unmet Needs of Maine's Aging Population*, as a way to share the organization's policy positions in order to start a conversation about the needs of Maine's aging population. The MGS prides itself on being a collaborative organization that is willing to help provide support and expert information about issues of aging in Maine. As we all work together to meet the needs of all people in Maine, MGS is available to help provide innovative ideas to help our state move forward in keeping Mainers in our state across the lifespan.

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Executive Summary

As many Maine policy makers, healthcare providers, and Maine residents are acutely aware, we are in difficult economic times. Leveraging available resources at the local, state, and federal levels is essential as we develop comprehensive policies related to aging in Maine. These policies ensure that our state is able to serve all of Maine's citizens. In summary, the primer highlights five areas of concern at this moment in time in Maine as follows:

1) Food Insecurity-

Maine has one of the highest rates of older adult percentages in the country related to food insecurity in the country. Some of the key reasons include:

- The federal Supplemental Nutrition Assistance Program (SNAP) program is extremely underutilized by older adults who may need support. In part due to the perceived stigma associated with the former "Food stamp" program, the use of an electronic benefits card, and perceived financial barriers to access.
- There are innovative programs in Maine being developed such as the Friends of Aroostook County which showcase the collaborative benefit of matching farmers, volunteers, and the aging network in meeting the needs of older adults nutritionally. These innovative endeavors in reducing food insecurity will require strong leadership as well as a collaboration between public-private organizations within Maine.

2) Support for Family Caregivers-

The most recent 2012 Maine Statewide Assessment on Aging identified key issues related to Maine caregivers of older adults. Of special note, is that 63% of family caregivers identified that caregiving interfered with their job, 55% stated that they had less energy for work. As we move forward, the Maine workforce will need to address these demands to support those who are caring for older adults. Identified areas in which caregivers are seeking support include:

- Housekeeping, and home maintenance
- Financial management and support in multigenerational homes
- Respite care to ensure that social networks and work relationships can be maintained.

This primer continues to highlight the special challenges presented to Maine families who care for frail older adults specifically those with dementia. Additional innovative ideas to help support Maine families are included further in the document.

3) Senior Housing-

Affordable and safe housing is central to the lives of older adults in Maine. Creative housing solutions including affordable independent housing, assisted living, longer term housing, and housing with access to community services is essential to the success of aging in Maine. Public-private partnerships with Maine developers and housing authorities can help create an environment that enhances healthy aging including use of universal design, and development of housing sites that are open to all income levels.

4) Early onset dementia and developmental disabilities-

As our population in Maine ages, additional challenges in providing care and research emerge including the areas of cognitive and developmental disabilities. Earlier onset dementia and Alzheimer's disease can impact a Maine family over a much longer period of time. In addition, the needs of people with developmental disabilities can change to require more specialized care from healthcare providers. Through:

- Research,
- Collaboration and coordination within the service network,
- Education of the healthcare workforce,

a community based lifestyle could occur for Maine people in a cost effective manner.

5) Elder Abuse-

Elder abuse and neglect continues to be a hidden issue throughout the state of Maine. Law Increased education that focuses on law enforcement, non-profit organizations, banks, and healthcare providers in Maine continue to increase their efforts in reducing elder abuse in Maine. The collaborative efforts of local community based TRIAD organizations (law enforcement, community organizations, and older adults) is a key example of how successful efforts can be in moving prevention efforts forward. Policy development to ensure that elder abuse is not tolerated in Maine and that Maine is a safe place to retire and age well is essential into the future.

Food Insecurity

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Alarming Increase in Maine Senior Hunger

Maine has the highest rate of very low food security in New England and the 7th highest rate in the United States. The increase in senior hunger is particularly alarming. Nearly one out of every eight Maine seniors is suffering from hunger or is under threat of hunger; a 38% increase from 2001. Programs designed to assist low-income seniors accessing the food they need are often underutilized or underfunded. As a result, too many low-income seniors suffer from poor nutrition. Studies have shown a direct link between poor nutrition or lack of food and common health issues such as obesity, diabetes, low blood pressure, and heart failure.

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Existing Food Programs Underutilized

The Food Supplement Program (also known as SNAP or food stamps), is severely underutilized by seniors. Only one third of Maine seniors who are eligible for the Food Supplement Program are receiving benefits, the lowest rate among all demographic groups. Seniors are less likely to know that they might qualify, are confused by the application process and hold misconceptions about the benefit, including about how it is used. They are concerned about the stigma and don't know that the benefits are used discretely with a debit card just like any other credit card.

The USDA runs two programs in Maine that help seniors access food. The USDA Senior Food Program gets food packages to low-income seniors once a month. Sadly, this program is underfunded and has a waiting list almost as soon as it is announced. The other program is the FarmShare program which provides low-income seniors with access to \$50 worth of fresh vegetables over the summer months. Obviously, this small amount, while useful, will not serve to address the issue of hunger in any real way.

Maine's Area Agencies on Aging (AAAs) also receive federal funding to provide seniors with access to home-delivered and congregate meals. Severe cuts to funding through Sequestration have resulted in tens of thousands of fewer meals being provided and long wait lists for home-delivered meals. All of the AAAs provide fee-for-service home-delivered meals at very low

A 2012 Brown University Study found that the more states spend on home-delivered meals under the Older Americans Act, the more likely they are to help people who don't need nursing home care to

costs. These programs are not funded by federal dollars. Proceeds from the fee-for-service meals fund additional nutrition and senior services.

