Medicaid and the Challenge of Paying for Nursing Home Care

by Marlene Stum and Estelle Brouwer

Medicaid has become a word charged with meaning. To some frail elderly, it means they won’t be turned out onto the streets when their money runs out, to others it means the government dole, pure and simple. To state and national policy makers, it represents a huge and growing piece of the budget and a vexing political problem with no easy solution. Do you cut Medicaid and make life even harder for the poor, or watch it continue to grow and eat up scarce resources that could be used instead for education, crime prevention, or a myriad other worthy purposes? When the nation’s growing elderly population is factored into the equation, the decisions facing policy makers become even more challenging. Similar to other states, Minnesota’s single largest category of Medicaid spending is for nursing homes, and total spending is increasing at an alarming rate. In 1993, skilled nursing care consumed one-third of Medicaid dollars spent in Minnesota—over $705 million.

In reality, Medicaid is one critical piece of a complex patchwork of public and private programs that the elderly and their families, as well as state and federal governments, must try to understand when decisions are made about paying for long term care. There is no doubt that the existing long term care financing “system” is proving costly in many ways to the chronically ill, their families, and to the bureaucracies involved. Many questions exist about the roles that family resources and government programs, such as Medicaid, can or should play in financing long term care.

Medicaid-related headlines and ads for professional advice on “avoiding nursing home costs” have led policy makers to ask if elders who don’t really need it are qualifying for and using Medicaid. Are families engaging in Medicaid estate planning, a practice of intentionally transferring wealth to other family members so that the elder qualifies for Medicaid coverage and avoids using personal assets to pay when long term care is needed? What family resources are really being used to meet the care needs of elders?

Few comprehensive studies have been published to date to determine the scope and prevalence of Medicaid estate planning. A recent study directed by the Minnesota Department of Human Services was the first to examine the extent and amount of asset transfers among a sample of nursing home residents. To our knowledge no researchers have spoken in depth with elders or their families about their decision making with regard to financing nursing home care. Most research has taken a fiscal policy perspective and attempted to examine the impact of current practice on state or federal government expenditures. In this study, we look through a family policy lens at the decisions individuals and the professionals who advise them make about paying for nursing homes.

Setting up the Study

The purpose of our research was to gain an in-depth perspective into family decisions about paying for long term care. Qualitative methods intended to help us gain a thorough understanding were used. During 1994 we interviewed forty-five families and sixty-five professionals. An advisory group was recruited to assist in refining the research questions, piloting data collection tools, and recruiting the sample. Group members included individuals with legal, consumer advocacy, and aging services expertise as well as representatives from government agencies related to long term care and professional organizations related to nursing homes.

Two types of families were recruited, those with an elder already in a nursing home (thirty-three families) and those with an elder diagnosed with a chronic illness but still living in the community (twelve families). Compared to the majority of the elderly population, these families were more likely to be dealing with decisions about paying for long term care. Roughly half lived in a metropolitan setting and half in a rural setting.

Families volunteered to participate in the study. They included a broad spectrum, from elders who lived on Social Security to millionaires, though a majority were middle class, with assets up to $100,000 plus a home. Their children also ranged across the entire economic spectrum. About three-fourths of the interviews were with the one family member most involved in financial and care decisions—typically a spouse or an adult child. The remaining interviews included two family members, both involved in financial decisions. Elders who were still living in the community typically participated in the interview, while those in nursing homes were unable to.

Financial planners, attorneys (including legal service), accountants, county human service workers, Medicaid eligibility workers, and nursing home social workers were included in the professionals interviewed. They represented the continuum of professionals most likely to be involved in assisting family members from planning ahead to crisis decision-making. Up to ten individuals in each professional group were interviewed. They were also drawn from both rural and urban settings.

Are Elders Planning Ahead?

Most of the elders in our sample had done some planning for retirement—but for a retirement both shorter and healthier than the one they were experiencing. Few had planned to live so long or to spend so much on health care. Denial of potential long term care risks and hope that they will escape such costs seems commonplace. Fear and worry about outliving one’s assets were very real for some, especially those who were eighty-five or older. Fear about what the future might bring financially had some elders not refilling medications and doing without needed home care help.

