



State of Illinois
Pat Quinn, Governor

Illinois Department on Aging
Charles D. Johnson, Director

Determination of Need, Service Cost Maximum Study

Prepared by:
Health and Medicine Policy Research Group
Center for Long-Term Care Reform

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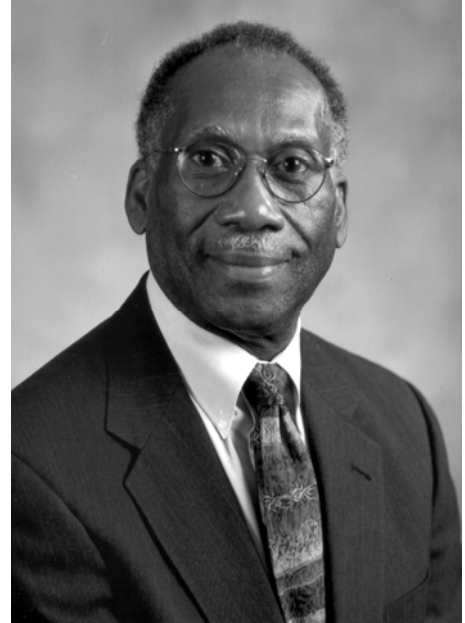
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Illinois Department
on Aging

Message from Director Charles D. Johnson

The Department on Aging is pleased to submit this report to the Illinois General Assembly as required under Public Act 95-565. This Act requires the Department, in part, to ensure that the Determination of Need (DON) instrument is accurate in determining the participants' level of need for the Community Care Program (CCP). The Department engaged in agreements with the Health and Medicine Policy Research Group and the University of Illinois Chicago to undertake this study. This study combined a quantitative analysis of the relationships between DON scores and client needs and a policy analysis looking back at the evolution of CCP and forward based on best-practices from six states: Arizona, Minnesota, Ohio, Vermont, Washington and Wisconsin.



The Determination of Need Study provides the first thorough external statistical analysis of the Community Care Program in more than a decade. The data will be useful for the General Assembly, legislative staff, researchers, academics, and advocates concerned about the efficacy, efficiency, and value of the program. Given that demand for state-supported home and community-based services is growing rapidly, the Department hopes that this analysis will inform the debate and help the state make informed choices about the future direction of this program.

The Department is grateful for the enthusiastic support for the study by the House Chief sponsor, Representative Sara Feigenholtz, the chief Senate sponsor, Senator John J. Cullerton, the bill's other sponsors, and the entire General Assembly for its vote on this and continuing support for the Community Care Program. The Department also acknowledges the efforts of Jane Addams Senior Caucus and other advocates whose concerns and interests led to the passage of this legislation. The Department expresses its appreciation to the Older Adult Services Advisory Committee for reviewing the preliminary findings and helping to refine the final analysis and recommendations.

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Health and Medicine Policy Research Group

Health and Medicine has more than 25 years of experience as an independent, not-for-profit policy center evaluating local and state health policy, with a special interest in the health of the poor and underserved. The policy group's two key tasks are to promote dialogue on health reform across the continuum of care among diverse constituencies and to interpret the needs of the state, city and county for health systems change. Health and Medicine not only contributes to local policy development, it also shares the lessons of the Illinois health system with national health policy makers through public testimony, meeting presentations, and comment. In 2001, Health and Medicine created its Center for Long-Term Care Reform to promote balancing Illinois' long-term care system in favor of home and community-based care.

Through its Center for Long-Term Care Reform, Health and Medicine has been intimately involved in the state's LTC reform process. The Center initiated legislative study groups in 2001, when the issue of LTC reform was just appearing in Illinois. It implemented community forums to define issues and trigger interest in LTC reform, conducted research in support of rebalancing, and participated in, and provided leadership for, the state's Older Adult Services Advisory Committee.

Thus, Health and Medicine has an established history of working with and supporting the Illinois Department on Aging in the reform process. It's committed to continuing to provide the support needed to enhance the Department's capacity to implement a well-designed, comprehensive, and responsive home and community-based LTC system in Illinois.

**Center for Research on Health and Aging
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The Center for Research on Health and Aging (CRHA) at the University of Illinois at Chicago was established in 1997. CRHA is co-directed by Susan L. Hughes, DSW, and Thomas R. Prohaska, PhD, who are joined by 14 other faculty/researchers across the University. The Center conducts rigorous applied research on health issues for older adults, including prevention, health maintenance, cost, quality, and effectiveness of health care delivery systems such as long-term care and managed care. CRHA provides consultation and service to the community, Illinois and nationally.

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Disclaimer

The authors are grateful to the state contacts for providing invaluable information for this report. Every effort has been made to provide accurate information on individual state long-term care systems. Any remaining errors are the sole responsibility of the authors.

Phyllis B. Mitzen and Rebecca Finer, Center for Long-Term Care Reform

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Executive Summary

The Determination of Need/Service Cost Maximum Study responds to Illinois Public Act 95-565, which directed the Illinois Department on Aging (IDoA) to ensure that the “determination of need (DON) tool is accurate in determining the participants’ level of need; to achieve this, the Department, in conjunction with the Older Adult Services Advisory Committee, shall institute a study of the relationship between the Determination of Need scores, level of need, Service Cost Maximums and the development and utilization of service plans ... and recommendations shall include all needed changes to the Service Cost Maximums schedule and additional covered services.” In addition, the Department on Aging must address legislative initiatives to expand Community Care Program (CCP) services beyond its current three core services of Home Care Aide, Adult Day Service, and Emergency Home Response.

In Illinois the Community Care Program serves people age 60 and older, and the Home Services Program (HSP) serves people with disabilities age 59 and younger.¹ Both programs utilize the same Determination of Need (DON) tool to determine program eligibility and allocate service dollars, but the DON-based Service Cost Maximum (SCM) schedule is significantly higher under the HSP. This has led to concerns about the equity and adequacy of the benefit provided under CCP and to calls for ‘senior parity’ in the state’s home and community-based long-term care systems.

A multi-level approach was designed to respond to three core questions critical to defining a rationale for changing the current Service Cost Maximum methodology to achieve an expanded and more flexible service package for aging services in Illinois.

1. Why is the DON-based Service Cost Maximum schedule different for the elderly and disabled populations? To what extent can these differences be explained by differences in the characteristics of the populations served?
2. How will the legislatively mandated changes in the Community Care Program’s service package — in particular, the addition of medication management, personal care/assistance and consumer direction – affect service utilization and cost? What are the implications of these changes for the current DON-based system of service dollar allocation?
3. How does Illinois’ approach to determining eligibility and need and allocating service dollars for older adults compare to best practices in other states?

