How Long-Term Care Services for Seniors are Currently Financed in Illinois

A “Map” of the Current Financing Structure

Prepared by the Finance Workgroup of the Illinois Older Adult Services Advisory Committee

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# How Public Long-Term Care Services for Older Adults are Funded in Illinois: A “Map” of the Current Financing Structure

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Finance Workgroup of the Illinois Older Adult Services Advisory Committee

How Public Long-Term Care Services for Older Adults are Funded in Illinois: A “Map” of the Current Financing Structure

Introduction

The Finance Workgroup of the Illinois Older Adult Services Advisory Committee (OASAC) was established to analyze the different financing options for reforming the long-term care system for older adults in Illinois. The first step in this analysis was to put together a comprehensive “map” of how the state’s long-term care system is currently financed; as it is essential to fully understand the system as it is presently structured before recommendations for reform can be made. Accordingly, the Finance Workgroup completed a broad review of how the primary publicly-funded long-term care programs and older adult services are funded in Illinois.

The map focuses on the key public long-term care “safety-net” services for older adults. Such programs include Medicaid long-term care facilities (nursing homes), Supportive Living Facilities, the Community Care Program, federal Older Americans Act Services and home health care. The Workgroup gathered cost, spending and enrollment data from the appropriate state agencies and industry groups; interviewed industry experts and agency staff; and researched the financing structure, administration, eligibility requirements and reimbursement rates of the core publicly-funded long-term care programs offered to older adults in Illinois. The study did not include a review of amounts spent on private-pay long-term care services.

The map includes analysis with a series of charts designed to show how the long-term care support system for older adults is funded in Illinois. The charts provide detailed information on financing issues such as comparisons of provider cost to provider reimbursement, comparison of enrollment trends by program and comparisons of enrollment and funding.

The data and analysis included in the map have been verified by the state agencies responsible for administering the long-term care programs and services studied. It is the Workgroup’s intent that this map will serve as a useful tool for the OASAC and its workgroups, as well as other lawmakers and advocates in designing good public policy with respect to the state’s long-term care system for older adults.

A special thanks is extended to Heather O’Donnell of the Center for Tax and Budget Accountability in gathering the necessary data and doing the analysis required for the map to be the most useful, and development of the numerous charts designed to complement the text. The Co-Chairs of the Finance Workgroup during the creation of the map were Pat Comstock, Stephanie Altman and Debbie Trueblood-Witt (former co-chair).

Overview of Who Pays for Long-Term Care for Older Adults

As individuals age, they often need assistance doing some of the basic daily tasks they once were able to do on their own. Long-term care services are designed to help older adults maintain their independence as they age while continuing to live in their home, or, if required, provide nursing home care during times of illness or injury, or for the remainder of life, if necessary. “Long-term care” generally means custodial “unskilled” care – that is, assistance with maintaining a home, errands, medication management, eating, dressing, bathing and other personal care tasks – as well as institutional nursing home care, but does not include basic health or acute care such as doctor visits, hospital stays or prescription drugs.
The overwhelming majority of older Americans are not prepared financially for long-term care when the need arises. According to the Congressional Budget Office, total public and private long-term care expenditures for the aging totaled $135 billion in 2004 alone.\(^1\) This amounts to $15,000 per affected adult for one year. Moreover, for the aging in need of more intensive long-term care, private nursing home care costs currently average about $70,000 annually.\(^2\) However, it is estimated that only a third of the aging have enough financial resources to pay for one year of nursing home care and another third do not even have enough to pay for one full month of such care.\(^3\)

Further, and contrary to conventional wisdom, Medicare, the public health insurance program for senior citizens, does not cover long-term care. While Medicare pays for short-term stays in skilled nursing facilities or home care services typically associated with post-acute care and rehabilitation, also known as “home health care,” Medicare coverage is otherwise limited to acute care services (doctor and hospital visits), and now, prescription drug costs. Simply put, Medicare does not pay for the kinds of long-term care support services many healthy older adults need as they age.

As a result, Medicaid – the federal-state health care program for low-income individuals and families – plays a vital role in providing basic long-term care services for older adults with little or no financial resources. While Medicaid is typically viewed by the general public as a program for low-income individuals, its role in financing long-term care for the aging who were once seen as middle-class is increasing due to the lack of financial means of most older adults to pay for basic long-term care when it becomes necessary.

As Chart 1A below shows, Medicaid paid for one-third of all long-term care expenditures for aging adults nationwide in 2004.\(^4\) Medicare covered 25 percent of long-term care that same year. However, this is misleading because it includes spending on Medicare home health care. Home health care is not “long-term” care, but rather, short-term, episodic care. It is intended to help rehabilitate an individual in their home or in a skilled nursing facility who has suffered a serious illness or injury. Generally, home health care costs are covered by Medicare only in special circumstances: If the senior is homebound, needs skilled nursing care – which is care that requires a licensed health professional – and needs only rehabilitative care. Medicare does not pay for 24-hour care in the home, nursing home care, or homemaker or personal care services for healthy aging adults needing some assistance with basic activities of daily living. While home health care plays a critical role in helping older adults recover from a devastating illness or injury, this analysis did not consider home health care as a “long-term” care support service. Accordingly, if Medicare home health care is not included as long-term care, Medicaid pays for nearly half – 47 percent – of all long-term care for the aging, as Chart 1B demonstrates.