“You saved and were careful and thought you were going to travel and do things and all of a sudden it all goes for nursing home care.” —Wife of husband with Alzheimer’s in nursing home for four years

“With either of the mothers, if you ever bring up planning ahead or financial issues, heavens, they are not old enough to discuss that. They both hope that they are run over by a car and will never have to face it (long term care).” —Daughter of mother and mother-in-law, both in mid-seventies

“We’ve never seen or talked to anybody about financing...What we thought we’d do is go the way we are until we run out of money and then figure out what to do.” —Husband with Parkinson’s and caregiver wife

Planning ahead for many meant living frugally and investing life savings in certificates of deposit (CDs). Many vow to only use their saving’s principal as a last resort. Daily needs are met with a combination of income from Social Security, personal investments, and a pension, if they are lucky.
A majority own a home with a paid off mortgage. It is not uncommon for two minimum wage-earners to have accumulated $100,000 in savings over a lifetime, not including the value of a home. While many had worked hard to save, their accumulated assets seemed slight in relation to the $4,000 a month nursing home care costs some were experiencing. A few elders were primarily living on Social Security income, getting along financially by living in subsidized housing, and limiting spending as much as possible.

While a majority of adult children spoke about the important role insurance could play in financial protection, only one couple had purchased long term care insurance as a result of their experience with his parents. A few families had been approached by long term care salespersons.

“We checked out long term care insurance and were almost convinced to take a policy on me, but it was $2,500 annually for that policy and I think people in our generation have a hard time with these high figures. It seemed as if I might pay that for twenty years before I needed it. My husband was not insurable due to his disease.”
— Wife in sixties of husband with Parkinson’s

What Goals do Families Have?

Decisions about finances and care frequently revolve around trying to meet one or more goals. Conflicts are typical as family members try to allocate limited resources among competing needs.

Quality Care. Family members consistently emphasize the priority of keeping the elder at home for as long as possible. Finding quality care to meet the elder’s needs was a top priority. Paying for the care and how decisions impact on any inheritance seemed rarely to be the driving force in what decisions were made. Decisions clearly involved more than dollars and cents. Emotional, physical, and financial costs all had to be weighed.

“You can’t really think too much about the financial part at first. You live with hope, you keep thinking this will get better. I can’t predict and I can’t plan too much.”
— Wife of husband with Alzheimer’s, now in nursing home

“We are trying desperately not to go to a nursing home. As far as financing, we will just have to deal with that when the time comes.”
— Husband with Parkinson’s and caregiver wife

The reality of not being able to predict or control an elder’s health contributes to the worry and fear family members experience. How fast will the Alzheimer’s disease progress? How much will medications be this month? Will the level of care needed at the nursing home change with costs possibly going from $3,000 to as high as $4,500 per month? Taking it one day at a time is often required given the unpredictable nature of chronic illnesses.

Financial Self-Sufficiency. Care for a frail elder is most often viewed as a private, family responsibility. Family help with caregiving as well as cash is expected. “My fair share” was a phrase commonly used as families talked about their obligations. This typically meant providing informal care until it became too burdensome or until the elder’s needs could no longer be met as well as using the elder’s income and assets to pay expenses.

“We feel that your assets are meant to take care of you during your lifetime.”
— Daughter of ninety-year-old mom in nursing home

“For someone who never had more than what you’d call, a little better than minimum wage job, she had accumulated quite a bit of money. Financial security was very important to her. All her money will go for her care, but she will receive the same care whether she is on Medicaid or not—she’s spent over $90,000.”
— Daughter of mom with Alzheimer’s

A majority of family members we interviewed expressed strong feelings about not wanting to rely on the government to pay for care except as a last resort.

