

Transform 2010

POLICY BRIEF—*Examining Issues Critical to the Age Wave*

Engaging and equipping Minnesotans to prepare for the age wave

Themes for Action

- Redefining work and retirement
- Supporting caregivers of all ages
- Foster communities for a lifetime
- Improving health and long-term care
- Maximizing use of technology

Transform 2010

is a project of the Minnesota Department of Human Services

In partnership with:

Minnesota Board on Aging & Minnesota Department of Health

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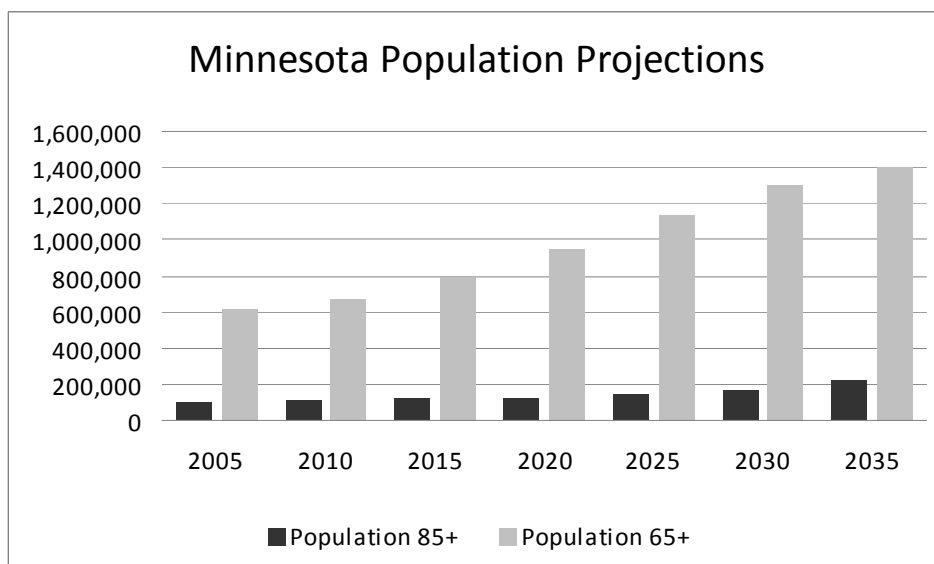
What Will Keep Family Caregivers Caring?

Policy alternatives for Minnesota

Background

Demographic Trends

2011 marks the beginning of a significant shift in Minnesota's demographic landscape toward a dramatically older population. This is the year when members of the large baby boom generation, born between 1946 and 1964, begin turning 65. According to the most recent forecast, between 2010 and 2035 the number of Minnesotans age 65 and older is projected to more than double, rising from 677,000 in 2010 to nearly 1.4 million in 2035 (1). For the same time period, the number of Minnesotans age 85 and older will also more than double, reaching 222,000. This historic trend is projected to decline slightly by 2060, at a point where nearly all members of the baby boom generation will have died, marking the end of a 50-year period (2).

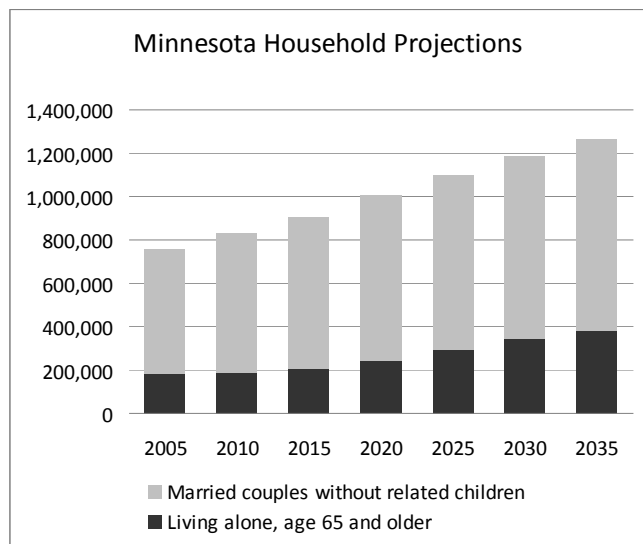


Source: Minnesota State Demographic Center, 2007

Trends in household composition and living arrangements also bear on this discussion. One trend that is significant is the reduction in the size of Minnesota families. In 1940, the average family had 3.8 members, whereas by the year 2000 it had reduced to 3.1. Projections indicate that the downward trend in family size will continue, falling to 2.8 by 2040 (3). This trend corresponds with the decline in number of children born to each woman. Women currently have on average 1.8 children, as compared to 3.7 in previous generations. The current average is strongly influenced by a growing segment of women who remain childless, 18 percent at present, as compared to 9 percent as recently as 1980 (3).

Families are not only growing smaller, they are increasingly dispersed. Growth in the number of Minnesotans who are unmarried and divorced has led to dramatic increases in the number of people living alone.

This same trend is true of Minnesotans age 65 and older. In 2010, it is projected that 187,500 Minnesotans age 65 and older will be living alone. By 2035 the number will grow to more than 383,000, which represents more than 27 percent of the age group and an increase of nearly 50 percent (4). The growing number of older adults living alone and the diminishing number of adult children is compounded by decisions of many adult children to settle in communities at a distance from their parents.



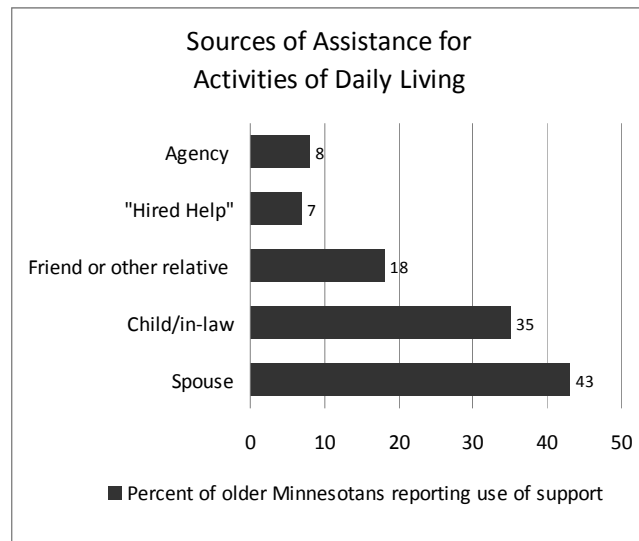
Source: Minnesota State Demographic Center, 2007

Family Caregivers

In 2006, the total number of family caregivers in Minnesota was estimated at 610,000, as compared to a total population of 5,170,000 (5). According to this estimate, 16 percent of Minnesotans age 18 and older are providing care and support to an adult family member. According to the 2005 Survey of Older Minnesotans, support is most commonly provided by a spouse or child/child-in-law, 43 and 35 percent respectively. Friends and other relatives provided support to 18 percent of survey respondents. Hired help privately arranged by the care receiver represented 7 percent of support, with formal services provided by agencies representing just 8 percent (2). Taken together, 92 percent of personal support to older adults is provided by immediate family members or informal helpers in the community.