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**Chart 1A: Spending on Long-Term Care, Including Medicare Home Health Care**

<table>
<thead>
<tr>
<th>Nationwide Spending on Long-Term Care for the Elderly, Including Medicare Home Health Care, 2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>Out-of-Pocket Payments</td>
</tr>
<tr>
<td>Private Insurance</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Medicaid</td>
</tr>
</tbody>
</table>

**Chart 1B: Spending on Long-Term Care Excluding Medicare Home Health Care**

<table>
<thead>
<tr>
<th>Nationwide Spending on Long-Term Care for the Aging, Excluding Medicare Home Health Care, 2004</th>
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</thead>
<tbody>
<tr>
<td>Out-of-Pocket Payments</td>
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<tr>
<td>Private Insurance</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Medicaid</td>
</tr>
</tbody>
</table>

Medicaid’s Role in Long-Term Care for Older Adults

Despite Medicaid’s ever-increasing role in providing long-term care to low-income older adults, rising health care costs – which are growing three times as fast as general inflation – are putting tremendous pressure on the federal government and states to contain Medicaid spending as all levels of government confront budgetary constraints. Aging individuals using long-term care services, while they make up only one-third of the Medicaid population nationwide, account for fully 86 percent of all Medicaid spending on older adults. The aging of the baby boom population over the next several decades – the Congressional Budget Office estimates that older adults will make up 20.5 percent of the population in 2040, up from 12.6 percent in 2000 – combined with limited private savings to pay for long-term care and longer life expectancies, indicate the increasing role Medicaid will play in financing long-term care for the aging in the coming decades. As a result, states, including Illinois, are re-evaluating how to administer long-term care for older adults with few financial resources in the most effective and efficient manner, in addition to responding to the needs and desires of the aging population.

Types of Long-Term Care Service Delivery Models

Long-term care is provided in two different types of settings: institutional care, which is provided in nursing homes and encompasses 24-hour nursing care, complex post-surgical medical care such as ventilator care, dialysis, wound care, intravenous drips, catheter and feeding tubes, and a full range of support services, as well as housing in a group setting that includes social interaction; and home- and community-based care, which provides older adults with the basic support services needed to allow the individual to remain independent and age at home. Historically, the bulk of public financing for long-term care has been directed to nursing home care until recent decades. To illustrate, in 1994, 81 percent of Medicaid long-term care spending was for institutional care. However, in response to demand for more options for home- and community-based long-term care services, many states, including Illinois, are examining their long-term care delivery systems. The main purpose of evaluating long-term care service delivery is to “re-balance” services in favor of a community-based care model, providing a continuum of care for older adults in need of long-term care services. Home- and community-based care services have increased to just over a third of total Medicaid long-term care spending in 2004, up from 19 percent a decade earlier. Nonetheless, states continue to wrestle with the most appropriate way to continue the shift in funding from an institutional care model to a community care model.

Illinois’ Publicly-Funded Long-Term Care Safety-Net for Older Adults

Generally, Medicaid services, including long-term care, are financed jointly by the federal government and the states. Medicaid is an entitlement program, which means the government must provide Medicaid health care benefits to everyone who is eligible for the program and enrolls, regardless of cost. In order to support open-ended costs, Medicaid is funded through a series of reimbursement mechanisms rather than government appropriations of a specific annual amount. To illustrate, when a health care provider treats a Medicaid recipient, the provider incurs the cost and then reports it to the state (the Medicaid recipient may contribute to the cost of his or her care through a co-payment, depending on the patient’s income level). The state then reimburses the provider the full amount based on state-set Medicaid reimbursement rates. As such, the public cost is initially borne by the state. In Illinois, the state dollars generally come from the state’s General Revenue Fund (GRF). The state then submits its Medicaid expenditures to the federal government, which reimburses a statutorily determined percentage of the state’s qualified Medicaid expenditures. The percentage of a state’s Medicaid expenditures the federal government covers depends on the state’s per capita income. Illinois’ federal Medicaid matching rate, which is technically called the Federal Medical Assistance Percentage, or FMAP rate, is 50 percent. This means the federal government reimburses Illinois for 50 percent of the state’s qualified Medicaid expenditures. Accordingly, after Illinois is reimbursed by the federal government for its Medicaid expenditures, the state and the federal government share equally in the cost of the state’s Medicaid program.
The federal Social Security Act sets out certain requirements that state Medicaid programs must meet in order for the state to receive federal Medicaid matching funds. With respect to long-term care, prior to 1981, only institutional care services were covered by Medicaid. Home- and community-based services (HCBS), on the other hand, generally were not Medicaid-covered services. In 1981, Congress enacted Section 1915(c) of the Social Security Act, allowing state Medicaid programs to provide home- and community-based long-term care services to individuals who require the level of care provided in institutional settings. In essence, Section 1915(c) allows the “waiver” of certain federal Medicaid requirements to cover HCBS in addition to institutional long-term care. As such, “Section 1915(c) waivers” allow states to receive federal Medicaid matching funds for HCBS as an alternative to institutional care. Most of the community-based long-term care services offered in Illinois are through Medicaid waiver programs. Like traditional Medicaid services, HCBS programs are paid for by Illinois’ Medicaid program with federal reimbursement of 50 percent of the state’s expenditures.

Illinois offers a host of programs for older adults in need of long-term care. The state’s long-term care safety-net consists of the following programs:

**Home- and Community-Based Programs**

- **Community Care Program (CCP).** CCP provides home- and community-based services to low-income older adults. CCP services include case management to determine the needs of the aging individual and what services are available to meet those needs; homemaker services, such as assistance with cleaning, laundry, shopping, errands, planning and preparing meals, and personal care tasks such as dressing, bathing and grooming; and adult day services. Emergency home response services were added in fiscal year 2007, but are not included in this analysis.

CCP is a Medicaid waiver program, meaning that the federal government and the state share in the cost of the program for services provided to Medicaid-eligible older adults enrolled in the Medicaid program. CCP eligibility is based on an individual’s assets, and is more generous than a traditional Medicaid waiver program, allowing older adults with up to $17,500 in assets to receive services.

Older adults meeting CCP program criteria but who are not enrolled in Medicaid are also eligible to receive CCP services. However, the state alone bears the full cost of CCP services provided to individuals not enrolled in Medicaid. The state currently requires potentially eligible older adults to apply for Medicaid but does not require Medicaid-eligible older adults receiving CCP services to be enrolled in Medicaid.