Other studies have shown home-delivered meals helps to reduce hospital readmissions. Until recently, SeniorsPlus operated a program in Androscoggin County funded entirely by the United Way. Through this program, seniors who were discharged from the hospital or nursing home received four weeks of Meals on Wheels and they found it did indeed help people from re-entering the hospital. Sadly, the United Way had to cut funding for the program.

Innovative Programs Emerging

Innovative responses to food insecurity, including targeted at seniors, are cropping up around the state and need to be replicated. For instance, Friends of Aroostook County are a dedicated group of volunteers who coordinate with farmers to donate land, use volunteers to grow food and use distribution chains, like Meals on Wheels, throughout the County to get free fresh produce to seniors and others in need. In 2010, they delivered 49,000 pounds of produce to people in need and facilitated the growing of an additional 25,000 pounds of produce by people who could grow their own.

Severe cuts to funding through Sequestration have resulted in tens of thousands of fewer meals being provided and long wait lists for home-delivered meals in Maine.

Another great example is a collaborative effort to address senior hunger was a Senior Food Prescription Program advanced by AARP, Preble Street, the Maine Association of Area Agencies on Aging and many health care associations to get health care providers. The goal was to educate health care providers about senior hunger and to get them to issue “prescriptions” for a call to their local

agency on aging to determine if the patient is eligible for SNAP. Health care practitioners are one of the most trusted sources for seniors. Seniors listen to and follow their advice. Tying the need for better nutrition to health also encourages seniors to act. This effort is on-going.

Recommendations

Recommendations include:

- Primary health care providers in Maine screen older adults for nutrition status to identify the highest risk individuals,
- Area Agencies on Aging and 211 Maine ensure that there is a referral focus on connecting seniors with local food resources,
- Communities provide support in collaboration with the farming communities, food banks, and innovative programs in meeting the needs of hungry older adults throughout Maine.

Conclusion

With no additional funding available at this particular time, and senior food insecurity on the rise, health care providers and aging advocates must continue to partner to ensure seniors are gaining access to and using available food benefits and sources. We also must work to build a collaborative community response to senior hunger.

Supporting Family Caregivers

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"There are four kinds of people in this world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers."

Rosalynn Carter

Family Caregivers are the Foundation of Maine's Long Term Care System.

The largest source of long term care services are not provided by nursing homes but by family caregivers. National statistics indicate that at least 70% of a state's aging population is cared for at home by family members. Thanks to the significant contribution of time, energy and finances of family caregivers seniors are afforded the security and familiarity of remaining in the home environment while at the same time saving the State of Maine millions of dollars each year in long term care costs.

Estimates indicate that there are 154,000 family caregivers in Maine. Maine caregivers of individuals with dementia alone contributed \$951 million dollars of unpaid services.

The enormous contribution made by family caregivers is rarely acknowledged and, one could argue, largely taken for granted by state policy makers. Family caregivers assist their aging family members with a myriad of tasks such as bathing, dressing, feeding, and managing incontinence. Many perform complex medical and nursing tasks such as wound care, ostomy care and medication management including IV's and injections.

For families who are caring for an individual with dementia caregiving becomes a 24/7 commitment as the disease progresses and the person requires constant supervision and total assistance. Maine's rural nature presents a special challenge in terms of direct care worker shortages, few physicians specially trained in geriatrics, and a lower socioeconomic status.

The need for family caregiving will increase significantly in the coming years. Not only is Maine the nation's oldest state by median age its population of the "very old" (over the age of 85) is growing rapidly with a 58% increase between 1990 and 2009. Maine's aging demographic, increased longevity, chronic illness, and an underfunded and overburdened long term care system will combine to create a perfect storm. Absent a comprehensive and targeted policy initiative the caregiving system that saves Maine taxpayers millions of dollars annually could easily collapse. The consequences for care recipients will be increased rates of institutionalization, higher risk of abuse and neglect, and decreased quality of life.

Absent a comprehensive and targeted policy initiative the caregiving system that saves Maine taxpayers millions of dollars annually could easily collapse.

Who Are the Caregivers?

- 35% of caregivers report their health as being only fair to poor.
- Working caregivers report that they suffer from poorer health than their non-caregiving counterparts.
- 40% to 70% of caregivers have clinically significant symptoms of depression.

According to the National Center on Caregiving, caregivers are largely middle-aged women caring for a spouse, parent, step-parent, in-law or grandparent. Thirty percent of caregivers are taking care of more than one person and many are working full or part-time. The average caregiver provides care for a little over 4 years, although dementia caregivers provide one to four years more care on average than caregivers caring for someone with an illness other than dementia.

National research has shown that caregiving can have a significant negative impact on caregiver's health. As many as 35% of caregivers report their health as being only fair to poor. Working caregivers report that they suffer from poorer health than their non-caregiving counterparts. 40% to 70% of caregivers have clinically significant symptoms of depression.

The 2012 Maine Statewide Assessment on Aging reported that more than 2/3rds of those responding to their statewide survey indicated having less time for other family members and having to give up activities like vacations and hobbies. About 60% indicated fewer connections with friends since taking on caregiver responsibilities. Forty-five percent (45%) reported exhaustion. In addition, 63% of working caregivers indicated that their caregiving responsibilities interfere with their work while 55% report they have less energy for work.