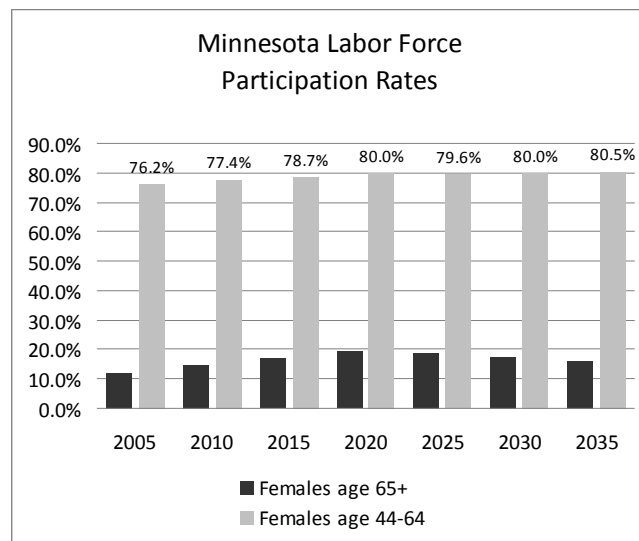
Statistically, the average caregiver in Minnesota is a 46 year old woman providing support to an older female, average age 77 (6). The majority of caregivers also fulfill other valuable roles as workers, parents or grandparents. A typical 46 year old woman in Minnesota would be a parent to one or more children. A family caregiver in this circumstance would be a member of the so-called "sandwich generation,"

addressing the needs of their aging parents while at the same time caring for their own children.



Source: Survey of Older Minnesotans, 2005

The average caregiver in Minnesota would likely also be in the workforce. In 2010, the projected workforce participation rate for women age 45 to 64 -- a time of life when eldercare is most common -- is just over 77 percent (7). This corresponds with reports indicating that nearly 60 percent of all caregivers are also working, the majority full-time (8). While less engaged in the paid workforce than their younger counterparts, older spousal caregivers age 65 and older also face dual roles. Some do work. The projected workforce participation rate for 2010 suggests that 14.5 percent of women age 65 and older will work, along with 23 percent of men in the same age group (7).



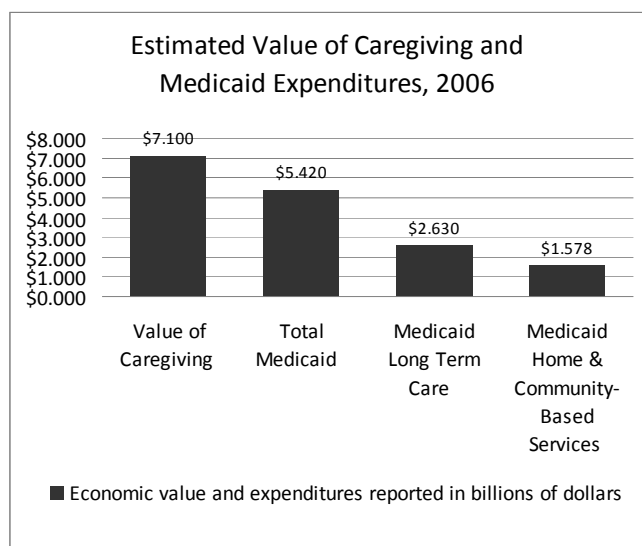
Source: Minnesota State Demographic Center, 2007

Reports that few people are financially ready for retirement coupled with the current economic downturn suggest that labor force participation rates among Minnesotans 65 and older will likely exceed current projections.

Economic Value of Caregiving

In 2006, the total estimated economic value of caregiving in Minnesota was \$7.1 billion, more than two and a half times the value of Medicaid investments in institutional long term care, and four and a half times that of Medicaid spending on home and community based services (5). In fact, the estimated annual value of informal caregiving in Minnesota even exceeds *total* Medicaid spending in medical and long term care services.

According to this estimate, informal sources of caregiving not only relieve the responsibility of the public and provide apparent cost savings; they comprise the largest real investment in the long term care support of older Minnesotans.



Source: AARP Public Policy Institute, 2007

A 2005 Minnesota Department of Human Services report also tried to put a value on informal support. It estimated that the State of Minnesota spends an additional \$30 million annually for each 1 percent decrease in informal sources of support (9).

Benefits and Burdens Experienced by Family Caregivers

Family caregivers engaged in the support of a loved one frequently report rewards and benefits associated with their role. Caregivers develop skills, knowledge and a personal sense of mastery. They also report satisfaction

demonstrating their love for another person and fulfilling their familial obligation as a son, daughter or granddaughter.

Caregivers also commonly experience considerable stress and burden. Time deficits, emotional strain, health risks, mental health problems, financial burdens, retirement insecurity, and foregone opportunities are all common burdens associated with caregiving (10). What follows is a collection of representative findings that illustrate the intensity and variety of strain experienced by many family caregivers. The findings have been organized under two major categories, health and financial burden.

Health Burden

Studies show that caregivers face many adverse physical health outcomes, including compromised immune systems, higher blood pressure and insulin levels, and an increased threat of cardiovascular disease (12, 13, 14). Other common indicators of worsening health among caregivers include: insufficient sleep, low energy levels, panic attacks, weight fluctuation, general pain, and more frequent headaches (15). Family caregivers also experience higher rates of depression (16). If unaddressed, caregivers often develop more costly, acute health care needs (17).

Financial Burden

Working caregivers who reduce work hours, stop employment or forego advancement opportunities earn less income and face greater economic insecurity in their retirement (18, 19). The financial impact is inordinately large for women, because they commonly reduce their paid work to care for children as well (11). Caregivers' limited financial resources are frequently devoted to their care receivers' needs, leaving fewer resources to support their own needs, such as health insurance (18). In addition to long-term costs, caregivers also face short term expenses. One caregiver survey reported annual out-of-pocket costs of \$5,531 for care receiver expenses, or roughly 10 percent of median income for the survey sample (19).