- **Older Americans Act (OAA) Services.** Services provided under the federal OAA are home- and community-based services. Under the OAA, older adults (aged 60 and older) are provided with (1) access services, such as case management, transportation, information and outreach; (2) in-home services, such as home-delivered meals, home health and respite; (3) community services, including congregate meals, health screening and legal assistance; (4) disease prevention and health promotion services, like medication management, health promotion programs and physical fitness programs; (5) caregiver services, such as information and assistance, counseling, training, support groups and respite; and (6) services for grandparents raising grandchildren, such as information and assistance, counseling, training, support groups and respite.

Any individual age 60 and older, regardless of income, and caregivers serving those individuals, are eligible to receive OAA services. OAA recipients are afforded the opportunity to contribute a cash donation to help pay for the services they receive.

The Older Americans Act provides for federal (non-Medicaid) funding for OAA services. The state, and local governments also contribute to the cost of services provided under the OAA.
Because these services are not Medicaid services, state spending for OAA services is not eligible for federal Medicaid matching funds.

- **Supportive Living Facilities (SLFs).** SLFs are assisted, apartment-style living facilities for low-income older adults. The program also provides personal and health-related services such as medication oversight, intermittent nursing care, personal care and other home services. The SLF program is covered under the state’s Medicaid waiver, meaning that the federal government reimburses Illinois 50 percent of its qualified SLF Medicaid expenditures. While private-pay older adults also live in SLFs, these residents cover their own costs.

**Institutional Care**

- **Nursing Home Care.** Medicaid-certified nursing homes provide low-income older adults with 24-hour nursing care; complex post-surgical medical care, such as ventilator care, dialysis, wound care, intravenous drips, catheter and feeding tubes; a full range of support services; and housing in a group setting that includes social interaction. All housing and living expenses are included as well as laundry and housekeeping services. Facilities are engaging in culture change initiatives making the facility more home-like and creating more resident choice in dining, activity programs and other enhanced living options, all contributing to increased quality of life. The federal government reimburses Illinois for 50 percent of its Medicaid nursing home expenditures.

This analysis of long-term care funding for the aging in Illinois includes only the programs listed above. There are other long-term care programs that play an important role in serving Illinois older adults, such as the Senior Help Line, the Program for All-Inclusive Care for the Elderly (PACE), the Elder Abuse and Neglect Program, and other programs and services administered by the Illinois Department on Aging. However, CCP, OAA services, SLFs, and Medicaid nursing home care are the core publicly-financed programs that make up Illinois’ long-term care safety-net for the aging, and therefore, are the focus of this analysis.

The primary long-term care programs for older adults are administered by the following state agencies:

1. Illinois Department of Healthcare and Family Services (HFS)
2. Illinois Department on Aging (DOA)

**How Public Long-Term Care Coverage for the Aging is Financed in Illinois**

In fiscal year 2005, Illinois spent a total of $1.4 billion on the primary long-term care programs for the aging listed above. As Chart 2 below illustrates, Medicaid (both state and federal funds) pays for the overwhelming majority – fully 85 percent – of these services.

As demonstrated by Chart 2, in fiscal year 2005, federal Medicaid dollars accounted for 42.5 percent of Illinois’ total Medicaid long-term care spending for the aging, while state Medicaid funds also accounted for 42.5 percent. As discussed above, Illinois generally pays for all Medicaid expenditures out of the state’s General Revenue Fund. Once these expenditures are approved at the federal level, the federal government then reimburses Illinois for 50 percent of such expenditures.

The Chart also shows that Illinois financed nearly 10 percent of long-term care spending for older adults with non-Medicaid dollars. The state does not receive federal matching funds on non-Medicare spending. The remaining 5.2 percent of long-term care spending came from federal (non-Medicare or Medicaid) funds and from local sources.
Chart 2: Public Funding Sources for Illinois’ Long-Term Care Safety-Net for Older Adults

Public Funding Sources for Nursing Home Care and HCBS for Older Adults in Illinois, FY2005

- Federal (non-Medicaid/Medicare), $50,077,691 (3.5%)
- Local, $23,958,619 (1.7%)
- State (non-Medicaid), $142,670,449 (9.8%)
- Federal Medicaid, $616,395,840 (42.5%)
- State Medicaid, $616,395,840 (42.5%)

Programs included: CDP, SLFs, OAAS and Nursing Home Care. Home Health Care is not included as a HCBC service.


Of all public funding sources for long-term care for older adults in Illinois, Medicaid funds fully 85% of such services.

Chart 3 below illustrates the trends in sources of financing for Illinois’ long-term care safety-net for older adults over the four year period between fiscal years 2002 and 2005. As shown, over the last four years Medicaid – which generally comes out of the state’s GRF – has financed between 83.6 percent and 86.7 percent of the state’s publicly-funded long-term care programs for older adults. The next most significant public funding source for long-term care for the aging in Illinois is non-Medicaid state General Revenue Funds. The GRF is the primary fund from which the state finances most public services. This funding stream went from a high of 11.6 percent in 2002, to a low of 9.8 percent in 2005. The chart seems to indicate that as the state has been able to increase Medicaid financing, drawing additional federal dollars to help fund long-term care services, it has been able to decrease other GRF long-term care funding. In essence, when the state is able to increase federal Medicaid funds, some of the state’s financial burden may be eased. On the flip side, when Medicaid funds decrease, other state sources are needed to fill in the funding gaps. While the study was unable to determine if there is a direct correlation between increased Medicaid funding and decreased non-Medicaid GRF spending, it is important to note this trend. The inverse relationship in funding steams is illustrated in 2005. That year, as Medicaid funding decreased by 1.5 percent, other state funding picked up the slack, increasing by 1.4 percent. While the percentage increase in non-Medicaid state funds may be small, it represented an additional $27 million the state spent in one year. Moreover, this increase in spending was done without federal Medicaid matching dollars that would help ease the state’s financial burden.
Medicaid is a reimbursement program. To trigger federal Medicaid matching funds, a state must expend some combination of state and local funds on Medicaid first. To illustrate, when a Medicaid recipient receives health or long-term care services, the provider incurs the cost, then requests reimbursement from the state. Once the state reimburses the provider, the state is then reimbursed by the federal government in an amount equal to that state's federal matching rate, multiplied by the state's actual qualified Medicaid expenditures from state and local sources. Illinois’ federal Medicaid matching rate is 50 percent, which means that the federal government reimburses the state for half of its Medicaid expenditures. The following chart illustrates how the funding system works:

**Chart 4: The Flow of Money in Medicaid Reimbursement**

It is important to note that states generally do not cover the full cost of the Medicaid services providers deliver. Rather, the state sets reimbursement rates for Medicaid services, and providers are generally paid less than the actual cost of service delivery.
Barriers to Enrolling in Medicaid: Estate Recovery for Long-Term Care Services

It is financially advantageous for Illinois to enroll older adults receiving publicly-funded long-term care services in Medicaid when they are eligible because the state receives federal Medicaid matching funds for eligible state expenditures, meaning that it is reimbursed by the federal government for 50 percent of its Medicaid expenditures; whereas, the state does not receive federal matching funds for other long-term care expenses it incurs. However, for individuals, there are significant deterrents to signing up for Medicaid-financed long-term care services. Because of increasing budget pressures and rising health care costs, in 1993, Congress began requiring states to implement “estate recovery” programs to recoup amounts spent on Medicaid services received once a person reaches age 55. For example, under Illinois’ estate recovery program, if an older adult is enrolled in a Medicaid long-term care program, the state must recover amounts spent for Medicaid long-term care services from the estate of the Medicaid recipient. This means the state is required to collect costs from assets in the estate, including a home. While a surviving spouse may retain and live in the home, the state is permitted to place a lien on the house and collect the money when it is sold.

Because of historic budget shortfalls, Illinois has focused more attention on its Medicaid estate recovery efforts in recent years. According to the U.S. Department of Health and Human Services, Illinois collected $21.3 million in estate recoveries in 2004, up from $17 million in 2002, or 25 percent. While estate recovery may be good fiscal policy, it may discourage older adults who are eligible for Medicaid to enroll because of the fear of losing assets they intended to leave to their children and grandchildren.

Home- and Community-Based Care versus Institutional Care in Illinois

In fiscal year 2005, Illinois’ publicly-financed long-term care system for aging adults consisted of institutional nursing home care and several programs that provide home- and community-based services. As Charts 5a and 5b below show, the state spent over $1 billion, amounting to nearly three-quarters of all long-term care funding for older adults, on nursing home care. The remaining 25 percent of long-term care dollars for the aging were spent on the three primary community long-term care services: Supportive Living Facilities ($31.3 million), the Community Care Program ($251.7 million) and services provided under the federal Older Americans Act ($88.2 million), for total spending on home- and community based services totaling $371.2 million.

Charts 5a and 5b: Illinois’ Long-Term Care Programs for Older Adults
While the state spends the lion’s share of elder long-term care funding on institutional care, such spending covers only 6.2 percent of all older adults in Illinois’ public long-term care system, as Chart 6 below demonstrates. Average annual Medicaid per-person spending on nursing home care for older adults in Illinois is $26,385.

Alternatively, the two primary programs which offer home and community long-term care services to aging adults are CCP and OAA. Combined, these two programs serve 93.4 percent of older adults in the Illinois public long-term care system, but comprise only 23.5 percent of all senior long-term care spending. For fiscal year 2005, the average annual amount spent per-person in CCP was $6,145, while the average annual amount spent per-person for services provided under the Older Americans Act was $153.

Spending for Supportive Living Facilities totals only 2.2 percent of all public long-term care spending for aging older adults and serves a very small percentage – 0.4 percent – of Illinois older adults receiving long-term care from the state. While SLF spending per-person is higher than CCP – approximately $11,682 annually per enrollee – this is less than half the spending of per-person nursing home care. Recognizing the benefit of SLFs – both financially and in serving the long-term care needs of older adults – the state has been rapidly expanding the relatively new program.

As illustrated, public spending on nursing home care far exceeds state spending on community-based long-term care services. That said, a comparison of program spending alone does not paint an accurate picture. One reason for the difference in spending levels between community and institutional care is that the level of care often required by nursing home residents is far greater than the level of care required for older adults who are able to remain at home with the help of support services. For instance, nursing homes provide around-the-clock direct care for residents with severe functional and cognitive deficits, whereas community-based services are provided only a few hours of the day or throughout the week for older adults able to live on their own. On the other hand, there may be some older adults living in Illinois Medicaid nursing homes who are able, and wish, to move back to their community, with the support of community-based long-term care services, but simply are not able to afford the costs associated with returning – housing costs being the principal barrier.

While Illinois is rebalancing its long-term care system in favor of offering more community-based options, it is important to note that the cost of caring for many aging nursing home residents may not be any less if they were moved to the community because of the level of care they require. In addition, for many nursing home residents, there may not be an alternative to institutional care, again, because of their needs.

**Chart 6: Long-Term Care Spending Compared to the Number of Older Adults Served**

<table>
<thead>
<tr>
<th>Program</th>
<th>Percentage of Older Adults Served</th>
<th>Annual Spending Compared to the Number of Persons Served for Illinois’ Major Long-Term Care Programs for Older Adults, FY2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing Home Care</td>
<td>0.2% (40,051)</td>
<td>0.2% ($88.2M)</td>
</tr>
<tr>
<td>Community Care Program</td>
<td>6.2% (40,800)</td>
<td>6.2% ($1,078M)</td>
</tr>
<tr>
<td>Supportive Living Facilities, 0.4%</td>
<td>(2,680)</td>
<td>2.2% ($31.3M)</td>
</tr>
<tr>
<td>Older Americans Act Services</td>
<td>47.2% (575,000)</td>
<td>17.4% ($251.7M)</td>
</tr>
<tr>
<td>Older Americans Act Services</td>
<td>6.1% (482,240)</td>
<td>2.2% ($31.3M)</td>
</tr>
</tbody>
</table>