In spite of the enormous contribution family caregivers provide to aging family members and the long term care system as a whole they are largely ignored and under supported. Ongoing state budget deficits and other pressing social concerns in recent years have meant that few legislative proposals that would benefit family caregivers have been passed or even offered. To avert a looming caregiver crisis a fundamental shift is needed in how Maine values and recognizes family caregivers.

Current State Policy

The 2012 Maine Statewide Assessment on Aging conducted by the University of New England provides some insight into the unmet needs of caregivers.

- 41% of caregivers responding indicated they had not used any services in the past year.
- Services to help with personal care or nursing were selected by 1/3rd of respondents as the most helpful service.
- Information to help caregivers to connect to services and caregiver support groups were the next most helpful services identified.
- Adult day programs outside the home were cited as the third most helpful service by respondents.

Of importance to Maine policymakers is the finding that
When asked what services they needed but were not receiving:

- 56% indicated needing financial assistance
- 54% needed assistance with housekeeping
- 53% need transportation services
- 49% report needing in-home respite care
- 45% need personal care services
- 41% need assistance with medicines
- 40% need assistance with shopping and meal preparation
- 38% need legal services
- 35% would like assistance with how to get other family members involved
- 34% need financial advice
- 33 % would like adult day care programs, and
- 25% need mental health services.

The Office of Aging and Disability Services within the Maine Department of Health and Human

Services has released their State Plan on Aging for 2012 – 2016 as required by the federal Older Americans Act of 1965. The plan focuses on statewide issues and notes that “...there has never been a more critical time for a coordinated, collaborative and integrated approach to delivering services in Maine.”

86% of respondents receiving services reported that the services they received may have enabled them to provide care for a longer time than they would have been able without the services.

In spite of the acknowledgement that a systematic approach is needed to assure access to services for aging Mainer’s the plan is light on specifics. The plan cites collaboration between the Office of Aging and Disability

Services, Maine’s Area Agencies on Aging, and other service providers and partners in the Aging Network to “...increase efficiencies, reduce duplication of services, and improve strategic planning to increase availability and quality of the services that older adults need most.” While noting the “ever increasing challenge” of caregivers in “trying to balance their own work and health care needs with the needs of those for whom they are caring” there are few specifics as to how OADS will go about expanding supports for caregivers.

Indeed, Goal 2, relating to “...assisting families and aging individuals to make informed decisions about and access existing health and long term care options”, relies primarily on collaboration and increasing outreach and advocacy. Goal 3, which speaks to “...allowing older adults to remain safely in their community through the provision of home and community-based services, including supports for family caregivers,” primarily relies on increasing caregiver awareness off existing services and assisting community organizations to build capacity to meet increasing demands.

While laudable goals, the State Plan on Aging introduces no new initiatives nor does it call for any increased funding to meet the growing population of older Mainers. The state’s ongoing fiscal crisis must be taken into account when considering any new initiatives or expanded services. However, it is incumbent upon the administration and policy makers to recognize that there are costs associated with what essentially amounts to maintaining the status quo.

The development of a comprehensive approach is critical. Absent such a system long term care expenditures will overwhelm state (and federal) budgets. Collaboration and increasing caregiver awareness will not solve the problems facing Maine's family caregivers.

Recommendations

Many states have turned to innovative programs to support family caregivers and reduce the burden on scarce public resources:

- **Tax incentives.** Caregiving imposes considerable direct costs on caregivers and their families, including medical services, medical devices and drugs not covered by the insurance, services and renovations for vehicles and home, supplemental income, food, clothing, and personal items for the elderly. Some states have passed legislation that gives a refundable tax qualified caregivers who provide unpaid care to a spouse, parent, sibling, child, grandparent, or step-relative on a daily basis. Some states have gone so far as to require that family caregivers who receive the credit must attend a specified number of hours of caregiver training, education, counseling, or support group sessions.
- **New sources of revenue.** Impose a new 1% tax on the annual premiums on certain individual and group Medicare and long-term care insurance contracts. The revenues from this tax would go to fund senior services.
- **Expanded workplace accommodation and family leave policies.** More than three in four employees need, but don't take, family and medical leave because they can't afford to miss a paycheck. While there has been some activity at the state level to improve workplace policies for working caregivers, more needs to be done. The culture of the workplace needs to catch up to Maine's changing demographics, and as it does, both employees and employers will benefit. When employees can take family and medical leave they need, employers get a workforce that is more focused at work, more stable and most importantly, more productive. Flexible work schedules, "cafeteria style" benefits, in-house support groups, and education, information, and referrals provided through employee assistance programs are but a few of the steps that businesses could be encouraged to take to support their caregiving employees.
- **Caregiver "coaching."** The Westchester, NY County Department of Senior Programs and Services developed a program called Livable Communities Caregiver Coaching Program (L3C) to develop a corps of volunteers with caregiver coaching skills to be a key part of the Department of Senior Programs and Services overall Livable Communities initiative. The initiative aims to make Westchester communities as senior-friendly as possible so older adults can remain in their homes as they age with dignity, independence and civic involvement.
- **Respite and home support.** Created in 1986, *Time Out* is a model intergenerational respite and home support program in which college students provide quality, low cost services to families caring for the frail elderly. College students provide caring companionship and supervision while creating a safe and stimulating environment for frail elderly. Students may assist with meal preparation, laundry, light grocery shopping, and assistance into the bathroom, as well as serve as medical escorts. Results were impressive:
 - Caregivers' stress scores decreased after being in the program;

- Caregivers reported that the program has enabled them to keep their family member at home longer.
- Care receivers are substantially less isolated.
- **Loan forgiveness programs to increase the supply of geriatricians.** "Geriatrics" is medical practice that addresses the complex needs of older patients and emphasizes maintaining functional independence even in the presence of chronic disease. Just as a pediatrician tends to the needs of a child, a geriatrician cares for the special needs of changing seniors.