The methodologies employed to answer these questions include: 1) a quantitative analysis of the relationship between client Determination of Needs scores,

¹ HSP serves people age 60 and older who have been ‘customers’ of the program prior to turning age 60.

characteristics, service costs and utilization in the CCP; 2) interviews of key informants to understand the history and provide a comparative policy analysis of the two programs; and 3) a comparison of best practices from six state programs: Arizona, Ohio, Minnesota, Vermont, Washington and Wisconsin.

Based on a detailed analysis of these questions, the following is a summary of the findings:

- 1) The Community Care Program is a good deal. The program serves large numbers of frail older adults at risk for nursing home placement. The actual service cost per person is considerably less than the nursing component in nursing home care.
- 2) The services provided in the Community Care Program are Homemaker,² Adult Day Services, Emergency Home Response (EHR) and Care Coordination. The services utilized by the vast majority of CCP clients are Homemaker, Emergency Home Response and Care Coordination. These services are geared more for clients with impairment in Instrumental Activities of Daily Living (IADLs) as opposed to basic Activities of Daily Living (ADLs).
- 3) Each of the best practice states offers a broader array of services to address the needs of waiver program participants. These states target services to clients who are likely to be institutionalized.
- 4) There is considerable unmet need for assistance among high-end DON score clients, especially with respect to basic ADLs. The study also shows that persons in the high DON score range of 68 to 100 receive approximately 2 to 3.67 hours of home care aide per day in a 7-day week, with the majority having significant cognitive impairment.
- 5) CCP clients have numerous chronic conditions. Responses to item 13 on the DON, “is the applicant able to follow the directions of physicians, nurses or therapists, as needed, for routine health care?” indicate that these clients have significant problems in managing their medications. The need for medication management is most frequent among clients with high-end DON scores (range 68-100) of whom 72% have an unmet need for this service. It is difficult to determine the percentage of clients for whom medication management will be an ongoing as opposed to a one-time service.
- 6) Based on the number of clients with impairment on the Mini Mental Status Examination (MMSE) and the number that scored a 2 or 3 on item 15, “can the applicant be left alone (e.g., able to recognize, avoid and respond to danger and/or emergencies),” many family caregivers are in need of short-term respite. Overall, 28% of total clients met the cut-off score indicating

² As of April 3, 2009, “Homemaker” service was changed to “In-Home” service.

moderate to severe cognitive impairment on the MMSE. An even greater proportion (66%) had scores of 2 or 3 on being alone. This percent is reduced to 36% after factoring in informal care. However, persons providing this informal care are likely to be in great need of this service.

- 7) The current allowable CCP Service Cost Maximum is less than 60% of the nursing component of the state's nursing home reimbursement rate. The amount that CCP clients actually use is 32.8% of the nursing component, well below what it would cost to provide services if that person were living in a nursing home. Some of the best practice states utilize 60% or 100% of that state's nursing component and others (Vermont for example) utilize the full nursing home rate to provide home and community-based services.
- 8) Improvements made in each of the state programs analyzed for this study were made possible through outside evaluations conducted by universities and evaluation entities.

Recommendations:

- Allow consumer direction for personal care assistants enabling clients to select and hire their own workers as they do in the Illinois Home Care Services program, and as is common for both aged and disabled in most of the best practice states. Persons in the high DON score range of 68 to 100 receive approximately 2 to 3.67 hours of home care aide per day in a 7-day week, considerably less than what is needed by clients who have significant cognitive impairment in addition to high unmet IADL and ADL needs. The number of units of service needed per day for significant ADLs such as bathing and continence may be as high as a full day for a small percentage of the high-end DON score clients who are both physically and cognitively impaired and need supervision. Personal care and personal care assistants can be part of the Service Cost Maximum schedule.
- Based on analysis of the data, 27% of clients could benefit from the addition of medication management. Need for medication management is most frequent among clients with high-end DON scores (range 68-100), of whom 72% have an unmet need for this service. It is difficult to determine the percentage of clients for whom medication management will be an ongoing as opposed to a one-time service. Medication management should be added as a new cost outside the existing SCM schedule.
- Family caregivers should be offered the option of short-term respite based on the number of clients with impairment on the MMSE and the number who scored a 2 or 3 on item 15, "can the applicant be left alone (e.g., able to recognize, avoid and respond to danger and or emergencies)." Overall 28% of total clients met the cut-off score indicating moderate to severe cognitive impairment on the MMSE. An even greater proportion (66%) had scores of 2 or 3 on being alone. This percent is reduced to 36% after factoring in

informal care. However, persons providing this informal care are likely to be in great need of respite. Short term respite may be an intermittent service and not provided on a regular basis. Respite should be provided as an additional service for those clients in need of it.

- Link Community Care Program Service Cost Maximums with the Medicaid nursing component of the nursing home rates. All best practice states indicated that their home and community-based program budget is based on or tied to their nursing home rate. Services in Ohio are set at 60% of Medicaid nursing home costs. In Minnesota's managed care program, the cost for an individual cannot be greater than the medical assistance nursing home cost for that same individual. Illinois' Community Care Program, as demonstrated by the Service Cost Maximum analysis in this study, is a very economical alternative to nursing home placement with no apparent fiscal waste. However, it does not offer some important services for people with high needs who are at greatest risk of nursing home admission. A basic premise of CCP is that it is designed to provide an alternative to those eligible for nursing home placement who prefer to remain in the community as long as the mean cost of the program does not exceed that of the nursing component of nursing home care. Linking the SCM to the Medicaid per diem reimbursement for the nursing component of nursing home care would accomplish this goal of cost neutrality while also enabling these high-risk clients to have their service needs met.
- The analysis of the distribution of services shows that the Community Care Program reaches many thousands of people and supports the informal care-giving structure for those who technically qualify, but who are not at immediate risk of nursing home placement based on measures of their functional capacity. The data raises questions, however, about whether the Community Care Program is well-suited to accomplish its stated goal of keeping people out of nursing homes. At the higher DON levels, very few people find the Community Care Program adequate to meet their needs. These clients represent those most at risk of nursing home utilization, and for whom additional expenditures in the community would be offset by savings in nursing home spending. Therefore, it is recommended that the Department conduct an independent evaluation of the Community Care Program to address questions that IDoA and policy makers must ask of a program that is intended to provide older adults with an alternative to institutionalization while maintaining budget neutrality.

While not based on Illinois CCP data, the following are points to consider based on analysis of the literature and best practice states:

- Illinois' waiver program serves people with resources above the level for Medicaid eligibility, thus enabling CCP participants to slow the Medicaid spend-down and retain assets, and to potentially remain in the community

longer. Each of the six states serves only Medicaid-eligible clients in their programs. Given concerns about the potential growth and sustainability of the program, Illinois may want to revisit its eligibility criteria.