Note: The total number of older adults served by the LTC system may be duplicated due to some program overlap. Data Sources: Illinois Department of Healthcare and Family Services, Illinois Department on Aging.
Specific Funding Streams Support Specific Long-Term Care Programs

In Illinois, as in many states, long-term care for older adults is currently structured so that specific funding streams are required to be used only for certain programs or services. Illinois’ long-term care financing does not permit consumer direction of long-term care public funds, but rather, requires that funds appropriated for institutional care may be used only for such care, while funds appropriated for community-based long-term care programs may only be used for those specific programs. Simply put, there is not one long-term care budget or fund that allows for public dollars to be spent according to the desire of the recipient to receive either community-based, or institutional, care when the need for state-financed long-term care arises. This type of global long-term care financing is called “Money Follows the Person” (MFP). MFP budgeting allows public long-term care funds to be used either for institutional care or community-care, depending on the individual’s needs and their desire to remain in their home.

It is important to note that Illinois recently applied for a federal MFP demonstration grant from the Centers for Medicare and Medicaid Services, which would allow the state to capture enhanced federal matching funds for specific services provided to individuals transitioning from nursing facilities to qualified residential settings.

Under the current long-term care financing system in Illinois, if an older adult in one long-term care program develops more extensive needs that the program can no longer meet, the public funds being used to pay for those services cannot be applied to a different program that would meet the individual’s needs. This is because the state budgeting system does not permit funds appropriated for one program to be used for another. Moreover, if the individual qualifies for one program, but not another, due for example, to income level, the individual will be required to pay for additional long-term care services from their own resources. For instance, if an older adult who does not qualify for Medicaid but receives CCP services needs more services than the program offers, the individual will either have to go without those services, pay for the additional services out of their own pocket, or wait until their financial resources are nearly exhausted until they qualify for Medicaid nursing home care. The rigid funding structure also works in reverse – prohibiting the use of amounts appropriated for Medicaid nursing home services to be applied to home-based services if an older adult wishes, and is able, to move back to their home after a period of institutional care. Under the current budgeting system, public funds used to pay for the older adult’s nursing home care cannot be applied to community-based care costs. Simply put, by appropriating state funds to specific programs rather than a global long-term care budget, some older adults in need of public long-term care may qualify for one program or service but not others, and may be relegated to one type of long-term care setting despite the desire – and level of care required – instead of another.

Chart 7 below illustrates the funding source for the major long-term care programs for older adults in Illinois. Three of the long-term care programs – Supportive Living Facilities, Medicaid nursing home care and the Community Care Program – are partially funded by Medicaid. Because Medicaid is a reimbursement program, this means that long-term care service providers, such as nursing home facilities, provide services to eligible older adults and are then reimbursed by the state. The federal government then reimburses the state 50 percent of its Medicaid expenditures. The federal government does not reimburse the state for non-Medicaid expenditures.

Illinois also spends state GRF (non-Medicaid) funds on CCP services provided to older adults who are not eligible for Medicaid or for those who are Medicaid-eligible, but are not enrolled. The state does not receive federal matching dollars for such spending. It is important to note that there are aging adults in the CCP program who are eligible for Medicaid but are not enrolled. While the data was not available to estimate the amount of state CCP funds that could qualify for federal Medicaid matching dollars if Medicaid-eligible older adults were enrolled as Medicaid beneficiaries, it is clear that the state is missing out on available federal funds that would help pay for the services provided to those individuals. As a result, the state is covering 100 percent of the service costs for these older adults, when, in fact, the state could receive federal Medicaid reimbursement if these individuals were eligible and enrolled in the Medicaid program.

On the other hand and as mentioned above, it is important to recognize that there are some disincentives to enrolling in Medicaid, such as estate recovery efforts and a perceived stigma associated with receiving public
assistance. For example, some Medicaid-eligible older adults receiving CCP services may not complete the Medicaid enrollment process despite the Department’s efforts to encourage them to do so. In addition, when older clients are applying for Medicaid, often for the first time in their lives, they may feel that applying for public benefits stigmatizes them and they may feel overwhelmed by the local application procedures.

Federal funding for OAA services is appropriated under the Older Americans Act, and is separate and apart from Medicaid funds, as Chart 7 shows. The state, as well as local governments, also contribute to OAA services. However, because these services are not covered under Illinois’ Medicaid waiver, the state is not permitted to receive federal Medicaid matching funds on state spending for these services.

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**Chart 7: Older Adult Long-Term Care Funding Streams**

- **Federal Medicaid**
  - The state is not eligible for federal Medicaid reimbursement for CCP Medicaid-eligible enrollees who do not sign up for Medicaid, requiring the state to cover 100% of the cost of covering services to these older adults.

- **Federal Non-Medicaid**
  - Services provided under the OAA are not eligible for funding through the Medicaid program.

- **State Medicaid (GRF)**
  - The state pays for services provided and is then reimbursed by the federal government for 50% of the state’s expenditures. The state pays providers of the different types of LTC services different reimbursement rates. Provider reimbursements generally do not cover the full cost of providing the service.

- **State GRF (Non-Medicaid)**

- **Local**

- **SLFs**
  - Eligibility is based on income and asset levels, and need
  - Administered by HFS
  - Assisted living and housing; intermittent nursing care; personal services

- **NHs**

- **CCP**
  - Eligibility depends on income and asset levels, and need
  - Administered by HFS
  - Direct and nursing care; support services; housing

- **OAAS**
  - All older adults are eligible
  - Administered by DOA
  - Case management, home-delivered and congregate meals, and other services

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Illinois’ Long-Term Care Programs for Older Adults

Institutional Care

Institutional Nursing Home Care

Illinois’ Medicaid program pays for nursing home care for low-income older adults in need of such care. An older adult determined in need of nursing home care qualifies for Medicaid-financed care if he or she has an annual income below a certain level, which is tied to the federal poverty level. However, living and transportation expenses are protected for a spouse. Additionally, the individual must own very few assets. The services provided in Medicaid institutional facilities include 24-hour nursing care; complex post-surgical medical care such as ventilator care, dialysis, wound care, intravenous drips, catheter and feeding tubes; a full range of support services; and housing in a group setting that includes social interaction. Other medical care, such as doctor or hospital visits, or prescription drugs, is not included in the cost of nursing home care. The Illinois Department of Healthcare and Family Services administers Medicaid-financed nursing home care for aging state residents.