Treating geriatric patients is very complex. More than 20% of older adults have at least five chronic conditions, such as heart disease, diabetes, arthritis, osteoporosis, and dementia. Common medical errors include causing unintentional problems by over medicating or by prescribing normal adult doses to elderly patient's thereby increasing disability and costs to the health care system as a whole.

Given the demographics of Maine's aging population it is estimated that 90 geriatric physicians are needed to address the complex needs of our seniors. In 2012 there were only 48 geriatric physicians practicing in Maine according to the American Geriatrics Association.

In 2005, South Carolina passed legislation creating an innovative and successful loan forgiveness program designed to attract more doctors with specialized training in geriatric medicine. This program forgives \$35,000 of student loan debt incurred during medical school for each year of specialized fellowship training in geriatrics. Applicants must agree to practice in the state for at least five years. California and Oklahoma are weighing similar legislation.

Finally, to successfully rein in the ever increasing cost of supporting an aging population **Maine must also adequately fund its state-funded home-based care programs.** Long waiting lists have become the norm. Policymakers must recognize that the need not only does not go away when it cuts home-based care budgets but, in fact, it increases exponentially as caregivers struggle alone under their heavy physical, financial, and emotional burdens. The net result is an increase in institutionalization as caregivers' burn out and makes the difficult decision to seek facility placement for a loved one. Under funding the very programs that support caregivers to continue in their role is poor public policy and poor fiscal policy.

Conclusion

Maine is facing an unprecedented increase in the number of older adults in Maine. The "silver tsunami" is upon us and threatens to overwhelm not only caregivers but scarce state resources. Supporting family caregivers is one of the most cost-effective long-term care investments we can make. As long as caregivers are able to provide care, they are often able to delay costly nursing home placements and reduce reliance on programs like Medicaid. Adequate funding of home and community-based supportive services is good public policy and good fiscal policy.

Resources

UCLA Vital Signs: Family Caregivers Need Support with Dementia.

<http://www.uclahealth.org/body.cfm?id=502&action=detail&ref=26&issueref=7>

Alzheimer's Disease Facts and Figures 2013.

www.alz.org/alzheimers_disease_facts_and_figures.asp

State Plan for Alzheimer's Disease in Maine.

http://act.alz.org/site/DocServer/ALZStatePlanwithAppendix_1_.pdf?docID=13641

The MetLife Study of Alzheimer's Disease: The Caregiving Experience

<https://www.metlife.com/assets/cao/mmi/publications/studies/mmi-alzheimers-disease-caregiving-experience-study.pdf>

Do Medicaid home and community based service waivers save money?

Home Health Care Services Quarterly. 2011 Oct; 30(4):198-213.

<http://www.ncbi.nlm.nih.gov/pubmed/22106902>

Cost savings from home and community-based services: Arizona's capitated Medicaid long-term care program.

Journal of Health Politics, Policy and Law. 1997 Dec; 22(6):1329-57.

<http://www.ncbi.nlm.nih.gov/pubmed/9459131>

Senior Housing

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Introduction

Our nation has an aging population, we know that, and we know that Maine is in the top 5 oldest states in the country. We know these statistics but do we know what this means for local housing markets and the impact it will have on our communities. The US Census projects that over the next 40 years the population of the 65+ group will increase by 48 million individuals at a rate of 120%. This far outpaces any other age group and will have a profound impact on the housing needs of these individuals in Maine.

Top States Where Older Adults Live

States with largest % of 65+ Residents:

Florida 17.4

West Virginia 15.7

Pennsylvania 15.3

Maine 15.1

Iowa 14.8

Hawaii 14.8

Source: US Census Bureau, 2009

As people age their needs change and more things become important – increased accessibility, lower housing expenses, lower maintenance and proximity to services becomes vital. The story is similar for many of our parents and grandparents. They worked hard, built a house together and raised a family. In many cases, people are still living in the same homes they built years ago and relying on that nest egg for the future.

Many individuals in this generation have options and we see it all the time. Some people leave Maine all together, some trade the cold winters for a warmer environment, but some don't have options. There are many residents living on fixed incomes that continue to stay at home as options for affordable housing are

limited, have long waiting lists and may force them to move outside of their community away from family and friends. Assisting living options are available but at a cost ranging from \$160 to \$190/day and require a specific need for assistance with activities of daily living (ADL's).

There are two groups that will need more housing in the immediate future. The first is the group of independent and self-sufficient seniors that are very active and need no assistance with their daily routines. The second is the group that needs help with daily living activities like cooking, administering medications, cleaning, etc. History tells us that the groups of independent seniors will, over time, need more services as years go on. Housing that can be nimble and account for their changing needs over time will be the most efficient use of resources.