- To meet the needs of people who require nursing home levels of care, nurses along with social workers (in most states this means BA or MSW social workers) provide assessment and care coordination. In some states, nurses consult with social workers who do the care planning; in others, nurses do the eligibility determination. As Illinois moves toward targeting clients who are at risk of nursing home placement, reintegrating nursing home residents to the community and introducing medication management to its service mix, there will be more people in the program with complex health and psychosocial needs. Many of the best practice states have standards for caseloads based on the complexity of the clients' situations. Illinois should consider the professional qualifications of the people who do the eligibility determinations/assessments and provide the care coordination, and should develop caseload standards.
- Much like Illinois' Home Services Program for people with disabilities, most of the states separate the eligibility determination function from the care planning function, giving the state more control over who is determined eligible for the program, and the ability to allocate and manage the care coordination function.
- Illinois needs to effectively harness technology to mesh the clinical, budgetary and management aspects of its programs. Washington State's computerized CARE tool, upon which Illinois' Comprehensive Care Coordination tool is based, triggers billing, provides management information at the local and state levels, and enables the state to monitor and evaluate the program. The CARE system is in the public domain.
- Global budgeting enables the best practice states to shift resources to where a person is being served. Each state has a different model that has been adapted to the culture and history of that state. Illinois should research and evaluate global budgeting models in other states and develop a method that works for Illinois to enable money to follow the person.

Introduction and Overview

Public Act 95-565 directs the Illinois Department on Aging (IDoA) to ensure that the “determination of need tool is accurate in determining the participants' level of need; to achieve this, the Department, in conjunction with the Older Adult Services Advisory Committee, shall institute a study of the relationship between the Determination of Need scores, level of need, Service Cost Maximums and the development and utilization of service plans no later than May 1, 2008; findings and recommendations shall be presented to the Governor and the General Assembly no later than January 1, 2009; recommendations shall include all needed changes to the Service Cost Maximums schedule and additional covered services.”

This directive replaces a provision in the legislation as introduced, which required IDoA to remedy the discrepancy in DON-based Service Cost Maximums (SCMs) for younger and older adults with disabilities in Illinois by promulgating rules to make the Service Cost Maximums in the Community Care Program (CCP) comparable to those utilized by the Division of Rehabilitative Services' (DRS) Home Services Program (HSP). The Home Services Program is the state's Medicaid Home and Community-based Services (HCBS) waiver program for adults with disabilities 59 years of age and younger. The CCP is the state's Medicaid HCBS waiver program for adults age 60 and older. Both the HSP and CCP utilize the DON to determine program eligibility and allocate service dollars, but the DON-based Service Cost Maximum schedule is significantly higher under the HSP. This has led to concerns about the equity and adequacy of the benefit provided under the CCP and to calls for 'senior parity' in the state's home and community-based long-term care systems. These concerns underlie Public Act 95-565's original 'comparability' intent and the DON study mandate.

Although the parity concern underlies the legislative mandate for the DON study, there are other reasons why a reconsideration of the DON-based Service Cost Maximum schedule as utilized in the CCP and the Illinois Department on Aging is critical at this time. In support of expansion of HCBS in CCP, several recent legislative initiatives have been forwarded. Public Act 95-565 expanded hours of service and added flexible senior services, personal care/assistance and consumer direction. Public Act 95-535 added Medication Management, subject to appropriation. Currently, the CCP indexes its DON-based SCM schedule to three core services: Home Care Aide, Adult Day Service and Emergency Home Response. Reconsidering this SCM structure will be critical to effectively integrating an expanded and consumer-directed service package into the CCP as required by Public Act 95-565. Reconsidering the appropriateness of the current SCM schedule will also be important for projecting future program costs and estimating reasonable budget growth for the CCP, given a changing service package.

The current study utilizes a multi-method approach to answering three core questions critical to defining a rationale for changing the Service Cost Maximum methodology, which is currently utilized by the Illinois Department on Aging to correspond to an expanded and more flexible service package. These are:

1. Why is the DON-based SCM schedule different for the elderly and disabled HCBS waiver populations? To what extent can these differences be explained by differences in the characteristics of the populations served?
2. How will the legislatively mandated changes to the CCP's service package – in particular the addition of medication management, personal care/assistance and consumer direction – affect service utilization and costs? What are the implications of these changes for the current DON-based system of service dollar allocation?
3. How does Illinois' approach to determining eligibility and need and allocating service dollars for older adults compare to best practices in other states?

Project Design and Methods

In order to address questions one and two, this study combines quantitative analysis of the relationship between client Determination of Needs scores, characteristics, and service costs and utilization in the CCP and HSP (to the extent data permits) with a best practice policy analysis in order to (1) develop a rationale and recommendations for changing the current Service Cost Maximum methodology to accommodate an expanded and more flexible service package within the Community Care Program and (2) evaluate the differences in service cost methodology and maximums between the waiver programs for younger and older adults with disabilities. The University of Illinois at Chicago research team addressed these objectives with the following activities/analyses:

- A. Conducting in-depth interviews with key informants to provide the background and history of IDoA and DRS Service Cost Maximum methodology and its relation to the Determination of Need tool and score.**
- B. Developing and analyzing a client-level data set to identify IDoA utilization patterns and client-level predictors of utilization and costs, with a comparison with DRS clients to the extent DRS data permits.**
- C. Developing and analyzing a sample of CCP clients at the upper end of the DON distribution to consider the adequacy of the current SCM structure for meeting their needs.**
- D. Translating an adequate/flexible service package into an adequate SCM methodology/schedule. Projecting program costs based on a modified SCM schedule.**

SECTION I: Findings from In-Depth Interviews with Key Informants

a. Sample/Procedures

Interviews were conducted with key informants: members of the research group who designed and developed the Determination of Need (DON) instrument and scoring procedures; retired and current administrators representing the Illinois Department on Aging, Community Care Program (CCP); Department of Rehabilitation Services (DRS); agencies and vendors providing services to clients in both programs and who continue to serve as advocates for the disabled and older adults. A total of 11 interviews were conducted, each lasting approximately one hour. The interviews used a standardized questionnaire guide (Appendix D) led by two members of the University of Illinois at Chicago research group (Sue Hughes and Tom Prohaska). Each interview was audio-recorded and key points were transcribed. Below is a summary of the responses across individuals as well as selected quotations.

b. Findings

1. What agency/group do you represent and for how long? What is your position and role with the agency/group?

The key informants represent considerable experience in serving disabled and older adults through their respective agencies in Illinois. They represent a variety of perspectives, including their employment as CCP and CCC trainers through the Illinois Department on Aging, and past/present directors of the Shawnee Alliance for Seniors, Home Services Team, Area Agencies on Aging, Division of Rehabilitative Services, and the Home Services Program. Many are currently retired and were present during the early development of the Community Care Program and development and use of the Determination of Need instrument for both DRS and CCP. A full list of informants is available in Appendix H.