“Anyone who’s been through the depression has a different outlook on things than my generation does. They have that old fashioned pride, I mean, to be on relief, would be just such a shameful thing that it just doesn’t bear raising the question.”
— Daughter of mom in nursing home for two years

“You have to do things you don’t like. We sold the farm and used that money to pay for his care, but then it don’t last long when it is $3,000 a month. We’ve always taken care of ourselves and our family members, and I never wanted to feel like I should be a burden on the county, or state, or wherever it comes from. He is on Medical Assistance (Medicaid) now and that bothers me. I haven’t told him. I don’t think he would like it, we have always been people who wanted to be on our own feet.”
— Wife of husband with Parkinson’s

“We thought about Medicaid disbursement it doesn’t seem ethical. It’s Mother’s money, let’s use as much of it as we can to take care of her.”
— Son of mother in nursing home

Financial Control and Privacy. Maintaining control over financial resources and their use is frequently mentioned as an important goal. Some elders even avoid getting advice from local professionals in order to keep financial asset information private. Family members sometimes spoke of avoiding Medicaid for as long as possible so they could maintain control over care decisions.

Financial Security for Spouse. Families often find that maintaining quality care for the elder competes head on with the financial security of the elder’s spouse. Actions taken to protect the healthier spouse, if any, vary with the level of available assets, a spouse’s age and health, and comfort level with spousal allowances under Medicaid. For many families ensuring that the healthy spouse has a place to live and sufficient income for daily living are priorities. Trying to figure out how long one’s assets will last, when to cash in what to cover the bills, and how to protect the spouse is often too much for families to cope with at one time.

“Every time we have to dip into savings to pay for some of Dad’s care, it is a real concern to Mom that eventually she is not going to have anything.”
— Daughter of dad with dementia in nursing home
Protecting the Family Business. Assets involved in a business were often treated differently from household income and assets. If the elder generation was involved in a family business, such as farming, protecting the business so that it could be continued through the next generation of family members was often a critical goal.

How Are Care Needs Being Met?

Family Caregivers. Every family story included the key role that family members’ skills and resources played in keeping elders in their own home or apartment and independent for as long as possible. As other research has suggested and the families in this study confirmed, it is the private, informal resources of family members which provide most of the long-term care for elders. The number of years that family members kept an elder independent ranged from one to fifteen (Table 1). Families with an elder in a nursing home had provided a mean of almost six years of community-based caregiving, while those with elders still in the community had provided a mean of two and a half years of care. The “costs” for family caregivers—both direct and indirect—are numerous and typically go unmeasured and often unnoticed.

If there is a spouse, they are the likely primary caregiver regardless of gender or their own age. When there is no spouse, it is often a daughter or daughter-in-law who takes on the primary caregiving role. Most families have a system of multiple caregivers. Some family members specialize in certain tasks, whether it is helping out with daily living or transportation to a doctor.

Community Support. Community-based services play a key role in making family caregiving manageable. In almost all families with an elder currently in a nursing home, some type of community support prevented earlier placement in a nursing home (Table 1). Family members talk about the importance of having a range of options.

Table 1. The Context of Long Term Care

<table>
<thead>
<tr>
<th>Elder in Nursing Home (33 elders)</th>
<th>Elder in Community (12 elders)</th>
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</thead>
<tbody>
<tr>
<td><strong>Elder Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>87 years</td>
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<tr>
<td>Range:</td>
<td>73-99 years</td>
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<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female:</td>
<td>21</td>
</tr>
<tr>
<td>Male:</td>
<td>12</td>
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<tr>
<td>Marital Status</td>
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</tr>
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<td>Married:</td>
<td>13</td>
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<tr>
<td>Widowed:</td>
<td>17</td>
</tr>
<tr>
<td>Never Married:</td>
<td>3</td>
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<tr>
<td><strong>Long Term Care Received From:</strong></td>
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<tr>
<td>Family Caregiving (prior)</td>
<td></td>
</tr>
<tr>
<td>Mean/Family:</td>
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<tr>
<td>Range:</td>
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<td>Total Years:</td>
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<tr>
<td>Live With Daughter:</td>
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<td>Community Support (prior number who used)</td>
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<tr>
<td>Assisted Living:</td>
<td>8</td>
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<td>Formal Home Care:</td>
<td>4</td>
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<td>Day Care:</td>
<td>2</td>
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<tr>
<td>Respite Care:</td>
<td>1</td>
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<tr>
<td><strong>Nursing Home Stay</strong></td>
<td></td>
</tr>
<tr>
<td>Mean:</td>
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</tr>
<tr>
<td>Range:</td>
<td>1-156 months</td>
</tr>
<tr>
<td>Median:</td>
<td>24 months</td>
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available in the community which are both affordable and provide quality care. They also talk about doing without needed services because they are unavailable, or not affordable, or because the elder refuses help from outsiders.