New housing strategically located in service centers throughout Maine will be a big part of any solution to address the housing needs of this group. New housing would need to be accessible and allow people to age in place accommodating their needs as they change over time. It will be close to their doctors and other providers they see regularly. It will allow services to come to them in a cost effective way and it will be affordable.

Importance

There is a lack of supply of housing to meet the needs of this population now and certainly in the next several years. The group of stakeholders is large. It includes family members, health care providers, emergency personnel, neighbors and community members. Families are helping their parents more and more each year as they struggle to keep the house in the form of cleaning, yard work or even having their parents move in with them. Health care providers are spending time traveling from rural house to rural house providing in home care which increases their cost and reduces their efficiency. Hospitals are dealing with more acute issues that could have been prevented by proactive in-home care and first responders are making wellness checks and frequent calls to homes to check on frail people.

The solution of increasing the supply of senior housing will not be easy or without huge cost but it's a necessary expense. The model of building market rate assisting living facilities has proven successful and new housing is being built all the time.

Currently, MaineHousing is prohibited from doing any new projects using tax exempt bonds as there has been a freeze at the State level on any new bond issuances.

Developers may also work with the State to provide some MaineCare beds for those with little to no income. This solution works well for those that have financial resources and those with little incomes that were able to sell the house they lived in for so long to use those proceeds to pay for care. As we all know, the past 3 to 5 years has seen the crumble of the housing market. People can no longer rely on their house as a nest egg for retirement as homes aren't selling and prices have dropped. This has severely limited options for retirees looking to make that next step.

The model of building independent housing for seniors hasn't been as prevalent or successful but is out there working. There are some developers that will build independent homes as part of a larger assisting living/retirement community and work with people to transition through the continuum of care. Again, this works well for people with resources. The options for people with lesser incomes aren't as common. Developers have been somewhat successful working with MaineHousing to develop housing that is affordable to seniors but it hasn't been at a rate that can keep up with demand.

Assessment

Most of the independent housing created today is financed by MaineHousing through the use of taxable or tax exempt bonds in conjunction with the Low Income Housing Tax Credit Program (LIHTC). These projects are awarded funding annually through a competitive process. The current scoring criteria didn't work well for developers looking to build new affordable housing

for seniors. This is the one program that provides the best funding for new projects. Any new strategy that works to address the housing needs of seniors in the future will need to include this program.

Recommendations

The wave of seniors is coming as we need to start planning now to be ready. The solution will be a mix of housing that will serve the needs of people, at every income level, and on every spectrum of the continuum of care. It will be located throughout the state, primarily in service center, close to services and designed in a way that changes with their needs.

- **Increase the housing supply.** New housing needs to be created to meet the needs of our aging population;
- **Access to low cost services.** It needs to be built in a way that allows seniors to access low cost in-home services and will change with their changing needs over time;
- **Handicapped accessibility.** It needs to be accessible to services and other amenities;
- **Affordable.** It needs to be affordable to people on the full spectrum of incomes;
- **Incentives.** Developers need to have incentive to build new units;
- **First time homebuyers.** Increasing supply for senior housing will open up affordable single family homes to first time homebuyers.

Next steps

- **Legislative task force.** Create a legislative task force, involving all stakeholders, to make a recommendation to the Governor with a plan to address senior housing issues;
- **Advocacy.** Advocate the need for more affordable housing with Maine Housing as they draft their new scoring criteria for 2013 and beyond.

Resources

“Housing an Aging Populations, Are we Prepared?”, Center for Housing Policy
<http://nlihc.org/article/two-new-reports-effects-aging-baby-boomers-housing-market>

Early Onset Dementia in Individuals with Intellectual & Developmental Disabilities

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Individuals with intellectual and developmental disabilities living longer

People with intellectual and developmental disabilities (I/DD) are living longer, largely due to better access to medical care, rehabilitation services, and improved living conditions. Individuals with I/DD in most developed countries now can expect to live into old age. This includes adults with Down Syndrome (DS) who once had a considerably shorter lifespan. With this extended life expectancy come new challenges for families, caregivers, government, health care providers, and social service agencies. This issue brief addresses the challenge of early onset dementia in individuals with I/DD and offers recommendations to help Maine prepare to meet the anticipated – and disproportionately high – demand for services that support seniors in this population and their caregivers.

In Maine, an estimated 3,500 people with developmental disabilities live at home with a caregiver who is over age 60.

Early onset dementia a profound challenge for families

In the United States, approximately 75% of older adults with intellectual and developmental disabilities live with family members, often parents. As the life expectancy of the general population continues to increase, more family caregivers find themselves providing custodial care in later life to relatives with I/DD. This poses significant hardship, especially for family caregivers dealing with their own age-related vulnerabilities. The general poor health status of individuals with I/DD is widely known. Early onset dementia substantially complicates care, taking an even greater toll on families.

Intellectual and developmental disabilities and risk of early onset dementia

Adults with DS comprise 10-12% of the adult I/DD population. This group is at significantly greater risk for developing Alzheimer's disease (AD) than the general population, and tends to develop it earlier in life. The average age of onset is 50. Most are diagnosed within three years of onset. The other neuro-developmental condition showing substantially high risk for dementia is brain injury or trauma.