As Charts 8a and 8b below show, Illinois’ Medicaid program paid for nursing home care for the full-time occupancy equivalent of 40,865 low-income aging individuals in fiscal year 2005. However, the number of older adults served by state Medicaid nursing homes decreased by 2,885 individuals since 2003. Despite the decline in the number of individuals in Medicaid nursing homes, spending increased slightly for the three years between fiscal year 2003 and 2005 – going from $1.058 billion in 2003, to $1.078 billion in 2005, an increase of $19.8 million, or 1.9 percent. However, spending in 2005 did not reach the level of Medicaid nursing home spending in 2002. In 2002, the state spent $1.115 billion on long-term institutional care, $36.3 million more than it spent in fiscal year 2005. In 2003, the state cut nursing home spending 5.9 percent. The increase in spending between 2003 and 2005 was driven by nursing home rate restorations and a new measure recognizing increased liability insurance costs. A rate increase of 3 percent was effective in July of 2004, and another increase was effective in January of 2005. In addition, increased utilization may also be a factor in the increase in spending levels.

The direct care component of institutional care represents 50 percent of what the state reimburses for the services provided. Moreover, also contributing to the high cost of nursing home care are housing costs (e.g., mortgage, utilities, etc.). This represents approximately 12 percent of Medicaid reimbursement. The remaining 38 percent of what Medicaid nursing home providers are reimbursed by the state is used for support services, such as housekeeping, laundry, and meals. These support services are similar to the types of services provided to older adults receiving community-based long-term care services.

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What the government reimburses nursing home providers is very different from what it actually costs to care for nursing home residents. Historically, Medicaid has paid health care providers low reimbursement rates for services provided when compared to the actual cost of performing the services. While the federal government and the states share in the cost of financing the Medicaid program, states are responsible for setting provider reimbursement rates for Medicaid services delivered. Low reimbursement rates have simply been one way to hold down public health care costs under increasing budget pressures at every level of government. Illinois is no exception.

Chart 9 below highlights that Medicaid spending does not cover the full cost of providing nursing home care to low-income older Illinois residents. According to the nursing home industry, Illinois currently reimburses Medicaid nursing home providers for the aging only 78 percent of the actual cost of providing care. The providers are then required to make up the difference between what Medicaid reimburses them and what the actual cost of service delivery is. The difference between Medicaid reimbursement rates and provider cost is often referred to as the “Medicaid shortfall.” Below-cost Medicaid reimbursement often causes nursing homes with a significant number of Medicaid residents to cost-shift, thereby charging private-pay residents higher rates to make up the difference in the Medicaid shortfall. The nursing home Medicaid shortfall in fiscal year 2005 totaled $237 million, or fully 15 percent of the total amount spent on Medicaid nursing home care by the state, nursing home providers and the residents, as Chart 9 shows.

Some low-income nursing home residents contribute to the cost of their care, depending on their income level. The resident’s contribution generally comes from their social security benefits and other income. In fiscal year 2005, low-income, aging Medicaid nursing home residents contributed $280 million to the cost of their care, or 18 percent of the total cost of their care, as indicated in the chart below.

**Chart 9: Actual Cost of Medicaid Nursing Home Care for Older Adults in Illinois**

<table>
<thead>
<tr>
<th>Component</th>
<th>Amount</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Federal Medicaid</td>
<td>$539.1M</td>
<td>33%</td>
</tr>
<tr>
<td>State Medicaid</td>
<td>$539.1M</td>
<td>34%</td>
</tr>
<tr>
<td>Medicaid Shortfall</td>
<td>$237.2M</td>
<td>15%</td>
</tr>
<tr>
<td>Client Contribution/Third Party Payers</td>
<td>$280.0M</td>
<td>18%</td>
</tr>
<tr>
<td>Actual Total Cost of Care</td>
<td>$1.6 billion</td>
<td></td>
</tr>
</tbody>
</table>

Data Sources: Illinois Department of Healthcare and Family Services for Medicaid liabilities and third party payer data; Illinois Health Care Association for the Medicaid shortfall (the amount by which Medicaid costs exceed provider reimbursement).
Home- and Community-Based Long-Term Care Programs

The Community Care Program

The primary program through which Illinois offers home- and community-based long-term care services to the aging is the Community Care Program. CCP is a Medicaid waiver program, meaning the state and federal government share equally in the cost of providing CCP services to low-income older adults who qualify and enroll in Medicaid. For aging adults who either are not eligible for Medicaid, or are Medicaid-eligible but do not apply for the program, the state bears the full cost of providing CCP services.

An aging adult is eligible to receive CCP services if he or she is at least 60 years of age, has no more than $17,500 in non-exempt assets, and is determined in need of long-term care services. The individual’s financial responsibility in the form of a co-pay for services received depends on income level. The state bears the remaining cost, with federal reimbursement for expenditures for Medicaid enrollees.

Administered by the Illinois Department on Aging, CCP provides older adults with case management services to help them determine what their specific needs are and what services are available to meet those needs; home services such as assistance with cleaning, laundry, shopping, errands, preparing and planning meals and personal care tasks such as dressing, bathing and grooming; and adult day services. However, the homemaker service is the core component of the CCP program. This service accounted for fully 84 percent of program spending in fiscal year 2005.