Many families spend down resources while the elder is in the community. It is not uncommon for assets from the sale of the home to be used for assisted living, or being able to live in an apartment or condo with some arranged services and support. Costs such as dental and eye care, prescription drugs, or insulin are typically paid for out-of-pocket.

Most families talk about how confusing it is to try and understand the constantly changing eligibility rules, benefits, and payments of various government programs and private insurance. For many, the fragmented delivery and financing of long-term care is simply too much to absorb or understand without third party assistance, which costs even more.

Nursing Homes. A consistent and clear message from the families we interviewed was the desire to avoid nursing home placement. In reality, families often come to realize that nursing home placement may be the best way to meet the care needs of their elder. Feelings of guilt and failure for not having tried hard enough are commonly expressed by the caregivers, regardless of how overburdened or overloaded their role may have been. Caregivers continue to be intimately involved with the elder after placement in a nursing home. Daily visits are common for spouses as are frequent visits by adult children during the week.

Two of the families we interviewed had elders on a waiting list for a nursing home due to increasing care needs. Elders already in a nursing home were typically older, female, and widowed. Nursing home stays ranged from one month to thirteen years with a median stay of twenty-four months (Table 1).

Who is Paying for Nursing Home Care?

Of the thirty-three families in our sample with an elder in a nursing home, all but one had used family resources to pay for care during part or all of the stay (Table 2). Of the thirty-two who had entered as private pay patients, a majority (twenty-five) remained private pay while seven had spent down and qualified for Medicaid. Private pay stays ranged from one month to thirteen years with a mean of just over two years. In our sample the average family, then, had spent $75,000 on nursing home care with future costs still unpredictable. These expenditures followed the mean 5.85 years of informal caregiving and out-of-pocket payments for community support.

What About Medicaid Estate Planning?

Awareness of Medicaid and the financial support it provides for nursing home care varies. Most families hope they will not need nursing home care. Even when an elder is diagnosed with an incurable, debilitating disease and there are expectations of increasing care, a majority of families do not appear to be consciously planning how they will meet such needs beyond their own family resources.

Most families learn the details of Medicaid rules upon application to the nursing home and it is at that time that they begin to explore burial trusts and to specifically consider gift giving allowed under the guidelines. Some families learn about Medicaid through support groups or through friends. One of the families in our sample had “programmed Mom for Medicaid” by establishing a trust in which Mom’s assets will be inherited by an adult child. In this family, informal care and assisted living had been provided and paid for with family resources for more than eight years prior to needing nursing home care. The inheriting adult child is paying the extra amount for a private room.

Another of the families in our sample, with an elder already in the nursing home, had planned to apply for Medicaid after reserving $60,000 for nursing home care. Assets had been rearranged to provide financial security for the remaining spouse and some assets had been transferred to adult children with the expectation that these assets would be used for the frail spouse should the healthy spouse precede her in death. In this case, the Medicaid application was never filed as the frail spouse died after two months of private pay and seven years of intensive home care by the surviving spouse.

Of the seven families who spent down to become eligible for Medicaid, five did not mention any specific planning or divestment activities beyond a burial trust.

“She still doesn’t know she’s on Medicaid. It would break her heart.”
— Daughter of mother in nursing home who spent down private resources

“You see, we didn’t think it would turn out this way. I feel really bad...I don’t want my mother on the dole, I think that’s terrible, but what else are we going to do?”
— Daughter of mom in nursing home who spent down private resources

Of the three families currently in the Medicaid application stage, two had gifted $2,500-$8,000 to adult children with the expectation that those assets would be used to support the extra cost of a private room, which Medicaid does not cover. In both cases, these families had already spent over $100,000 on the elder’s care, not counting informal caregiving.