About 25% of people with DS over 40 will develop AD, and 66% over 60 will develop it.

Other intellectual and developmental disabilities are not associated with a higher rate of dementia than that found in the general population, but they are associated with *earlier onset*. With the exception of DS and brain injury, people with I/DD experience the same range of dementias as the general population, but

onset often occurs in the 60's. Like individuals with DS, most individuals in this group are diagnosed within three years of onset.

Prevalence

It is difficult to determine the number of adults with intellectual and developmental disabilities who are experiencing cognitive decline, i.e., dementia or mild cognitive impairment because many of these individuals have been in the lifelong care of family caregivers and are not known to providers. Conservative estimates are that there will be 54,000 individuals with I/DD and cognitive decline living in the United States by 2020, and that about 33,000 adults with developmental disabilities and dementia will be living at home with older family caregivers. Nearly twice as many will be living in out-of-family-home settings. These individuals are highly dependent and their care has a high impact on caregivers. Due to their eligibility for Medicaid, they will also exert a large impact on long-term care resources. Because Maine has the highest rate of disabilities in the northeast, and among the highest rate in the nation, it is crucial that we prepare to serve this group with highly skilled and affordable long-term care. This must involve accurately estimating and tracking the size of this population in our state.

Dementia a worldwide crisis

The World Health Organization (WHO) estimated the number of people with dementia worldwide at 35.6 million in 2010, and that number is expected to almost double every twenty years, reaching 65.7 million in 2020 and 115.4 million in 2050. Right now, over 37,000 Maine people have been diagnosed with some form of dementia, and this number is expected to reach 53,000 by 2020. Approximately 6% of those suffering from AD are between the ages of 65 and 74; 45% are 75 to 84; and 45% are 85 or older.

Our state's mortality rate from AD is substantially higher than the national average. Maine also has a more rapidly aging population than any other state. One out of four Mainers is expected to be over the age of 65 by 2030. The fastest increasing segment of our population is citizens over 85 years old. There are 147,000 dementia caregivers in the state providing the equivalent of 900 million dollars of care. These caregivers experience significant emotional and financial stress as a result of their work. This has a direct impact on their employment and work performance, which in turn affect our economy. In light of these realities, it is reasonable to expect that many older family caregivers of adults with I/DD will themselves be incapacitated by dementia or other illness, whether or not the relatives in their care develop dementia. Consequently, we face a daunting demand for long-term care.

Integrated coordination of aging and disability services an efficient use of resources

Since the 1980's, when it was first recognized the individuals with I/DD were living longer, the systems that were separately serving the aging and developmental disabilities populations have been increasingly integrated. Rapidly rising Medicaid program costs urged states to initiate managed care plans for health care and long-term supports for individuals with developmental disabilities. In 2003, the Administration of Aging and the Centers for Medicare and Medicaid Services jointly sponsored the Aging and Disability Resource Centers (ADRC) initiative. This

streamlined access to long-term services and supports for seniors and younger people with disabilities. In the coming years, ADRC's will play in critical role in connecting eligible individuals to the expanded long-term supports and services provided under the Affordable Care Act.

In keeping with the aging/disabilities service delivery structure, the State of Maine recently merged its separate offices on aging and disability to form the Office of Aging and Disability Services (OADS). In its 2012-2016 State Plan on Aging, the OADS anticipates increased demand for long-term care of adults with I/DD: "Because adults with developmental disabilities in Maine are living longer, families have a longer responsibility of care and as aging caregivers can no longer provide care, increased focus must be given to planning for the long-term care needs of those with developmental disabilities."

National Alzheimer's Project Act becomes law

The National Alzheimer's Project Act (NAPA) became law in 2011 (Public Law 111-375). This law mandates the creation of a national strategic plan to address the escalating Alzheimer's disease crisis in the U.S. and calls for the coordination Alzheimer's disease efforts across the federal government. This law requires that DHHS submit an annual report to Congress between 2012 and 2025. Among other objectives, it calls for enhanced support for caregivers; expanded research; and establishment of *special task groups on I/DD*. At the state level, the Maine Chapter of the Alzheimer's Association recently collaborated with many statewide stakeholders to draft the Maine State Plan on Alzheimer's Disease and Related Dementias that includes as a priority the need to enhance resources for individuals with I/DD and dementia.

National Task Group on Intellectual Disabilities and Dementia Care Practice (NTG)

The National Task Group on Intellectual Disabilities and Dementia Care Practices (NTG) was organized in 2010 to create an action plan for transformative supports and services related to dementia-related impairment among adults with I/DD and to follow the NAPA process. The NTG combined the efforts of the American Academy of Developmental Medicine and Dentistry, the Rehabilitation Research and Training Center on Aging with Developmental Disabilities – Lifespan Health and Function at the University of Illinois at Chicago, and the American Association on Intellectual and Developmental Disabilities.

In 2012, the NTG published 'My Thinker's Not Working' – A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports. The document outlines a wide range of recommendations for meeting the most critical needs of this population and those who care for them. NTG concludes: "Primary care and supports for adults with an intellectual disability affected by dementia can be primarily provided within the community and appropriate services can preclude institutionalization."