2. Are you or have you been involved in the development, revision or use of the Illinois Determination of Need instrument? If yes, describe your role.

These informants have considerable experience with the development and changes in the Determination of Need instrument and assessment procedures and Service Cost Maximums. One informant was a central figure in the research design and analysis in the validation of the DON instrument in 1989. Several informants were useful in recreating the history and revisions in DON scoring and range categories and the allocation of Service Cost Maximums for DON score ranges for both CCP and HSP. However, none of those interviewed had the complete understanding of service cost allocation by DON score categories across both programs that use the DON to determine SCM and services – the Illinois Department on Aging Community Care Program (CCP) and the Department of Rehabilitation Services Home Services Program (HSP).

3. & 4. What is your understanding as to how a client is scored for a specific disability on the DON (Column A) and for unmet need for informal care assistance on the DON (Column B)?

The key items of the DON assessment tool contributing to the total DON score are provided in Appendix F. Three components of the assessment are relevant for this report: the reported capability of the client in performing basic and instrumental activities of daily living (Level of Impairment **Column A**); the level of need for assistance on basic and instrumental activities of daily living taking into account the level of available and reliable informal care assistance provided (Unmet Need for Care **Column B**); and level of cognitive impairment as measured by the Mini Mental Status Examination (**MMSE**). Scores for Column A and B range between 0 (performs or can perform all essential components of the activity) and 3 (can not perform the activity and requires someone to perform the task (may assist in small way)). Given that there are 15 items that comprise the impairment items, individuals can score up to 90 points if they cannot perform any of the activities (45 points Column A) and have no informal assistance to perform the activities (45 points Column B). Scores on the 11-item cognitive assessment MMSE can range from 30 (no impairment detected) to 0 (significant cognitive impairment). The MMSE is a widely used general screening tool, which screens for the presence of cognitive impairment and is not used as a diagnostic tool (Folstein, Folstein and McHugh, 1975). As such, it is used to help establish a plan of care for the client. Instructions on the use of the MMSE note the following ranges as indicative of levels of impairment:

Score	Level of dementia
26 or more	Normal cognition
21 to 26	Mild dementia
10 thru 20	Moderate dementia
Less than 10	Severe dementia

If the MMSE score is equal to or less than 20, the client is given 10 additional points to be entered into the total DON score. The additional 10 points added to the 90 from Columns A & B bring the total possible DON Score to 100.

- Policies in the field may impact scoring.** Several procedures make it difficult to determine the true level of unmet client need. More than one informant reported that column B (unmet need for assistance) is rescored lower if the client refuses services offered by the case manager to address the specific unmet need. This can result in a considerably lower total DON score. We do not know how prevalent this practice is or whether it is unique to the Community Care Program. Also, if case managers know that the CCP client is going to be admitted into a nursing home, he or she is not scored on Column B. Both of these practices make it very difficult to draw conclusions about client characteristics, DON scores and appropriateness of Service Cost Maximums.

- **Client and family perspectives may impact scoring.** One informant reported that clients are reluctant to admit that they have limitations in daily activities as it may be used against them as a reason for nursing home placement. Also, older clients assessed without the presence of the caregiver responsible for addressing the unmet need will often overestimate the level of assistance that would be provided by the caregiver(s). This can lower column B scores and the client can be provided inadequate assistance.

5. How frequently is eligibility/service need re-assessed?

Reassessment of the DON is required annually. Reassessments may also occur when changes occur in the client's condition as reported by the client, family, service provider or after any hospitalization.

6. How were the SCMs for the CCP program set? What analyses were performed to derive the caps? Was any other method used to derive them? What percentage of clients are under/or at the cap limit?

Derivation of the SCMs: The Service Cost Maximums (SCMs) are defined for specific interval levels of unmet need on the DON, the allowable dollar amounts that can be paid for services for clients. The SCMs differ for each type of service currently provided by CCP or HSP. Different SCMs exist in CCP for Home Care Aide and Adult Day Service. Emergency Home Response services are included in Home Care Aide SCMs offered by CCP. Similarly, different SCMs exist for the services covered by HSP that include personal care assistance, nursing care, emergency home response, home delivered meals, housing modifications and others. An important difference between the two programs is that far more services are included in the Division of Rehabilitative Services' HSP than in the Illinois Department on Aging's CCP.

The overall cost for the entire Community Care Program initially was set at the maximum Medicaid nursing home monthly reimbursement rate statewide in Illinois in 1980. This overall cap was used because the Medicaid waiver stipulates that the cost of community care provided to clients under either waiver (aged or adult disabled) cannot exceed the cost of nursing home care for those same clients (cost neutrality). At some point the SCMs were set at the mean reimbursement for the nursing component of the Illinois Medicaid per diem reimbursement for a month of nursing home care. Respondents believed that both the CCP and DRS programs began with the same set of SCMs (dollar values) for the same DON interval scores that were obtained using the same version of the instrument. According to Dr. Jean Blaser, former IDoA/CCP deputy director, IDoA lower-end costs shown in 1980 were pegged at \$300, the cost at that time for sheltered care, and \$598, the average cost at that time for nursing home care. In 1982, after the DON was developed, the same basic SCM ranges were retained. In 1983 the SCMs were reviewed against the Illinois Department of Public Aid (IDPA; now Healthcare and Family Services, or HFS) point system then being used to reimburse for nursing home care. At that point, according to Dr. Blaser, IDoA had more low-scoring clients than DRS because IDoA was grandfathering in less-impaired clients who had been accepted into the program in prior years (those with scores between 11-29). The Bureau of Budget

(BOB) also supported lower SCMs for IDoA clients in lower score ranges, and IDoA SCMs were revised as shown below, Table A:

Table A. IDoA Service Cost Maximums over time

1980		1982		1983	
Score	Mo. Cost	Score	Mo. Cost	Score	SCM
11-29	\$150	26-40	\$300	<28	\$150
30-49	\$307	41-55	\$450	28-32	\$431
50-69	\$464	56-75	\$598	33-45	\$538
70-74	\$572			46-56	\$607
				57-67	\$717
				68-78	\$842
				79-87	\$911
				88-96	\$980

7. Are the Service Cost Maximum ranges useful?

In general, respondents felt that the SCM ranges were useful in establishing guides for amounts of services. “The only thing I’ve heard is that the highest impaired groups seem to fall a little short of what they need. Definitely medication management, integrated money management, and assistive technology are needed.” The SCM ranges are a way to make sure service amounts relate to DON scores. “I don’t know what case managers would base care plans on without them. The ranges 57-67, 68-78, and 79-87 are very problematic because they represent very impaired people. The needs often exceed what the client can receive because 24-hour care is really needed but family can’t always fill in the gaps. Without the caps, service costs would float upward and regional variation could become extreme.”