An overwhelming majority of families who were private pay had estimated the number of years for which they thought they could cover care before assets were depleted and had no intention of divesting assets to qualify for Medicaid. In other cases, transfers may have been made to adult children, but sufficient assets remained to pay for the elder’s care for many years, if needed.

Insight Into Planning

We interviewed sixty-five professionals in positions to offer advice or counsel to families. There was general agreement among them that most people are not planning far ahead for how they will pay for long term care. Many professionals said that people start thinking about how they will pay for long term care today and were doing so for a few years ago. They attribute this trend to two factors—the steep rise in nursing home costs and increasing media and community attention to planning options that are not explicitly forbidden by the law.

Families who are doing Medicaid estate planning are generally neither the very rich nor the very poor, according to the professionals. Many lawyers and financial planners told us they suggest to their clients who have assets in excess of about $400,000 (excluding their home) that they don’t need to transfer assets because the earnings on their investment in any year would be sufficient to cover the cost of their care. They assume that people are most concerned about protecting their assets—the principal—and that they will be com-
comfortable paying for their own care as long as they can do it out of their current income and not jeopardize their children’s future inheritance or their own nest egg.

**Decision-Making Realities**

In general, professionals find their clients have one of two philosophies—the “I lived through the Depression and I’ll pay my own way no matter what” philosophy or the “I’ve been a taxpayer all my life, I’m entitled to use government programs, and I’m determined to leave something for my kids” philosophy.

Nursing home costs are the long term care costs most feared by the elderly and their families. In Minnesota, they range from about $30,000 to $40,000 per year. To protect themselves, families are using a range of options, including various forms of trusts (revocable, irrevocable, living), prepaid burial, life estates, and “gifting programs” carefully designed to meet the letter of Medicaid law. Overall, the professionals we interviewed said life estates are the most commonly used transfer option. It is a way of ensuring that the home will pass on to their heirs rather than being sold to finance nursing home care.

Clients rarely purchase long term care insurance, though some lawyers and financial planners actively encourage them to. Others believe it is not a wise investment—the premiums are too expensive for the less wealthy, while the wealthy don’t really need it.

We observed some variations among the professionals in how they interpreted the law and Minnesota’s Medicaid rules. One Medicaid eligibility worker, for example, reported, “I view a client who is very helpful to their aged parents with more compassion... I may read the rules a little tighter” for those who appear to be more greedy and haven’t helped their elders out.

Professionals expressed varying degrees of comfort with current Medicaid law.

“I try and do what the law allows, even if sometimes it makes me grit my teeth... If it’s legal and it’s what they want to do, I’ll do it for them, even though it wouldn’t be my choice.”

—A rural Minnesota lawyer

“I don’t believe in giving away of assets.”

—A Medicaid eligibility worker in rural Minnesota

A Twin Cities financial planner made the point that current Medicaid law creates mixed incentives because it implicitly allows for asset transfer. “Is a financial planner doing wrong if they help individuals with assets play by the laws? Don’t blame professionals for doing their job—change the laws instead.”

While professionals generally approached their clients’ situations from a rational perspective, they viewed their clients’ decision-making processes as anything but rational.

“They like to talk about it [planning], but very little action is taken until the crisis is created. I wish I had a nickel for every time someone had come in and said, ‘Well, my husband just went in the nursing home. Now what do we do?’”

—A financial planner

“Most of the questions get asked by neighbors over coffee, or in the coffee shops... That’s where a lot of it starts... And that’s where the myths start too, and the horror stories get shared—over coffee. In fact, I’ve had calls in the middle of coffee. They’re sitting with somebody and one of them will get up and call me. ‘Is this true?’”

—A financial planner

Many of the professionals interviewed reported that it is common for people to come to them with the assumption that Medicare will pay for their long term care, though Medicare pays long term care costs only under very limited circumstances.

By the time an elder reaches the nursing home, families have often spent large amounts of time as well as income and assets. Nursing home care increases the costs to $30,000 to $40,000 a year.
insurance, and subsidized as well as unsubsidized community-based services all play their part. To improve the current long term care “system” will require at least four types of changes.