Current Support for Family Caregivers

A limited number of services addressing the needs of caregivers have been available in Minnesota since the early 1980s (3). Within the past ten years services have expanded considerably, urged on by the landmark amendment to the Older Americans Act in 2000, which included the enactment of the National Family Caregiver Support Program (NFCSP) and Title III-E federal funds to support new and existing services. Congress' Appropriations Bill for Fiscal Year 2008 allocated \$1.3 billion to the Administration on Aging for all Older Americans Act programs, of which \$160 million was designated for the NFCSP (20).

Minnesota's allocation of Title III-E dollars in 2007, with the addition of special project grants, amounted to \$2.4 million. Services for caregivers delivered through Elderly Waiver (EW) and Alternative Care (AC) Programs totaled \$.43 million, while state-funded respite and community service grants amounted to \$1.3 million. In-kind and cash value generated by grantee matching was a substantial \$2.1 million (6). Taken together, the investment was \$6.3 million for caregiver support services in 2007. While this funding is beneficial, it represents only 1.5% of the State's share of Medical Assistance for nursing facilities (i.e. \$410 million in 2007). Minnesota funded services fall into five major categories:

- information about available services;
- assistance in arranging supportive services;
- education, counseling, coaching and support groups;
- respite from various caregiving responsibilities; and,
- supplemental services (e.g. home modifications, emergency response systems).

In 2007, 38,000 family caregivers received more than 164,000 hours of service across these major categories. Consumer survey results in the same year indicated high levels of satisfaction. Caregivers reported that Title III-E caregiver services: helped them cope better (97%); improved their ability to provide care (97%); and, will help them provide care longer (95.8%).

Eligibility for caregiver support services varies by program and funding source. Services funded by Title III-E dollars are open to people of all income groups, though they target caregivers or care receivers of lower incomes and underserved communities. Support provided through the EW and AC is limited to caregivers whose recipients qualify for the programs, which are both income and asset-tested. More informal options for support also exist. Services provided by Living-At-Home/Block Nurse Programs, parish nurses and community centers are supplemented by the support of caregivers' neighbors, friends and family.

Policy Issue

A historically large older adult population poses a challenge to Minnesota. The dramatic increase in the number of individuals age 85 and older is especially concerning, as people in this age group most frequently require support and assistance with day-to-day tasks. The trend toward smaller, dispersed families and older householders living alone suggests that fewer individuals will be on hand to provide care just as their need for support becomes most critical. Fewer in number, family caregivers will face higher demand

from their older family members and burdens greater than the current generation.

Minnesotans have demonstrated remarkable support for their older family members, but Survey of Older Minnesotans results suggest that this support is waning. As recent as 1988, the percentage of long term care support provided by informal sources was 97 percent, as compared to 92 percent in 2005 (3). Given this downward trend, the commitment of Minnesota family caregivers cannot be assumed as a constant as we move forward. The fiscal realities and constraints of providing publicly-funded care for a growing number of older Minnesotans makes the role of family caregivers essential to sustaining their quality of life. In fact, family caregiving may be among the most important factors in affording the cost of future long term care, but only if the needs of the caregivers are recognized and sufficiently met.

Policy Alternatives

If family caregivers are to play an essential role in the support of older Minnesotans and their continued service cannot be taken for granted, how do we best ensure and sustain their involvement? The policy alternatives portion of this brief will present approaches to caregiver support across three major types: caregiver support services, caregiver financial support, and working caregiver support. While these three types of support are not mutually exclusive as categories, they provide a way to present and analyze a broad landscape of policy options. It should be noted that the options themselves are also not mutually exclusive. In fact, it is quite likely that a multi-faceted approach, as is currently underway in Minnesota, is most promising.

Each of the three policy alternative types includes an introduction to the topic area, followed by a discussion of policy approaches that may warrant our attention, support and investment. In each section, we have selected one policy option to analyze in greater depth, providing PROs and CONs to adopting the approach. The approaches treated in greater depth are summarized below:

Caregiver Support Services

- Investing in customized and evidenced-based services to address the diverse needs of caregivers is analyzed, because it promises positive outcomes for caregivers and a targeted, cost effective approach.

Caregiver Financial Support

- Delivering targeted tax credits to caregivers is evaluated due to public interest, recent legislative proposals and popularity of the strategy.

Working Caregiver Support

- Expanding paid sick leave benefits to include eldercare is reviewed because it meaningfully assists working caregivers, and is an incremental reform appropriate for a time of historic fiscal challenges.

Caregiver Support Services

Formal state-wide coordination of caregiver support services began in early 2001 after the reauthorization of the federal Older Americans Act established new funds for the development of the National Family Caregiver Support Program (NFCSP). With the promise of approximately \$2 million apportioned to Minnesota on an annual basis, a vision for a state-wide system of caregiver support developed. During this time, specific goals, outcomes and components of the system were first articulated.

Early Vision for a Caregiver Support System

Beginning in 2001 and into the present, the Minnesota Department of Human Services, the Minnesota Board on Aging, Area Agencies on Aging and key partners recognized the critical importance of family caregivers and the importance of a statewide system of support to prevent further declines in caregiving. The central goal was to build a collaborative and integrated network of support that was person-centered, affordable, accessible and diverse to meet the needs of caregivers. Services would “wrap around” the caregiver, supporting caregivers of all ages, cultural backgrounds and income levels. This system would improve the availability, quality and duration of informal care in Minnesota. In addition to providing older Minnesotans a sustainable pool of high quality informal caregivers, early planners also expected outcomes for caregivers. A successful system would result in informed, trained, healthy caregivers of any culture or age directing care decisions and providing quality care and support as long as they desired.

To pursue this vision and achieve stated goals and outcomes, planners identified major system components, service strategies and priorities. Major system components included: local planning, consumer information and access, new services, community and volunteer involvement, and broad income eligibility to ensure support for low- and middle-income caregivers. Initial strategies for new services included: employer-based programs, services for long-distance caregivers, caregiver coaches, and innovative approaches to respite (both informal and formal).

Early intervention and service use was made a priority. However, the system would accommodate caregivers’ unique needs, encourage their acceptance of help, and be

available when the caregiver was ready (at a so-called “best serviceable moment”). A first-of-its-kind, state-wide public awareness campaign helped caregivers self-identify and seek information and services. The campaign also informed health and social service providers of an underserved, somewhat invisible caregiver population.

Evolution of the Caregiver Support System

Since 2001, the vision and goals of the caregiver support system have remained much the same, while certain strategies and priorities have evolved. The central aim is two-pronged: 1) to improve outcomes for caregivers such as reducing caregiver stress, improving self-efficacy skills and satisfaction with roles; and, 2) to improve the quality and duration of care provided by family, friends and neighbors. Recent language has explicitly linked the endurance of informal caregiving to the reduction of public expenditures on formal long term care services. The growth of flexible respite care, consumer-directed care, and the caregiver coach service model are important developments in more recent years. The payment of family caregivers as Personal Care Assistants under the AC and EW programs was also begun during this time.