Recommendations

The following recommendations are derived largely from work of the NTG, OADS, and the 2013 Maine State Plan for Alzheimer’s Disease and Related Dementias.

- **Research.** Support funding for research on prevalence, population characteristics, and effects of I/DD and early onset dementia on long-term care resources
- **Training.** Increase support for training professional and informal caregivers in the specific skills required to provide quality care to individuals with both I/DD and dementia
- **Skills Curriculum.** Establish/adopt a universal dementia skills curriculum for training families and augmenting training of health professionals and direct care providers working with the I/DD population
- **Grow the workforce.** Increase workforce in the area of geriatric health care and dementia care
- **Screening & Assessment.** Develop/adopt standardized screening and assessment instruments adapted for use with individuals with I/DD
 - **Early Detection.** Implement periodic screening procedures for early detection of dementia in adults with I/DD
 - **Best Practice Guidelines.** Outline/adopt “best practice” guidelines for dementia care for adults with I/DD
 - **In-home Support.** Enhance in-home supports for families that are able to continue providing care at home to promote “aging in place” to the greatest extent possible
 - **Respite Care.** Increase respite options and funding for family caregivers, including adult day service centers (ADSC)
 - **Community-based Housing.** Develop/adopt “best practice” models in community-based housing for those with I/DD and dementia
- **Age in Place.** Increase support for community-based living options that allow individuals with I/DD and dementia to “age in place” in their communities when family living is no longer a viable option, including specialized residential programs
- **Long Term Care.** Increase funding for long-term care supports and services.

“Primary care and supports for adults with an intellectual disability affected by dementia can be primarily provided within the community and appropriate services can preclude institutionalization.”

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Elder Abuse

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Introduction

Elder abuse can take the form of physical, sexual, and emotional or psychological abuse, as well as neglect, self-neglect, abandonment, and financial or material exploitation.ⁱⁱⁱ Elder abuse can take a significant physical, emotional, psychological, and financial toll on our state's older adults and research has shown that the likelihood of dying within the next decade is three times higher for those who are victims of abuse as opposed to those who are not.ⁱⁱⁱ Nationally, financial abuse alone costs older adults more than \$2.6 billion dollars annually.^{iv} In addition to the costs to older adults, elder abuse burdens the health, legal, and social service systems. Although the scope of elder abuse in Maine is still not fully understood, Maine government, nonprofits, and the private sector are increasingly taking steps to combat elder abuse. One simple

It is estimated that around 14,000 older adults in Maine are abused each year.

way that legislators can help support older adults in Maine is through passing low or no-cost legislation which can help facilitate the prosecution of elder abuse cases.

Context and Importance of the Issue

- Abuse of older adults can take various forms from physical, sexual, and emotional or psychological abuse, as well as neglect, self-neglect, abandonment, and financial or material exploitation.^v
- In the state of Maine, it is estimated that approximately 5% of older adults are victims of exploitation, neglect or abuse every year and around 84% of these cases are not reported.^{vi}
- There are significant costs that result from abuse of older adults. Across the nation, it is estimated that financial abuse costs older adults \$2.6 billion dollars every year.^{vii}
- Abuse of older persons can have significant impacts on their health and wellbeing, with research showing that those who have been victims of elder abuse are three times more likely to die in the next decade than those who have not been abused.^{viii}
- Elder abuse not only impacts older adults themselves, but result in significant costs to the investigative and legal system as well as health and social services systems that are estimated to be in the tens of billions of dollars annually in the United States.^{ix}

Assessment

The scope of elder abuse in Maine is still not fully understood, but recent years have seen increasing efforts by government, nonprofits, and the private sector to raise awareness and

educate stakeholders about elder abuse, develop effective interventions, and pass legislation to more effectively prosecute perpetrators of elder abuse and protect victims.

Key legislative actions during the 125th legislative session included the following:

- In 2011, LD 1374, *An Act To Protect Seniors and Incapacitated or Dependent Adults from Abuse* was signed into law. The Bill closed a loop-hole which prevented the seeking of a protection from abuse order against spouses of adult children, grandchildren, and non-cohabitating relatives and caregivers, all of whom can be potential perpetrators of elder abuse.
- On April 15, 2011, LD 401, *An Act to Enhance Penalties to Protect Senior Investors* was signed into law. This Bill created increased penalties for violations of the Maine Uniform Securities Act involving victims 65 and older.
- On June 10, 2011, LD 939, *An Act To Enhance Mandated Reporting and Prosecution of Elder Abuse, Neglect and Exploitation* was signed into law which included provisions to improve elder abuse prosecution, as well as to streamline mandated reporting requirements for elder abuse.
- On June 7, 2011, LD 787, *An Act to Establish an Elder Victims Restitution Fund* was signed into law. This law established a fund for victims of financial abuse who are due restitution from perpetrators but have not received restitution.^x

In addition to legislative action, numerous nonprofit, private sector, and community groups have been engaged in combating elder abuse. The following is not an exhaustive list, but is representative of some of the current efforts to address elder abuse:

- The Maine Association of Area Agencies on Aging (M4A) has been key in supporting the creation of legislation to help facilitate prosecution of elder abuse cases, increase penalties for elder abuse, and secure justice for elder abuse victims.
<http://www.maine4a.org/index.php?id=216>
- Maine Triads are local coalitions consisting of partnerships between law enforcement, older adults, and service providers dedicated to promoting older adult safety. Elder abuse is one of the major issues tackled by these grassroots collaborative efforts and they help to promote awareness of elder abuse through task forces and other means.
- Maine's public and private higher education institutions have also been active in educating health and social service practitioners about elder abuse through activities such as the University of New England's Maine Geriatric Education Center, which partnered with AARP to develop an online course for health professionals to educate them about financial and material exploitation of the elderly:
<http://www.une.edu/mainegec/courses/aarp.cfm>. The UMaine Center on Aging, in partnership with the Maine Health Access Foundation and numerous stakeholders in elder abuse prevention developed online educational courses for recognizing elder abuse, as well as developed elder abuse screening protocols for physicians.