8. Have there been changes in the SCM ranges? What were the changes and the justification for changing these ranges?

Several changes have been made to the dollar value of the SCMs over time. In the state fiscal year of 1989 IDoA, DRS and IDPA (now HFS) undertook a study of the DON at the request of the federal Health Care Financing Administration, now Centers for Medicare and Medicaid Services (CMS). IDoA expanded the study to evaluate how best to assess dementia. As a result of the study, the Mini Mental Status Exam (MMSE) was substituted for the Short Portable Mental Status Questionnaire (SPMSQ), with persons who scored 20 or fewer points being awarded 10 additional points. Shopping was deleted from the ADL/IADLs, resulting in a total of 15 impairment items. Eligibility was changed from 28 to 29 points, to be one standard deviation below the mean DON score for nursing home residents.

The new Service Cost Maximums were set as shown in Table B, below. In November of 1992 the State of Illinois had to respond to a budget crisis and both IDoA and DRS were asked to trim their waiver program expenditures. DRS handled the request by closing intake to new cases for a period of time and by closing the cases of some of their lower-scoring clients. In contrast, IDoA maintained open intake but again reduced the SCMs for the clients with lower-level DON scores. As data shown below indicates, SCMs for persons in the 29-32 and 33-36 categories were cut by 50%.

Within a matter of months, DRS, based on a court order (McMillan vs. McCrimon), reverted to accepting lower-scoring clients but still maintained their cost structure, which continued to be pegged to the nursing component of the Medicaid nursing home reimbursement rate, with incidental increases to reflect wage increases for personal care attendants over time. In contrast, the cost structure for IDoA became divorced from nursing home reimbursement with subsequent changes in the dollar amounts based on increased payment rates for the types of services covered. Table B below compares the DON scores and SCMs for CCP in 1991, 1992 and its present level in 2008.

Table B. IDoA Service Cost Maximum (per month): 1991; 1992; 2008.

Points	1991 SCMs	1992 SCMs	2008 SCMs
<29 (grandfathered)	\$160	\$100	-----
29-32	465	190	\$341
33-36	580	300	629
37-45		480	951
46-56	690	600	1,180
57-67	880	700	1,548
68-78	1,020	910	1,778
79-87	1,200	1,240	2,152
88-100	1,400	1,445	2,820

A comparison of current SCM under the HSP DRS Disabled Individual Medicaid Waiver and the Community Care Program is provided in Table C below.

Table C. Comparison of Service Cost Maximum between persons served under the HSP Disabled Individual Medicaid Waiver and the Community Care Program by Total DON Score Categories 7/1/2008

DON Score CCP	Regular SCM Home Care Aide	DON Score HSP	SCM Disabled Medicaid Waver
29-32	\$384	29-32	\$1,593
33-36	629	33-40	1,830
37-45	951	41-49	2,036
46-56	1,180	50-59	2,437
57-67	1,548	60-69	2,865
68-78	1,778	70-79	3,097
79-87	2,421		
88-100	2,820	80-100	3,329

The Community Care Program (CCP) and the Department of Rehabilitation Services (DRS) do not have identical DON score category ranges. CCP has a total of eight categories or DON Score ranges for SCMs while the HSP program has seven categories. However, comparisons of SCMs can be made for several categories including the low (29-32) and high (79-100) DON score ranges. There is considerable discrepancy in SCM dollars allowed between CCP and DRS for enrollees with low-end DON scores (29-32). CCP clients in this range have an SCM of \$384 while disabled individuals in the HSP program have an SCM of \$1,593 — a

difference of \$1,209, which is more than four times the rate for older adults in CCP. Similarly, CCP clients who are most frail and disabled (DON score 79-87, 88-100) have a mean SCM of \$2,602, compared to \$3,329 for the highest DON score range (80-100) enrollees served under the Disability Medicaid Waiver. CCP clients in the highest two DON score categories have \$727 less per person per month than persons in the HSP. This translates to a difference of 47–74 hours more of actual service available to the HSP client. (Divide \$727 by the 2008 HSP rates @ \$9.85/hr. and the CCP rates @ \$15.35/hr).

9. Should elderly persons with similar DON scores receive service cost caps similar to those received by persons served under the disability waiver? Why? Why not? Is there a better way to handle this issue?

Respondents overwhelmingly believed that SCMs should be similar for both sets of clients if the services provided are similar, and several respondents suggested that a good way to start remedying current inequities between the two programs would be to make similar services available to both groups. This would entail, at a minimum, expanding the current array of services available to CCP clients to include medication management and personal care assistance and assistive technologies.

10. What advice do you have for Illinois in terms of changing SCM levels and cutoff scores for SCMs?

According to respondents, the federal poverty level is too low for clients whose income is above it to be charged co-payments for CCP services. Personal care is an issue. Many adult children don't want to help their parents with personal care. Personal care assistance often makes the difference between staying home or ending up in a nursing home. Incontinence is one of the main factors that make personal care a difficult issue for family members.

11. In your opinion, is there an inequity in current SCMs and services offered to clients? If so, what changes would you recommend?

The following direct quotes indicate the consistent affirmative nature of responses to this question.

- “We need a broader service package. To keep people in their homes, we need a richer variety of covered services.”
- “We have to address how the DON is scored so that it does not penalize family help but rather rewards it. Family help does not always continue at the same rate that it was originally scored.”
- “People with the same DON score should receive the same SCM cap. Illinois should determine the cost effectiveness of a program based on expenditures for the entire population rather than focus on single outliers of extreme cost. Under the current SCM structure, there is tremendous inequity in the aging program.”

SECTION II: Findings from Analyses of IDoA Community Care Program Sample

IDoA provided the data used for analyses. The data was sent as an electronic file to the University of Illinois at Chicago and was secured with access limited to only the research team. This project received approval by the University Institutional Review Board. The data file and data variable description file were consistent and complete.