Most recently, evidence-informed and evidence-based services have become the focus of system planners. This shift reflects both the expanding role of Evidenced Based Practice across all human services disciplines and the growing strength and size of the caregiver research literature. Four major strategies, informed by research evidence, seem most important at present and are outlined below: 1) providing multiple sources for service information and access; 2) targeting at-risk caregivers; 3) customization of services; and, 4) multiple component interventions.

1. Provide Multiple Sources for Information and Access

One critical aspect of the caregiver support system development is the Minnesota Help Network. Since 2001, the Senior LinkAge Line®, a state-wide telephone-based information and assistance service, has played a larger role informing caregivers and connecting them to important services. In 2008, the Senior LinkAge Line® provided information and assistance to nearly 13,000 family caregivers. In 2003, the Minnesota Help Network launched MinnesotaHelp.Info an online information service which expanded access to 24 hours a day. In August of 2006, MinnesotaHelp.Info launched a new feature called Long-term Care Choices Navigator (LTCCN). An award-winning online service, LTCCN provides family caregivers 24-hour access to content tailored to their information needs. Since its inception, LTCCN has had 11,500 non-duplicated visitors and more than 100,000 visits overall. The success of the

Senior LinkAge Line® led to the creation of the Veterans LinkAge Line® and Disability LinkAge Line® in the late 2000s, which are also a route for family caregivers to gain critical information and access to services and supports.

The success of the Minnesota Help Network has exceeded expectations, and it will continue to play an important role as a source of information and access for caregivers. However, to reach a greater number of caregivers, partnerships with health care providers and community organizations may be advisable. If these organizations were to intentionally reach out to caregivers, information and access to services would likely improve. Since the majority of caregivers also work, employers may be a further partner. Places of worship and informal neighborhood organizations might also be a source of information and point of access for caregivers.

2. Target At-Risk Caregivers and Extend their Care

Caregivers who are at-risk are more likely to deliver poor quality care, experience a decline in health, and ultimately terminate their caregiving role prematurely. Research has revealed common risk factors associated with caregiving. Caregiver strain, stress and burden are most prominent in the literature. Scales and instruments for measuring the degree of strain and stress have been developed and tested. Depression and health inventories have also been used to identify the personal health impacts of the role.

Circumstantial risk factors associated with caregiving have also surfaced in the research. Three factors figure most prominently: 1) providing care to people with cognitive or behavioral impairments (e.g. dementia); 2) co-residing with a care receiver; and, 3) suffering under significant personal health or economic burden. Service approaches that target at-risk caregivers would take into account the risk factors common to caregiving. This strategy seems sensible, and a good investment. The dollars spent on caregivers at greater risk of ceasing their role might delay the need for more costly, publicly funded long term care services.

3. Customize Services to Meet Unique Caregiver Needs

The strategy of service customization helps to ensure that the client is at the center of the process. While customarily care receivers have been viewed as the sole client in need of support, caregivers are increasingly recognized as clients in their own right, with their own needs. Service customization also emphasizes consumer choice. Historically, caregivers have been provided a collection of standard services, but the trend is toward offering services that accommodate the unique and changing needs of an individual caregiver. As with targeting at-risk caregivers, screening tools and assessments can greatly inform this process. To ensure that

caregivers receive timely and tailored support, Caregiver Coaches or Support Planners play a key role to guide customization.

Unlike a traditional case manager, to whom a caregiver may defer authority, Caregiver Coaches and Support Planners are accountable to their caregivers. The goal of the Caregiver Coach is to support and strengthen the caregiver, in their knowledge and skills, in their role as an advocate and care coordinator, and in their personal and lifestyle goals. While the term "case manager" suggests caregivers are a *problem needing management*, "caregiver coach" suggests that caregivers need support and encouragement to develop expertise and a sense of self and even pride in their role. Caregiver Coaches and Support Planners link caregivers to formal and informal supports, but they are also a service in their own right, providing dynamic and timely direct support.

4. Provide Multiple-faceted, Evidence-Based Services

Dynamic situations call for dynamic responses. Depending on the life circumstances of caregivers, their length of time in the role, and the unique needs of their care receiver they may need different forms of respite, education and training, or supplemental support. A working caregiver may benefit from information and support delivered at the workplace, whereas an eighty year old caregiver of a spouse with Alzheimer's may desire training on the disease and best practices of care of her husband. Research has shown that a strong dose of just one service many not be enough. There is rarely such a silver bullet. Instead, a collection of services delivered in concert seems most promising.

Policy Alternatives

Three Minnesota Initiatives Charting our Way Forward

Three current Minnesota initiatives attempt to tie together the essential service components described above. All of the initiatives are invested in similar basic outcomes: caregivers most in need will receive support first; 1) caregivers will experience less stress and depression and greater social support and mastery; 2) caregivers will improve the quality and extend the duration of their care; and, 3) caregivers will rely less on more costly forms of long term care support, such as nursing home care. The three initiatives described below – the Live Well at Home Nursing Home Diversion project (NHDP), the Tailored Care™ Caregiver Assessment Demonstration (T-Care), and the Family Memory Care Alzheimer's Demonstration – provide examples of the cutting edge of caregiver support, and where we may want to make further investments.

Live Well at Home Nursing Home Diversion

Minnesota was awarded an 18-month Nursing Home Diversion Grant from the Administration on Aging in 2007 to develop an evidence-based Rapid Screen tool for targeting and triaging persons at-risk of nursing home placement, and their family caregivers. This grant-funded effort came to be called the Live Well at Home Project. Dr. Joseph Gaugler of the University of Minnesota was contracted to provide research, design assistance, and to conduct the evaluation of the risk screen and related processes. The Rapid Screen addresses seven identified risk factors, and uses an income eligibility threshold that is based upon the state's Alternative Care Program.

During the development phases, a new service process called Diversion Support was created to specifically serve at-risk care receivers and caregivers identified by the Rapid Screen. Diversion Supports include risk management interventions, self-directed planning and purchasing support, resources, and a Support Planner who facilitates the customized service approach. Tools and processes are currently being tested and could eventually be integrated into the state's Minnesota Help Network, long term care, health care, and aging systems. Current public funding streams (e.g. Title III, state grants, and Alternative Care Program) will be leveraged to provide ongoing support for the expansion and integration of the approach. The project is scheduled to be completed by June 30, 2009 and further development efforts are expected.