Charts 10a and 10b below illustrate CCP annual spending in Illinois and the number of older adults receiving CCP services between fiscal years 2002 and 2005. Showing a commitment to expanding community-based long-term care services for the aging, the state increased CCP spending by $41.4 million, or 19.7 percent over the four year period. During this time, enrollment increased by 1,611 individuals, or 4.1 percent. Average annual spending per CCP enrollee in 2005 was $6,145. In addition, in fiscal year 2007, the state expanded CCP services to include emergency home response as a core service and funding to allow for home modifications, such as wheelchair ramps, grab bars and other home improvements to further prevent aging older adults from turning to premature nursing home entry due to gaps in community-based long-term care services.

Charts 10a and 10b: Annual CCP Spending and Older Adults Served

Chart 11 below shows that Medicaid (GRF) pays for just under half — 48 percent — of CCP program spending, while the state non-Medicaid GRF spending covers the other half. For non-Medicaid state spending, Illinois does not receive federal Medicaid dollars. Accordingly, the state is losing federal Medicaid dollars on services provided to Medicaid-eligible CCP enrollees. If the Department on Aging were able to enroll these individuals in Medicaid, the
state would bear only half the cost of serving these adults. Again, it is important to recognize that no matter how hard the Department works to enroll Medicaid-eligible CCP recipients in Medicaid, some will choose not enroll simply because of the estate recovery rules discussed above. The DOA does not have data on how many CCP recipients are Medicaid-eligible but are not enrolled in the Medicaid program. Therefore, no estimate could be made on how much the state would save if it received federal reimbursement for Medicaid-eligible CCP recipients.

The DOA, which administers CCP, does not have data on the actual cost to the agency of providing program services. Rather, the Department only tracks expenditures. Therefore, it was not possible to determine if federal and state financing covers the actual program costs.

**Chart 11: CCP Program Spending by Source**

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Federal Medicaid</td>
<td>$61.6M</td>
<td>24%</td>
</tr>
<tr>
<td>State Medicaid</td>
<td>$61.6M</td>
<td>24%</td>
</tr>
<tr>
<td>Client Contribution/Third Party Payers</td>
<td>$4.4M</td>
<td>2%</td>
</tr>
<tr>
<td>State GRF (Non-Medicaid)</td>
<td>$128.5M</td>
<td>50%</td>
</tr>
<tr>
<td>State Medicaid</td>
<td>$61.6M</td>
<td>24%</td>
</tr>
</tbody>
</table>

Data Source: Illinois Department on Aging. The Department is not required to do cost-based reporting; therefore, actual program cost data was not available. As such, the Medicaid shortfall could not be determined.

Note: "Client Contributions" are amounts collectible from program recipients. However, the state is not able to collect all amounts due. Accordingly, the state does not receive the full $4.4 million to spend toward the CCP Program. Rather, this represents the total amount it would receive if it were able to collect all amounts due from enrollees.

It is important to note that CCP client contributions shown in Chart 11 above are amounts *collectible, but not necessarily collected*, from program enrollees. The state is simply not able to collect all such amounts due. Accordingly, Illinois does not receive the full $4.4 million shown in Chart 11 to spend toward the program. Rather, this amount represents the total amount it would receive if it were able to collect all amounts due from enrollees.

**Services Provided to Older Adults under the Federal Older Americans Act**

Under the federal Older Americans Act, which was enacted in 1965, aging adults of any income level are eligible to receive long-term care services. The services provided under the OAA are wide-ranging and include case management, transportation, adult day services, homemaker services, home health, respite, legal assistance, counseling, congregate meals, medication management, elder rights protection and other senior services. However, the core OAA services are home-delivered and congregate meals, which account for nearly two-thirds of total program spending.

OAA services are administered by the Illinois Department on Aging through the 13 Area Agencies on Aging (AAAs). Pursuant to the OAA, Illinois has divided the state into 13 regions, called Planning Service Areas, and each region has a AAA. Each AAA is responsible for planning, coordinating and advocating for a comprehensive and coordinated system of services for the aging within their Planning and Service Area.
As Charts 12a and 12b indicate, OAA services reached 575,000 older adults in fiscal year 2005. The vast majority of these older adults are served by the local service providers who receive grants and contracts from their regional AAA. The AAA and the local service provider assist in linking older adults to needed services in their community. Between 2002 and 2005, the number of older adults assisted by OAA services increased by 43,164 individuals, or 8.1 percent. During this same period, funding rose from $81.8 million to $88.2 million, an increase of 7.8 percent. OAA spending per program enrollee averaged $153 for fiscal year 2005, the same amount spent per enrollee in 2002.

Charts 12a and 12b: Spending and the Number of Older Adults Served under the Federal Older Americans Act

Older Americans Act services are funded primarily from federal OAA funds allocated to the state. As shown below in Chart 13, in fiscal year 2005, half of all funds supporting OAA services were federal dollars. State GRF spending represented 14 percent of all OAA spending. OAA state spending is non-Medicaid state spending and is therefore not eligible to draw federal Medicaid matching funds. A significant amount of local funds also contribute to OAA services. In fiscal year 2005, local funds equaled nearly a quarter of all OAA spending in Illinois. In addition, older adults receiving OAA services contribute to 12 percent of overall OAA spending. Data was not available to determine the actual cost of providing OAA services, as compared to public spending.

Chart 13: Older Americans Act Services: Program Spending Sources, Fiscal Year 2005

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The Community Care Program and services provided under the federal Older Americans Act are the two primary programs through which aging Illinois residents receive home- and community-based long-term care services. In fiscal year 2005, the state spent $340 million on both programs. It is important to highlight that while OAA services and CCP are community-based programs, each provides different types of long-term care services needed by the aging who desire to remain at home but need some assistance with activities of daily living. For instance, the hallmark of CCP is that it provides homemaker services to the aging. The main OAA services, on the other hand, are home-delivered and congregate meals, and transportation assistance. Homemaker services represent less than one percent of OAA spending. Therefore, there is little program overlap between CCP and services provided under the OAA.