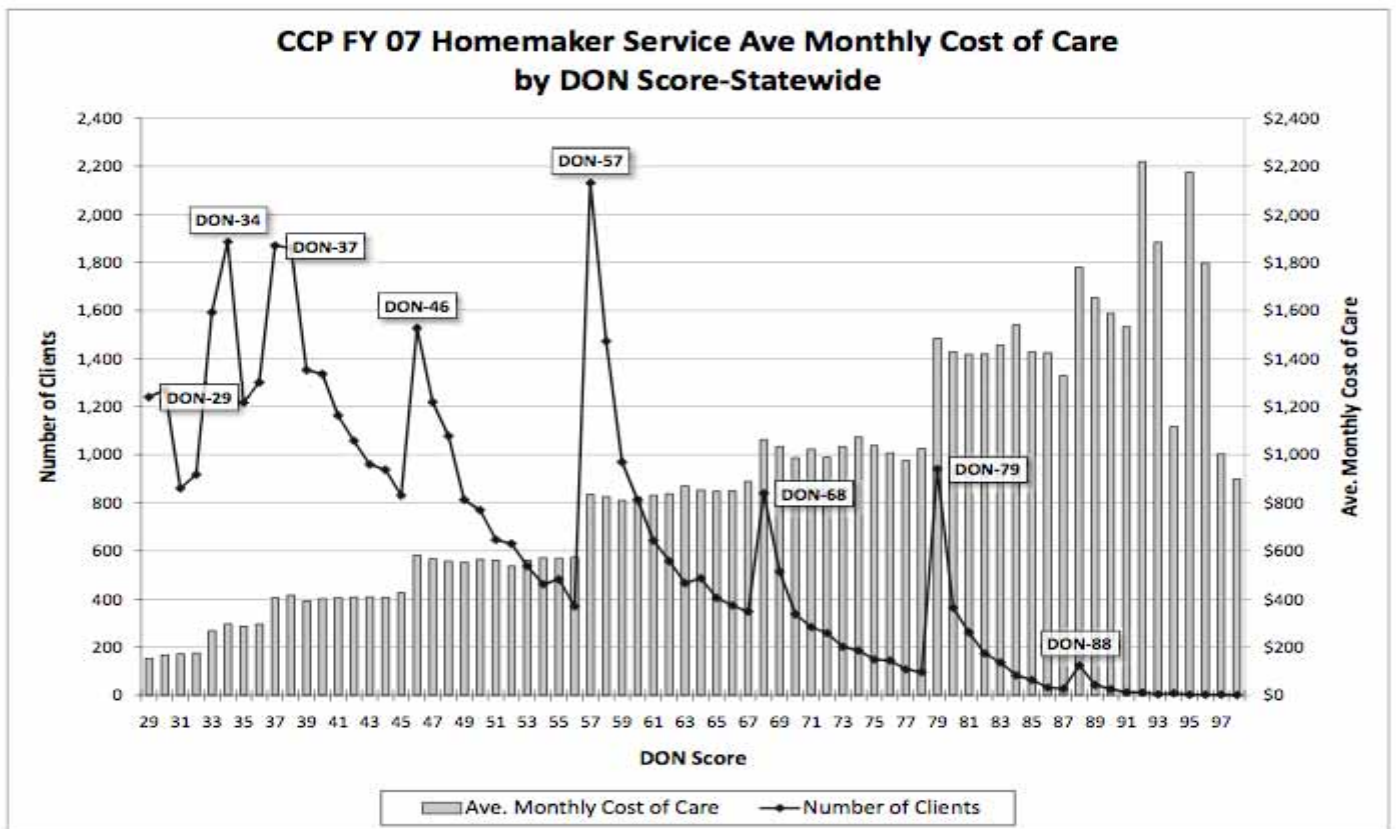
Sample: A total of 51,947 Community Care Program (CCP) recipients for the month of April 2008 were selected for analysis. This sample represented the full CCP client roster for that month. **Table 1** presents the distribution of CCP services received. Services noted include demonstration programs and services not routinely provided to the general CCP client base such as *Cash and Counseling* and *Enhanced Community Care*. These demonstrations include a very small portion of CCP clients and have

**Table 1:
Distribution of CCP services received**

Home Care Aide	Adult Day Service	Comprehensive Care	Senior Companion	Emergency Home Response	Cash and Counseling	Managed Comprehensive Care	Enhanced Community Care	Frequency	Percent	Cum Frequency	Cum Percent
.	Yes	938	1.81	939	1.81
.	Yes	.	.	140	0.27	1,079	2.08
.	.	.	.	0	.	.	.	10	0.02	1,089	2.10
.	.	.	.	0	Yes	.	.	1	0.00	1,090	2.10
.	.	.	.	Yes	.	.	.	3,112	5.99	4,202	8.09
.	.	.	.	Yes	.	.	Yes	2	0.00	4,204	8.09
.	.	.	.	Yes	.	Yes	.	4	0.01	4,208	8.10
.	.	.	Yes	Yes	.	.	.	11	0.02	4,219	8.12
.	.	Yes	188	0.36	4,407	8.48
.	0	3	0.01	4,410	8.49
.	Yes	1,284	2.47	5,694	10.96
.	Yes	Yes	2	0.00	5,696	10.97
.	Yes	.	.	Yes	.	.	.	173	0.33	5,869	11.30
.	Yes	.	Yes	2	0.00	5,871	11.30
0	10	0.02	5,881	11.32
0	.	.	.	Yes	.	.	.	1	0.00	5,882	11.32
Yes	32,233	62.05	38,115	73.37
Yes	Yes	.	2	0.00	38,117	73.38
Yes	.	.	.	0	.	.	.	5	0.01	38,122	73.39
Yes	.	.	.	Yes	.	.	.	12,648	24.35	50,770	97.73
Yes	.	.	Yes	63	0.12	50,833	97.86
Yes	.	.	Yes	Yes	.	.	.	48	0.09	50,881	97.95
Yes	.	Yes	2	0.00	50,883	97.95
Yes	Yes	831	1.60	51,714	99.55
Yes	Yes	.	.	Yes	.	.	.	232	0.45	51,946	100
Yes	Yes	.	Yes	Yes	.	.	.	1	0.00	51,947	100

different SCMs and payment structures. In order to more accurately examine factors associated with service costs, participants in these programs were excluded. Only individuals receiving Home Care Aide services or receiving Home Care Aide Services plus Emergency Home Response (EHR) were included for analysis. Both services are provided within the same SCM structure. These two groups comprise the majority of the clients (44,881 or 86%). An additional 576 individuals were excluded due to missing values for the individual items in Columns A and B in the DON, resulting in a sample of 44,305 clients used to examine impairments and their relationship to service use and costs.

Figure 1 shows the distribution of CCP clients on the full range of DON scores along with their average monthly cost of Home Care Aide service. Several patterns are worth noting. First, with respect to DON scores, the majority of clients (30,193 or, 68%) have scores at the lower end of the DON score range (29 to 56), while relatively few clients have scores of 79 or higher (2,325 or 5%). Second, a higher number of clients occur in the first score of each of the DON ranges than any other scores in the range. For example, there are considerably higher number of clients who receive scores of 29, 34, 37, 46 and 57. Each of these scores corresponds to cut-off scores for DON range categories. With respect to average monthly dollars used, a general increase in average monthly cost per client is seen with increasing DON score. It is important to note that because of the low number of individuals in the



higher DON score categories, estimations of average monthly cost for these clients are unstable. However, as later analyses will show, the total cost of clients in this category to the CCP is proportionately less than other, lower DON score categories.