Tailored Care™ Caregiver Assessment Demonstration

Minnesota is one of six states piloting the Tailored Care (T-Care)™ caregiver assessment process for supporting family caregivers. T-Care™ is an evidence-based approach grounded in the Caregiver Identity Theory, and principally developed by Dr. Rhonda Montgomery of the University of Wisconsin-Milwaukee. The approach recognizes that caregiving creates an identity discrepancy resulting from a change in roles (e.g. from a daughter to a caregiver or a spouse/partner to a caregiver). The literature suggests that this identity discrepancy creates stress and imbalance for the caregiver. The T-Care™ process uses a screen and thorough assessment to measure and score the caregiver's emotional levels and needs, and offers customized strategies via decision-making maps to address the identified emotional stress and needs.

Much like the Diversion Support approach described above, the service customization is delivered by a supportive professional, in this model, a Caregiver Coach. The T-Care™ assessment helps establish the unique and most

important needs of the caregiver. Currently, Minnesota has twenty-one certified Caregiver Coaches providing T-Care™ assessments and customized services at twenty-five locations. The full assessment and follow-up coaching is targeted to caregivers scoring medium to high in six risk categories in an effort to maximize the use of scarce funds and service resources.

Family Memory Care Alzheimer's Demonstration

The Family Memory Care Initiative is funded through the Minnesota Board on Aging from funds received through the federal Administration on Aging Alzheimer's Demonstration grant. This caregiver initiative translates the results of over 20 years of research conducted through the New York University Silberstein Institute by Dr. Mary Mittelman, which demonstrated on average an 18 month delay in nursing facility placement. The initiative establishes a state-wide network of Memory Care sites in health care and community service settings where memory care competent Caregiver Coaches work with families and the medical clinic to strengthen family-based care. An initial research to practice grant supported the development of four Memory Care sites. An expansion grant, running from 2008 to 2011, allowed the initiative to engage five additional partners across the state.

The Family Memory Care Initiative works with spousal caregivers of people with memory loss to improve the ability of the caregiver to withstand the difficulties of caregiving. The need for nursing facility placement of the person with memory loss is reduced by improving support and minimizing family conflict. The spouse and family members participate in six individual and family counseling sessions in a 4 month period, and usually participate in caregiver support groups. Caregivers can call their Coach anytime with questions, if they need help finding services or addressing a crisis. Early results of this initiative show that depression and impacts of disruptive behaviors are reduced, family involvement and support in caregiving has increased and the caregivers are indicating that they will be able to continue to provide care even as the caregiver situation increases in difficulty.

Policy Option 1:

Invest in an expanded, state-wide caregiver support system. The improved system would include service customization to target the needs of at-risk caregivers and the use of evidence-based services.

Since 2001, Minnesota has made a great deal of progress in the development of a state-wide caregiver support system. The National Family Caregiver Support Program (NFCSP) services portfolio and dedicated funding provided an

excellent platform for more recent developments. The focus on ensuring information and access, targeting at-risk caregivers, supplying supports that address the specific risk factors, and employing a collection of evidence-based services promises a future caregiver support system that is smarter.

The system is smart because resources are targeted at caregivers and families most in need and the service interventions are customized and tested (and sometimes proven) by the research. If targeted interventions truly improve the well-being of caregivers and delay the use of more costly, publicly funded long term care services, the cost savings would be a good return on our investment.

PRO

- Family members who view themselves as caregivers more readily identify and use services for caregivers (21, 22).
- Caregivers are more likely to delay institutionalization of care receivers if they receive support early (21, 34).
- Early service utilization helps caregivers avert a crisis (21, 22).
- Multi-component, evidence-based interventions have been shown to delay nursing home utilization up to 18 months (23).
- Evidence-based screening and assessment tools help ensure that caregivers most at-risk and in greatest need receive support (22).
- Services customized to assessment results promise greater impact and cost effectiveness. Delivering services without an assessment could result in the delivery of unneeded and ineffective services (22).
- Caregiver-centered models empower caregivers to play a central role in the coordination and delivery of services (21).
- Equipping and supporting family caregivers in the community ensures overall quality of care for care recipient (e.g. if caregivers are ill or coping poorly, recipient care plans and discharge orders get executed improperly) (21).
- This option complements emerging, national trends related to customized, consumer-directed care (21).
- Data from more scientific assessments could inform caregiver outcome trends and future support system development (21).

CON

- Screening and assessment tools may be perceived by caregivers as intrusive and stigmatizing; especially if they are delivered on more than one occasion, by more than one professional (e.g. "Is there something wrong with me?").

- Health care and community services providers – key partners in support system expansion – are slow to view caregivers as clients (21).
- Financial incentives are lacking to encourage health care and community service providers to conduct full caregiver assessments (21).
- Certain elements of evidence-based models may be difficult to implement in both rural and urban settings. Rural settings may not be able to deliver certain, recommended service supports.
- T-Care™ assessment tools are still being tested and are not ready for broad dissemination (22).
- Integrating current initiatives and demonstrations into one successful approach may prove difficult.
- Exemplar models of fully implemented state-wide caregiver assessment tools and protocols do not yet exist in the US (21).

Caregiver Financial Support

Caregivers devote a significant amount of time to their role, on average 20 hours per week. A smaller segment of caregivers, nearly 20 percent, report providing more than 40 hours per week (11). And as the saying goes, "time is money." The estimated, cumulative value of this time (\$7.1 billion in 2006) surpasses total annual Medicaid expenditures in Minnesota (5). In this way, family caregiving represents a tremendous financial asset for the public, but it also represents a financial liability for caregivers. To date, caregivers providing this valuable family and public service have largely gone uncompensated. While there are notable personal and social benefits associated with the caregiver role, and clear gains for the public, caregivers often net large financial burdens.

Caregiving Can Reduce or End Paid Employment

The most substantial liability for caregivers is the negative impact caregiving has on their paid employment. Working caregivers, representing 60 percent of all caregivers, frequently reduce hours, increase use of un-paid leave, and face salary plateaus due to foregone advancement opportunities. A smaller number of working caregivers elect to retire early or otherwise leave the workforce. In the short-run, this means a tightened household budget, a serious enough problem. In the long-run, however, it frequently means a financially insecure retirement.

Long-term Financial Costs for Caregivers

When working caregivers reduce their hours, wage earnings, and employer-sponsored retirement plan contributions, the cumulative effect is very damaging. A 1999 report estimated

average life-time wage and salary losses as a result of caregiving at \$550,000 (24). A separate 1999 report submitted a higher, yet comparable estimate of \$659,139 (combining projected wage wealth loss with Social Security and private pension losses) (18). Women and men alike face such burdens, but women fair far worse.