**Supportive Living Facilities**

Medicaid Supportive Living Facilities are assisted living facilities for low-income older adults in Illinois. Administered by the Illinois Department of Healthcare and Family Services, SLFs offer apartment-style housing, health-related services, intermittent nursing care, personal care, medication oversight, and homemaker services to residents. For residents enrolled in Medicaid, the state and federal government share in the cost of the program, with the federal government reimbursing Illinois for 50 percent of its eligible SLF expenditures. SLF Medicaid residents are responsible for paying for the cost of room and board, while Medicaid pays for the covered services. The amount of a resident’s contribution is based on income. Residents not enrolled in Medicaid cover all their own costs.

SLFs are an alternative to nursing home care and allow aging individuals to live independently and take part in daily decision-making. Older adults receiving CCP services are not eligible to participate in the SLF program.


Charts 14a and 14b below show SLF annual Medicaid spending and the number of Medicaid residents between fiscal years 2002 and 2005. SLF spending increased 848 percent over this period, going from $3.3 million in 2002, to $31.3 million in 2005. The number of SLF Medicaid residents increased at nearly the same rate, going from 315 older adults in 2002, to 2,680 in 2005. This trend illustrates not only the demand for more community-based long-term care services over traditional nursing home care, but Illinois’ commitment to providing older adults with alternatives to institutional care.
Fully 83 percent of spending on SLFs for Medicaid residents comes from both the state and federal government, as Chart 15 below demonstrates. Illinois is reimbursed by the federal government for 50 percent of its expenditures for SLF Medicaid residents. These residents also contribute to 17 percent of total program spending. Because SLFs are a relatively new program in Illinois, data on the Medicaid reimbursement rate paid to SLF providers as a percentage of cost was not available. Therefore, this analysis was not able to determine whether a Medicaid shortfall exists.

For older adults who are either not able to continue maintaining their own home, or need more support services than CCP and OAA offer, but do not need the level of care provided in a nursing home, SLFs are a good alternative. However, for long-term care provided outside an individual’s traditional home, the state spends far more on institutional care than Supportive Living Facilities, as Chart 16 below indicates. For residential long-term care alternatives outside an individual’s home, Illinois spent nearly 94 percent of residential long-term care on

Data Source: Illinois Department of Healthcare and Family Services. Medicaid spending is based on program liabilities. Because SLFs are a new state program, provider cost data was not available. As such, the Medicaid shortfall could not be determined.
nursing home care and only 6 percent on SLFs. However, the state has recognized the benefits of SLFs through its rapidly increasing annual investment in the program.

![Chart 16: Public Funds Directed to Older Adult Long-Term Care Residential Settings Outside the Home](image)

**Chart 16: Public Funds Directed to Older Adult Long-Term Care Residential Settings Outside the Home**

Publicly-Funded Residential Settings Outside the Home for Older Adults in Illinois’ Long-Term Care System, FY2005

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing Homes</td>
<td>93.8%</td>
</tr>
<tr>
<td>Supportive Living Facilities</td>
<td>6.2%</td>
</tr>
</tbody>
</table>


**Publicly-Funded Home Health Care in Illinois**

Although home health care was not designed to be “long-term” care, it nevertheless plays a vital role for aging individuals who need rehabilitative care following a serious illness or injury. Publicly-funded home health care coverage is primarily provided through Medicare. However, Medicaid also pays for such care. Home health care offers “skilled” nursing, which requires care by a licensed health professional, either at home or in a skilled nursing facility, for assistance in recovering from an illness or injury. For example, an aging individual may need home health care in order to recover from a broken hip. Medicare generally does not pay for home health care for longer than 60-day episodes. Home health care does not pay for nursing home care, 24-hour home care, or custodial support services, such as assistance with maintaining a home, meal preparation or personal care tasks (bathing, dressing, etc.).

As Chart 17 below indicates, if home health care is considered part of the long-term care safety-net for aging individuals in Illinois, it makes up 60 percent of all home- and community-based long-term care spending on older adults throughout the state. However, it is important to note that once an individual has recovered from the illness or injury to which the home health care relates, if they need additional care, they must turn to other long-term care programs or services for assistance.
As Chart 18 below reveals, Medicare pays for fully 99.5 percent of all public funds spent on home health care for older adults. Medicaid pays for the remaining 0.5 percent of public coverage. Medicare generally covers the actual cost of providing health care services. Accordingly, there is no home health care Medicare shortfall. Medicaid, however, pays less than Medicare for most services and generally does not cover the actual cost of providing services. The home health Medicaid shortfall for fiscal year 2005 was $1.2 million, meaning that private providers subsidized this amount. Home health care patients pay for one third of their home health care costs, either from their own financial resources, or through private insurance as the chart demonstrates.
Charts 19a and 19b below show home health care spending trends and older adults served annually between fiscal year 2002 and 2005. Public home health care spending increased from $411.1 million in 2002, to $566.9 million in 2005, an increase of 38 percent. During the same period, the number of older adults served increased by 25,710 individuals, or 22 percent.

Charts 19a and 19b: Illinois Home Health Care: Annual Spending and Older Adults Served
Data Sources

All public program data was obtained from the state agency charged with administrating the long-term care service. “Program liabilities” were used to measure state spending rather than state expenditures. Program liabilities are the amounts incurred for services actually provided within a fiscal year. Tracking the total liability amount for a fiscal year eliminates the possibility of counting the unpaid, deferred obligations left over from the prior year.
Endnotes

3 Id.
5 Kaiser Commission on Medicaid and the Uninsured.
7 Id., CBO.
8 Kaiser, Id.
9 Id.
10 42 U.S.C. § 1396d(b).
15 The full-time occupancy equivalent is derived by summing the lengths of stay for all recipients and dividing by 365 days per year.
16 Illinois Health Care Association.
How Long-Term Care Services for Seniors are Currently Financed in Illinois

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