A. Characteristics of CCP Clients and Determination of Need Profiles

1.1 Overall Client Characteristics

Table 2 provides a summary of the demographic characteristics of clients receiving Home Care Aide with and without EHR services. The mean age of clients is 77.9 with a range of 60 to 114. As expected, the majority of the clients are women (74.35%) and either White (51.94%) or Black (35.67%). Hispanic and Asian clients both comprise about five percent of the client base (2,273 and 2,385, respectively). Also included in Table 2 is the 2007 estimated population for Illinois by race/ethnicity. As shown, 85% of persons 60 years and older in Illinois are White, 11.4% are Black and 5.5% are Hispanic/Latino. While there are some demographic differences between CCP clients and the general older adult population, these findings are not unexpected given disparities in disability among older adults (Kelley-Moore & Ferraro, 2004). In terms of living arrangements, it is important to note that most clients live alone (60%), followed by living with their spouse (18%) or with children (14%).

Table 2: Demographic Characteristics of CCP Populations

Receiving Home Care Aide and Home Care Aide plus Emergency Home Response Service

Characteristic	N	%CCP	%Illinois
Age (mean) 77.92			
Gender			
Male	11365	25.6	
Female	32940	74.4	
Race/Ethnicity			
White	23012	51.9	85.17
Black	15802	35.7	11.41
Am Indian	35	0.08	0.21
Hispanic	2273	5.1	5.55
Asian	2385	5.4	3.25
Other	797	1.8	1.8
Living Arrangement			
Alone	26822	60	
With spouse	7999	18	
With children	6333	14	
With other relatives	1803	4	
With non-relative	535	1	
With spouse and children	674	1.5	
Other	139	0.3	

CCP clients are served within 13 Regional Planning and Service Areas (PSA) across Illinois. **Table 3** presents the distribution of home care aide clients by PSA. Also included in this table are the mean total DON score and the average dollar amount utilized by DON for each PSA. As can be seen in the table, distribution of clients statewide follows population distributions, with almost 60% of CCP clients residing in the Chicago/Cook County area (City of Chicago 44%, Cook County/Age Options 15%). The smallest number of CCP clients is served by West Central/Quincy PSA. In terms of total DON score, mean scores ranged from a low of 40 (East Central/Bloomington and South Central Midland) to a high of 54 (Cook County/Age Options). Average dollar amounts utilized by DON also ranged considerably from a low of \$768 (East Central/Bloomington, Champaign Decatur) to a high of \$1,194 (Cook County/Age Options). Variations in service utilization may be due to regional variations in cost or availability of services, or variation in the acceptability of services within different

population subgroups. These variations were not addressed in this study. There were minimal differences among clients by PSA in age, gender and marital status (data not shown). However, ethnic diversity was greatest in the Chicago area compared to the rest of the state. While the ethnic distribution of CCP clients in Illinois is primarily White (52%) or Black (36%), the majority of Chicago clients are Black (58%) followed by White (24%), Hispanic (8.8%) and Asian (6%), reflecting diversity that might be expected in large urban area.

Table 3:
Distribution of Clients by Regional Planning and Service Area

Planning and Service Area	Frequency	Percent	Mean Total DON Score	Utilized*
City of Chicago	19,686	44.43	50.13	1,077
Cook County (Age Options, Inc.)	6,647	15.00	54.13	1,194
Northeastern	2,582	5.83	51.29	1,095
Southwestern	2,246	5.07	46.16	952
East Central: Bloomington, Champaign, Decatur	2,209	4.99	40.31	766
Southern (Egyptian Area Agency on Aging)	2,199	4.96	40.83	768
Northwestern	1,922	4.34	45.39	915
Western: Quad Cities	1,676	3.78	42.65	841
Central (Lincolnland Area Agency on Aging)	1,670	3.77	44.32	892
Central: Peoria	1,216	2.74	45.96	945
South Central (Midland Area Agency on Aging)	1,017	2.30	40.64	776
Southeastern	829	1.87	48.58	1,022
West Central: Quincy	406	0.92	46.92	970

* Mean monthly dollars utilized by DON per client

1.2 Characteristics of CCP Clients by Total DON Scores

As noted earlier, the DON scores range from 29 to 100 with eight categories of range scores. **Table 4** provides the number and percent of clients in each of the eight categories as well as the distribution of demographic characteristics for each category. Almost two-thirds of clients are in three mid-range categories (37-45 = 25.5%; 46-56 = 19.3% and 57-67 = 19.6%) while only 5 percent of clients are in the two highest DON score categories (79-87 and 88-100). Several demographic trends are evident.

Table 4:
Demographic Characteristics by DON Score Category

DON Category	N	%	Mean Age	%Female	%Alone
29-32	4,290	9.7	76.47	68.28	67.16
33-36	5,999	13.5	76.33	71.91	70.51
37-45	11,370	25.5	76.89	74.74	68.81
46-56	8,534	19.2	77.72	75.03	61.74
57-67	8,667	19.6	79.19	76.25	52.11
68-78	3,120	7.0	80.76	75.32	39.52
79-87	2,083	4.7	81.84	79.07	37.59
88-100	242	0.5	82.23	78.51	35.54
Total	44,305	100			

Consistent with what one expects, DON scores tend to increase with age. The percentage of females also increases with higher DON score categories. Although living alone is more common at the lower DON scores, over one-third of clients in the highest DON score category (88-100) live alone (35.5%).

There are clear differences by ethnicity in total DON score (**Table 5**). White older adults comprise almost 70% of the clients in the lowest DON score category (29-32) and only 33% of those in the highest category (88-100). The opposite pattern occurs with Black CCP clients. They comprise 22% of clients in the 29-32 DON category but almost one-half of clients in the highest category (88-100). Again, these finding may be a result of health disparities in disability among older adults (Kelley-Moore & Ferraro, 2004).