Women Experience the Greatest Burden

Women make up as much as 75 percent of all caregivers (25). This gender imbalance is largely due to a persistent cultural expectation that women assume the role of primary caregiver, even as traditional gender roles increasingly bend and blend. This expectation holds true for child care as well as eldercare.

Child care and eldercare responsibilities create similar circumstances, though with an important difference: the workplace disruptions associated with eldercare typically happen during mid-life, peak income-earning years. Taken together, the impact of child care and eldercare responsibilities on workforce participation is significant. In fact, research findings suggest that women on average spend roughly ten additional years out of the workforce as compared to men, 11.5 years and 1.3 years respectively (26).

In addition to spending time out of the paid workforce raising children and caring for older adults, compensation disparities between women and men, though narrowing, still persist. With fewer years in the workforce and lower compensation, women face smaller Social Security benefits, employer-sponsored pensions, and personal savings balances (24).

For some female caregivers, financial insecurity in late life will mean growing old in poverty. A 2006 study found that early and mid-life caregiving responsibilities significantly increased the risk of poverty in late life as compared to non-caregivers (11). The same study reported that the risk is heightened depending on other factors such as the degree of work stoppage, changes in marital status, or health decline (11).

Short-term Financial Costs for Caregivers

Long-term financial liabilities are most burdensome, but more immediate out-of-pocket costs also burden caregivers. Expenses incurred related to their care receiver's medical care, food, transportation, and home care needs are most notable. A 2007 study reported average estimated out-of-pocket expenses at \$5,531 per year, or roughly 10% of the median income of the survey group (i.e. \$43,026) (19). While respondents commonly limited their own discretionary spending to afford these costs, they also tapped savings or

delayed home repairs and personal health care purchases to meet their care receiver's needs. Lower-income caregivers took more drastic measures, spending less on such basics as food, clothing and utilities. The study reported higher costs for long-distance caregivers (\$8,728), as opposed to caregivers who lived with or near the recipient of their care (\$5,885 and \$4,570, respectively) (19).

Policy Alternatives

Reform Social Security

One way to help address the long term financial costs of caregiving would be to modify existing Social Security policy to account for the unpaid work of caregivers. Since female caregivers may lack other sources of retirement income, strengthening their Social Security benefits could be an effective way to bolster their economic security. In fact, in 2004 Social Security represented the primary source of income for 41 percent of unmarried women, age 65 or older (3). Social Security has proven to be a tool for reigning in poverty among adults 65 and older, and could extend similar protection to family caregivers (11).

One approach to Social Security reform would be to institute a caregiver credit that would stand-in for lost compensation. While not paid-out as income, the credits would be recorded as earnings by the Social Security Administration and count toward the calculation of their benefits. Caregiver credits awarded for up to five years of a person's employment history would help ensure that time spent outside the paid workforce would not unduly penalize caregivers. A second approach would be to augment the amount of income reported during a caregiver's five lowest income-earning years. The adjusted values for those five years would approximate the average compensation caregivers earned in other income-earning years, and raise their overall benefit (24).

Provide Direct Cash Payments or Assistance

Direct and indirect transfers of cash to caregivers are increasingly common in Western, industrialized nations (e.g. Australia, Canada, France, Germany, and Sweden) (27). Such money transfers are often intended to sustain caregiving and thereby reduce public expenditures on more costly institutional care. A latent, if not articulated, goal of any money transfer is to acknowledge the public value of caregiver contributions. Sometimes the money is delivered as a refund for caregiver out-of-pocket expenses. In more generous instances, the money provides direct compensation for their caregiver duties. Only in this latter case would a policy have any real impact on caregivers'

long-term financial security. The former approach would address out-of-pocket costs incurred by the caregiver.

Promote and Expand Consumer-Directed Care

In Minnesota, the most common way public cash reaches family caregivers of older adults at present is through the Community Directed Community Supports (CDCS) program of the Elderly Waiver (EW) and Alternative Care (AC) programs. As income-tested programs, AC and EW provide home and community based long term care services for poor and lower income older adults. Minnesota is not alone in this approach. As of 2002, 139 home and community based support programs in the United States offered a consumer-directed option, with half providing the service model to older adults (29).

While consumer-directed models centered on caregivers as the primary client are in development, models that center on the care receivers are established. Current consumer-directed models provide cash to care receivers who, with the guidance of a professional support planner, decide their own service needs and contract for their own care. When faced with the need to hire help for activities of daily living (ADLs), older adults have shown a strong tendency to hire family members. In this way, public funds are being used to pay family caregivers of poor or low income older adults. Currently, only a tiny fraction of EW and AC clients are using this model. One policy approach would be to promote and strengthen the existing CDCS model. An outcome of this effort would be financial support for family caregivers.

Provide Tax Credits or Deductions

Across the United States, consumer-directed services have only one real popular rival in terms of delivering cash benefits to caregivers: tax credits and deductions. Especially since the enactment of the National Family Caregiver Support Program (NFCSP), few legislative approaches to caregiver support have received more attention than tax incentives. Between 2004 and 2008, approximately 30 bills were introduced across 14 states, with multiple attempts made in California, Hawaii, Kentucky, Massachusetts, Minnesota, New Jersey, and New York. Several attempts at caregiver tax bills were also made at the federal level in both the 109th and 110th Congress (30). To date, a caregiver tax credit or deduction has yet to be enacted (30). The specific design of each caregiver credit or deduction has varied according to amount, qualifications, and administrative delivery.

Proposed tax credits range in value from \$500 to \$3,000 per year, whereas tax deductions top off at \$5,000 per year. Sometimes caregivers alone are eligible for the credit, while in other cases care receivers also qualify. Recipients of the

benefits must usually fall below a certain Adjusted Gross Income level. They are also often expected to pay a certain percentage of their income toward specified eldercare related expenses to gain the credit or deduction (30).

In 2007, two separate bills were introduced in the Minnesota Legislature that if enacted would have extended a tax credit to qualifying caregivers (HF 313 / SF 696 and HF 2178 / SF 1931). HF 313 / SF 696, the Minnesota Home Care Credit act, focused exclusively on a credit for caregivers, whereas HF 2178 / SF 1931 sought to establish a Family Care Credit alongside a wide array of programs and services focused on other long term care priorities.

Policy Option 2:

Provide a caregiver tax credit that targets caregivers most at-risk of attrition and care receivers most at-risk of nursing home placement. Require credit recipients to participate in select, evidence-based services to ensure greater caregiver support and retention.