- The Maine Council on Elder Abuse Prevention is a statewide coalition of government, business, nonprofit, and community stakeholder volunteers who meet regularly to share information and help coordinate efforts to address elder abuse in the state of Maine. The recently formed group is in the process of developing a website, planning events for World Elder Abuse Awareness day, mapping assets for the prevention of elder abuse in Maine, and the development of a curriculum for bank employees to assist them in identifying signs of financial abuse and how to report abuse.
- The Elder Abuse Institute of Maine is a statewide organization that provides training and consultation about elder abuse and neglect, provides advocacy and referral for supports for victims of elder abuse, and assists in the development of state and local coalitions working against elder abuse: <http://www.eaime.org/index.php?page=home>
- Martha's Cottage is a transitional home in Maine capable of housing and providing support services to up to 3 older women who are victims of domestic violence: <http://www.eaime.org/resources/martha-s-cottage/>
- Legal Services for the Elderly provides free legal services for economically disadvantaged older adults in Maine through the provision of phone-based civil legal support and in the case of elder abuse and financial exploitation cases, staff attorneys: <http://mainelse.org/>
- Adult Protective Services, part of Maine DHHS Office of Aging and Disability Services, is tasked with the protection of incapacitated and/or dependent adults through the provision or arrangement of services.
- The Long-Term Care Ombudsman Program advocates for long-term care consumers in Maine through investigating and resolving complaints of Mainers in long-term care facilities. Long-Term Care Ombudsmen are key elements in preventing elder abuse in long-term care facilities.

Identify the implications

The effort to help combat elder abuse will be continuing in the 126th Legislature. A Bill titled “An Act to Protect Elders and Vulnerable Adults from Exploitation” was submitted on behalf of the Maine Association of Area Agencies on Aging which will help to overcome one of the main barriers to prosecuting financial exploitation of the elderly, which is the issue of consent. Essentially, the bill would clarify the existing consent statute to state that individuals with cognitive impairments such as dementia cannot provide consent. Undue influence (manipulation of a trusting relationship of a dependent person) is also established as an activity that can nullify consent. Clarifying these aspects of undue influence and consent will allow for the more effective prosecution of elder financial abuse cases.

Recommendations

- **Maine Legislature Should Take a Leadership Role.** Although stakeholders are engaged in combating elder abuse, more can be done, and the Maine Legislature is in a key position to help facilitate low cost solutions such the proposed bill described above which will allow for more rigorous prosecution of elder abuse.
- **Maine State Plan on Aging.** We recommend legislators review Maine’s State Plan on Aging 2012-2016 to see how they can support the goals, objectives, and strategies of Maine’s Plan, Goal 1 of which is to “Protect the rights of aging and disabled adults, and enhance the response to elder abuse, neglect, and exploitation.”^{xi}
- **Triad.** Take part in meetings of your local Triads, as well as statewide collaborations such as the Maine Council on Elder Abuse Prevention.
- **Research and Education.** Help further the understanding of the scope of the problem and the development of effective interventions through supporting efforts to research elder abuse in Maine and develop effective interventions to prevent elder abuse and educate citizens on this issue.

Conclusion

Elder abuse impacts thousands of Maine adults each year and results in significant human and financial costs, not just for the older adult, but for the health, social services, and legal systems. While efforts to combat elder abuse are increasing, more needs to be done to ensure the safety of Maine’s older adults and the legislature can play a key role by crafting low-cost legislation which will allow for streamlined prosecution of elder abuse cases and enhanced penalties.

ⁱ http://www.ncea.aoa.gov/ncearoot/Main_Site/FAQ/Basics/Types_Of_Abuse.aspx

ⁱⁱ <http://www.eaime.org/index.php?page=fast-facts>

ⁱⁱⁱ <http://www.eaime.org/index.php?page=fast-facts>

^{iv} <https://www.metlife.com/mmi/research/broken-trust-elder-abuse.html#findings>

^v http://www.ncea.aoa.gov/ncearoot/Main_Site/FAQ/Basics/Types_Of_Abuse.aspx

^{vi} http://www.maine.gov/ag/elder_issues/PotentialLegalRemedies-EJTPMaine2009.pdf

^{vii} <https://www.metlife.com/mmi/research/broken-trust-elder-abuse.html#findings>

^{viii} <http://www.eaime.org/index.php?page=fast-facts>

^{ix} <http://www.preventelderabuse.org/>

^x http://www.maine4a.org/index.php?id=20&sub_id=213

^{xi} <http://www.maine.gov/tools/whatsnew/attach.php?id=427427&an=1>