- **Simplify and Integrate.** The current delivery and financing “system” is too complex in terms of access, eligibility, paperwork, and being able to understand who pays for what. Family members and professionals are spending limited resources on just trying to understand options and consequences before they can make informed decisions. The current system is a major source of frustration for family members trying to provide quality care for an elder. Some families “decide not to decide” because they are overwhelmed, and many families must rely on a variety of professionals in order to understand their options. Professionals struggle to keep up with changing policies and rules, and sometimes offer different interpretations of what the options are.

- **Build Supportive Systems.** Family members are trying to provide quality care for their elders and keep them as independent as possible. To do so, they need access to a continuum of long term care services in a variety of settings. They clearly prefer community-based care, but equal access, affordability, and quality issues must be addressed if such services are to be fully used. Services which assist and support informal caregivers as well as the elder can play a critical role in extending family and therefore public resources. Subsidized adult day care, for example, allows an informal caregiver to provide unpaid care, keep an elder at home, and prevent what may be much more costly institutionalized care.

- **Keep the Safety Net.** There are limits to families’ availability and ability to pay. A continuum of quality community-based and nursing home care is essential to meet the needs of elders who are without social support or who have limited personal assets. The safety net needs to take into account the impact of eligibility criteria on both the elder’s care choices and the financial protection for a remaining spouse. Without an adequate safety net, violence will be unrelenting, caregivers will be overburdened, and spouses will be financially insecure. For some elders, Medicaid is a reasonable option.

- **Provide Clear and Consistent Messages.** Families and professionals consistently emphasize the need for policies that provide more givers. As one adult child in his forties said, “if they keep shifting the target around, what most people find is that you never put an arrow into your bow. In other words, don’t plan, don’t set anything aside, because they are going to shift it on you and there is no point of doing it.” The Minnesota legislature is currently considering changes to make it more difficult to dispose of assets and still retain eligibility for Medicaid. The discrepancy between what is considered legal and what is considered proper confuses both families and professionals. Consistent messages would reduce the fear and worry about the use of private and public funds. Myths about who pays continue and need to be replaced with a realistic understanding of financing options and potential consequences for elders and their families as well as for state and federal governments.

**Public Policy Implications**

The delivery and financing of long term care is a complex policy issue which continues to be addressed through legislation, regulation, and enforcement. The experiences of the family members and professionals we interviewed offer important insights for policymakers as the debate about long term care continues.

First, it is important to recognize that both public and private resources are needed. Families as well as various public programs are already spending significant amounts of their own resources. Resources being used by families include caregiving skills as well as income and assets. Policymakers need to consider how far family resources can be stretched before needs go unmet and elders as well as family caregivers are at risk.

Claims that a majority of families are divesting and voluntarily becoming poorer to qualify for Medicaid did not hold true for the families we interviewed. A few were divesting, and one in five in small amounts. Gifts were often given with the expectation that they would be used to cover expenses not covered by Medicaid. The meaning of divestment and transfer of assets varies among family members as well as among professionals. It is also important to remember that not everyone who divests will eventually use Medicaid.

It is essential to understand the use of both private and public, human and economic resources through the continuum of long term care options, from informal to formal care. To look at the use of resources in nursing homes, or in the community, or to ignore informal caregiving gives an incomplete picture of the total resources that are used and needed.

A systems approach is critical for understanding the true impact of long term care on families as well as on state and federal coffers. Transferring assets to qualify one’s spouse for Medicaid, for example, may provide the financial protection a younger, healthier spouse needs to stay off Medicaid or other government programs in the future. The complexity of the system comes partly from the number of income streams feeding into long term care. Social Security, private pensions, Medicare, long term care

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This article summarizes a larger study report on financing long term care by Stum and Brouwer which will be published by CURA later this year. Readers interested in receiving the full report may order a copy by calling CURA at 612/625-1551. The study was supported by an interactive research grant from CURA and the Office of the Vice President for Research, University of Minnesota. Interactive research grants have been created to encourage University faculty to carry out research projects that involve significant issues of public policy for the state and that include interaction with community groups, agencies, or organizations in Minnesota. These grants are available to regular faculty members at the University of Minnesota and are awarded annually on a competitive basis.