Three important features make the most recent Minnesota caregiver tax credit bills (HF 313 / SF 696 and HF 2178 / SF 1931) stand-out from earlier versions. Both bills call for the creation and implementation of an evidence-based assessment tool that would measure caregiver burden. Caregivers with the highest level of burden would receive a credit first. A well-devised assessment would help ensure that the credit benefits those who are most at-risk of ending their caregiving role.

A second feature of each bill also measures risk, this time the risk of care receivers being placed in nursing homes. According to the bills, professionals administering the caregiver burden assessment would also be asked to provide proof that the care receiver would require nursing home care in the caregiver's absence, or is otherwise at risk of placement if the caregiver remains unsupported.

Finally, the bills require all qualifying caregivers to complete eight hours of approved caregiver training, education or counseling services. This service requirement establishes an additional barrier to caregiver attrition, especially if the approved options are evidence-based services that have been shown to reduce burden and sustain family caregivers.

Through these three measures, the two bills attempt to target caregivers most at risk of leaving their role, and care receivers who are most at risk of placement in institutional care. These improvements of a widely popular policy approach make further analysis of a caregiver a tax incentive a valuable exercise.

PRO

- Tax credits based upon the assessed burden of caregivers and linked to participation in evidence-based caregiver support services will reach caregivers most at-risk of leaving their role.
- Tax credits targeted at caregivers most at-risk of attrition could produce cost savings in publicly funded long term care services that would off-set the financial cost of the credit.
- Tax credits may provide an incentive for caregivers to enroll in evidence-based support services, which demonstrate a track-record of sustaining caregivers.
- Assisting caregivers with out-of-pocket expenses related to caregiving might free-up household income that could be devoted to personal savings and retirement (31).
- A number of western, industrialized nations have adopted caregiver tax incentive programs, including Canada, and may serve as administrative models for the US and Minnesota (28).
- Tax credits elevate the importance and highlight the social value of family caregiving.

CON

- Tax credits would likely elevate the social value of family caregiving but would not deliver measurable economic cost savings for the state (32).
- Tax incentives do not appear to motivate caregivers to initiate or maintain their role (32, 33).
- Multiple eligibility requirements may improve benefit targeting, but may also pose barriers to participation.
- Evidenced-based support services have proven more effective at extending the life-span of caregivers. Services should figure more prominently in any proposed caregiver tax credit (34).
- Financial benefits related to eldercare set up circumstances ripe for financial exploitation by relatives of older adults (35, 36).
- Tax credits and deductions provide delayed, rather than immediate relief (28).
- Tax credits address short-term, out-of-pocket costs, while doing little to ameliorate long-term financial consequences associated with caregiving.
- A tax credit reliant on the human services system to verify and rank the potential recipients would likely be administratively costly.
- Similar caregiver tax credit proposals have yet to be enacted in Congress or in other State Legislatures.

Working Caregiver Support

60 percent of family caregivers are also employed most full-time (7). Approximately 2 out of every 10 employees are caregivers; this proportion often doubles in workplaces with large numbers of middle-aged females (7, 37). As the population ages, a growing percentage of workers will become caregivers. At the same time, Minnesota's workforce will grow smaller. In fact, current projections suggest that our labor force growth rate will fall by 60 percent over the next decade (37). In this context, Minnesota will increasingly need working caregivers to perform both roles: providing informal support to aging family members and participating in the workforce.

Working Caregivers Face Financial Burdens

Working caregivers experience well-documented burden and strain balancing their work and caregiving roles. Working caregivers face financial burden, frequently reducing their work hours, foregoing advancement opportunities, taking unpaid leave, and even leaving their employment (18). These financial burdens are made worse by expenses they incur providing care to their family member.

Working Caregivers Face Health and Other Burdens

Working caregivers also face non-financial burdens, such as stress from a lack of time and work-life imbalances. These stresses commonly result in caregivers neglecting their own self-care in favor of the care receiver's well-being (15). With family caregiving responsibilities commonly lasting around five years, such a lengthy period of insufficient self-care can lead to serious physical and mental health consequences for caregivers (7). While this is a serious personal health concern for caregivers, it represents a potential public health issue as Minnesota's population ages (38). Caregivers who experience serious health changes are more likely to need chronic or acute care themselves and may be at greater risk of placing their care receiver in a nursing home.

Employers Face Costs Due to Working Caregivers

Employers face costs associated with working caregiver health decline. Employer-based health plan costs increase as employee health and wellness decrease and working caregivers experience greater chronic and acute health care costs. In addition to the cost of providing health care to employees, employers face other documented costs associated with working caregivers who go unsupported. Working caregivers who routinely miss work, leave work early or come in late, or permanently reduce their hours can

negatively impact productivity and force employers to replace the missing hours with new hires (39). Even caregivers who take unpaid leave pose costs, whether related to hiring temporary replacements or the strain experienced by colleagues who cover their work responsibilities.

We Need Working Caregivers to Work and Provide Care

If we agree with the premise that working caregivers will increasingly be needed as workers *and* as caregivers, we need to manage the risks and costs associated with unsupported working caregivers. The public faces costs if caregiver strain and burden force earlier use of institutional care for care receivers. Employers face costs if unsupported working caregivers demonstrate higher absenteeism and health care usage rates and lower productivity and retention rates. Fortunately, there are practical options for employers and caregivers to help working caregivers balance and maintain both roles.

Policy Alternatives

Promote and Adopt Flexible Workplace Policies

Adopting flexible workplace policies that address the needs of employers and working employees is an attractive, low-cost strategy. Flex-time scheduling, a modified daily schedule, or telecommuting can solve many work-life balance issues for working caregivers, and if devised well, meet employer productivity goals. Phased-in retirement, temporarily reduced hours, and gradual return-to-work options might enable some caregivers contemplating permanent retirement or leave, to stay in the paid workforce (37). A flexible and supportive workplace environment can lead to greater employee recruitment, retention and satisfaction. It can also reduce stress and improve wellness among working caregivers.

Cover Eldercare Cost through Flexible Spending Accounts

Policy makers, in cooperation with employers and working caregivers, could pursue broader workplace policy alternatives. Working caregivers invest both money and time into their caregiving role, so workplace policies addressing these two scarce resources are most valuable. One option would be to modify current flexible spending accounts so that they could be used for elder care expenses, ideally for dependent *or* non-dependent parents and parents-in-law. This would allow working caregivers to use pre-tax money on annual out-of-pocket expenses associated with eldercare. Something similar could be pursued with Health Savings Accounts, which are steadily growing in popularity.

Reform and Expand FMLA in Minnesota

Delivering more time to working caregivers would also be valuable, paid-time-off being the most desirable. One option would be to expand the Family and Medical Leave Act (FMLA) in Minnesota. Minnesota has shown the will to reform FMLA extending it to employees of businesses with twenty-one or more workers as compared to fifty in the federal version (39). Minnesota could strengthen FMLA benefits further and cover employees who have been with their current employer less than one year. Perhaps the most important reform would be to expand the criteria for using FMLA to allow working caregivers to take leave not just for their child, spouse or parent, but their seriously ill parent-in-law, grandparent, grandchild, or sibling as well. A more transformational change to FMLA might include offering paid leave or partially paid leave, which was enacted in California as the Paid Family Leave in 2002, and implemented beginning July 1, 2004 (40).

Adopt Universal Paid Time Off

Another significant, new policy direction would be to adopt a universal paid-time-off policy in Minnesota. Currently, most workers who enjoy some sort of paid-time-off receive the benefit in segments: vacation, sick leave, holidays and floating holidays. Universal paid-time-off would allow workers to roll together all of their time off and manage it as their circumstance demands, whether for leisure, illness or family responsibilities, including eldercare.

Strengthen Current Paid Sick Leave Benefits

Short of adopting universal paid-time-off, policy makers and employers could ensure that all Minnesota workers receive paid sick leave. A cost effective policy would establish accrual of paid sick leave based on the size of the employer, and the number of hours worked by the employee. Minnesota considered a bill on this proposition during the 2007 legislative session (SF 1324 / HF 1334).

A more incremental change to paid sick leave policy has also been considered in the legislature in recent years. The bills proposed extending current sick leave to cover care for more than just oneself, child or spouse (SF 2618, 2006; SF 378 / HF 061, 2005; HF 3054, 2004). Had they been enacted, the bills would have allowed working caregivers to use paid sick time to care for a sibling, parent, stepparent, grandparent, or another dependent residing in the employee's household.

Policy Option 3:

Extend current paid sick leave coverage to include the care of dependent and non-dependent older adults, such as parents, step-parents, parents-in-law, and grandparents.

The Healthy Families, Healthy Workplaces Act (SF 1324 / HF 1334), briefly referenced above, was introduced during the 2007 Minnesota legislative session and endeavored to extend paid sick leave to all workers who met minimal qualifications. It also moved to expand the reasons for which an employee could use the benefit.

According to an advocacy organization in support of the Healthy Families, Healthy Workplaces Act, approximately “one million Minnesotans—46 percent of Minnesota workers—are not able to take a paid sick day when they are ill” (41). Minnesota is reflective of the nation’s record in this respect (42). This and other evidence suggests that the United States and Minnesota may need to consider significant reforms around its paid sick leave policies. However, in a time of historic fiscal challenges, this brief will analyze an incremental, rather than transformational reform, that still promises support for many working caregivers.

Earlier Minnesota legislative initiatives referenced above (SF 2618, 2006; SF 378 / HF 061, 2005; HF 3054, 2004) endeavored to extend the coverage of paid sick leave to the care of more than self, child or spouse. Unlike earlier legislation, the policy option reviewed here expressly includes *non-dependent* older adults, rather than *dependents* only. Some family caregiving relationships lead to shared households and older adults becoming legal dependents, but this is the exception rather than the rule. A policy position covering only dependent older adults is too narrow to have a meaningful impact.

PRO

- Employers who offer paid sick-leave experience higher workforce retention rates and lower turn-over and replacement costs (44).
- Caregivers who are able to use paid sick leave to attend to customary eldercare may avert a crisis and avoid longer-term absences.
- Caregivers would experience less financial burden and greater economic security through fewer lost wages.
- Caregivers would face a reduced risk of job loss due to current, unauthorized uses of sick leave (44).
- Employers viewed by working caregivers as supportive yield improved morale and greater loyalty (37).
- Employers may experience reductions in health care plan use due to greater employee self-care and wellness (44).

- Minnesota may see cost-savings related to publicly-funded nursing home care and home and community-based services if adult children maintain their dual roles as working caregivers (44).
- Minnesota may experience faster and more successful nursing home and acute discharges if adult children are available for the transition (44).

CON

- Employers may believe that this policy change would raise costs rather than save costs (45).
- Employers may fear that extending the scope of sick leave coverage will lead to future expansions of the policy and further costs.
- Employers may view the policy as an imposition, wanting instead to determine their own leave policies (45).
- Caregivers could incur and protest wage deductions to share the cost of an expanded sick-leave benefit.
- Caregivers who provide care to a domestic partner, friend, sibling or other family member would not benefit from this incremental change.
- Minnesota may do better to expand paid sick leave coverage through employer tax incentives rather than through a universal mandate (43).
- Minnesota may make a greater impact through a transformational change that would include minimal paid sick leave for all workers.
- Minnesota may be perceived by some as an over-regulated state unfriendly to employers (45).

Conclusion

A historically large older adult population poses a challenge to Minnesota. The dramatic increase in the number of individuals age 85 and older is especially concerning, as people in this age group most frequently require support and assistance with activities of daily living. The trend toward smaller, dispersed families and older householders living alone suggests that fewer individuals will be on hand to provide care just as the need for support becomes most critical. Fewer in number, family caregivers will face higher demand from their older family members and burdens greater than the current generation.

The fiscal realities and constraints of providing publicly-funded care for a growing number of older Minnesotans makes the role of family caregivers essential to sustaining their quality of life. In fact, family caregiving may be among the most important factors in affording the cost of future long term care, but only if the needs of the caregivers are recognized and sufficiently met.

This brief has laid out a wide variety of alternatives, with special attention given to three approaches: investing in a smart, evidence-based caregiver support system; delivering targeted tax credits for caregivers; and, expanding paid sick leave benefits to include eldercare. Each approach promises some advantages for caregivers and some gains toward meeting the needs of an aging population with proportionately fewer family caregivers and potentially fewer fiscal resources.

While some would suggest that family caregiving is a familial responsibility that ought to be pursued solely out of love and obligation, and that support for caregivers seems to go against common social values, this view yields inaction on an issue of tremendous importance to the health and welfare of Minnesotans. On the other hand, those who see support for family caregivers solely as a means to reduce public expenditures on long term care services in the short-term should be cautious in their approach. While family caregivers deliver savings for Minnesota tax payers, if they put themselves at risk in the process, Minnesota may be faced with a generation of caregivers who have divested in their own health and economic security. In thirty years, when caregivers in mid-life reach old age their financial insecurity and poor health will become a new cost for the public to bear.

Policy alternatives that sustain caregivers in the short-run and make a material impact on public long term care expenditures are valuable pursuits. However, alternatives that fortify caregivers for the long-run, while still addressing public fiscal concerns meet a higher standard that should be the real focus of our public policy pursuit.

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