Table 5:
Ethnicity/ Race by DON Score Category

Category by Total Don Score	White		Black		AmIndian		Hispanic		Asian		Other	
	N	%	N	%	N	%	N	%	N	%	N	%
29-32	2,976	69.37	963	22.45	2	0.05	113	2.63	188	4.38	48	1.12
33-36	3,545	59.10	1,855	30.93	5	0.08	192	3.20	305	5.09	96	1.60
37-45	6,610	58.14	3,746	32.95	8	0.07	484	4.26	364	3.20	158	1.39
46-56	4,529	53.07	2,904	34.03	6	0.07	432	5.06	486	5.69	177	2.07
57-67	3,513	40.53	3,811	43.97	8	0.09	610	7.04	529	6.10	196	2.26
68-78	1,135	36.38	1,370	43.91	3	0.10	239	7.66	303	9.71	70	2.24
79-87	622	29.86	1,042	50.02	2	0.10	178	8.55	194	9.31	45	2.16
88-100	82	33.88	111	45.87	1	0.41	25	10.33	16	6.61	7	2.89
Total	23,012	51.90	15,802	35.70	35	0.08	2,273	5.01	2,385	5.40	797	1.80

As expected, cognitive impairment is increasingly common with increases in DON score category. The CCP assessment procedure includes a screening for cognitive impairment using the Mini Mental Status Examination (MMSE) tool (Folstein, Folstein and McHugh, 1975). Individuals who score at the moderate to severe dementia range receive an additional 10 points to their total DON score. The MMSE is a practical screening assessment measure widely used in clinical and non-clinical settings and is critical to understanding the capability of the older clients and their service needs. The findings presented in **Table 6** summarize the association between the MMSE and total DON score. This is reported using two methods: first using the mean score for the MMSE and second using the percent of clients above the cut-off score used to adjust the total DON by 10 points. The threshold score for receiving the 10 additional points is 20 or less. The most common threshold score used to indicate cognitive impairment is 23 or 24 (McDowell, 2006). Using 23/24 as a reference, the score of 20 or less used by CCP is a conservative estimation of cognitive impairment.

As expected, increasing cognitive impairment is associated with higher total DON score. Less than 1% of clients in the lowest DON score category met the threshold of 20 or less compared to more than 90% of clients in the two highest categories. Significant cognitive impairment in older adults contributes to limitations in basic and instrument activities of daily living and often presents considerable burden to the primary caregiver (Ory, Hoffman, Yee, Tennstedt and Schulz, 1999). Cognitive impairment is a significant factor contributing to nursing home placement and is associated with ability to perform instrumental and basic activities of daily living (ADLs).

Table 6. Mini Mental Status Examination (MMSE) Mean and Percent above Cutoff

Category by Total DonScore	N	Mean	Median	%Cut off +10 pts.
29-32	4,290	27.23	28.00	0.51
33-36	5,999	26.68	27.00	1.62
37-45	11,370	25.68	27.00	8.08
46-56	8,534	22.87	24.00	28.77
57-67	8,667	19.47	20.00	50.06
68-78	3,120	13.51	15.00	81.38
79-87	2,083	10.22	10.00	93.61
88-100	242	8.20	8.00	97.52
Total	44,305	22.53	25.00	28.34

Instrumental and Basic Activities of Daily Living; Need and Unmet Need

A major component of the DON assessment tool is the evaluation of activities of daily living both in terms of impairment level in physical functioning and unmet need for assistance in performing the activities. The items that comprise this section of the DON instrument include basic activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Impairment in such ADL items as eating, dressing and bathing represent more severe levels of disability. IADL items include such things as being able to prepare meals, and do laundry and housekeeping. IADL tasks are more demanding and complex than ADLs and reflect the older person's ability to live independently in the community. The ADL and IADL items in the DON were selected from several well-known scales designed to assess personal functional status among adults, including the OARS Multidimensional Functional Assessment Questionnaire (OMFAQ; Fillenbaum, 1975, 1988) for the IADLs and the Index of ADL (Katz and Akpom 1976). Both the IADL and ADL measures have demonstrated reliability and validity, and continue to be used broadly in research and community practice (McDowell, 2006).

The DON instrument (Appendix F) includes 15 individual items pertaining to activities of daily living. These include items considered to assess higher-level functioning or instrumental activities of daily living (IADLs, e.g., being able to do laundry and housework) and more basic Activities of Daily Living (ADLs, e.g., being able to bathe and dress oneself). These items are measured in terms of functional impairment or the level of inability to perform the function (Column A) and also in terms of unmet need for assistance in performing the activity after taking into account the level of assistance provided by family and others (Column B). **Table 7** shows level of impairment and unmet need for each of the 15 items included in the DON. A score of 0 is defined as the person performs or can perform all essential components of the activity. A score of 1 is given when the client performs or can perform most of the essential components of the activity, while 2 means an inability

to perform most of the components and 3 means the client cannot perform the activity at all and requires someone to perform the task. As might be expected, the greatest number of clients are impaired in housework, meal preparation, laundry and activities outside the home (99+% with a score greater than 0 in Column A). However, substantial impairments were also found for bathing, grooming, dressing and transfer (90+% with a score greater than 0).

Table 7:
Percent Distribution of Impairment Level and Unmet Need
for Assistance by Individual IADLs and ADLs

IADL	Impairment (Column A)				Unmet Need (Column B)			
	0	1	2	3	0	1	2	3
Manage Money	21.3	17.4	26.9	34.4	76	16.1	7.13	0.77
Telephoning	11.4	43.2	34.7	10.7	18	56.1	24.5	1.45
Preparing Meals	0.3	6.18	56.2	37.3	3.87	28.4	60.2	7.54
Laundry	0.08	1.01	24.6	74.3	1.44	10.7	43.8	44.1
Housework	0.01	0.34	23.4	76.2	0.54	9.31	43.2	47
Outside Home	0.32	6.06	49.6	44.1	2.91	35.2	54.2	7.74
Routine Health	10.9	38.9	35.3	14.9	24.3	49	25.3	1.34
Special Health	50.2	9.69	18.7	21.5	92.8	3.69	2.89	0.67
Being Alone	10.6	29.4	44.7	15.3	17	46.9	34.2	2.01

ADL								
	0	1	2	3	0	1	2	3
Eating	32.3	39.8	24.3	3.54	41	40.1	18.3	0.53
Grooming	5.23	35.8	44.8	14.2	17.3	40.7	38.3	3.73
Bathing	1.47	16.7	58.3	23.5	10.7	32.5	50.1	6.74
Dressing	3.38	37	46.2	13.4	14.3	39.9	42.4	3.39
Transferring	8.21	32.8	46.1	13	16.8	49.1	32.1	1.96
Continence	26.3	35.3	27.5	10.9	42.9	35.9	20	1.24

While assistance from informal caregivers helps to reduce needs for assistance, considerable unmet needs remain in this sample. Unmet need for assistance is also scored from 0 to 3, with 0 indicating that the need for assistance is met; 1, met most the time; 2, not met most the time and a moderate risk to health and safety to the client is present; and 3, assistance is seldom met and there is a maximum risk to health and safety. As shown in **Table 7**, the greatest of these residual unmet needs can be seen in items related to home care services (meal preparation, laundry and housework). However, there is also considerable residual unmet need for assistance with the basic activities of daily living related to personal care assistance (bathing 89%, grooming 83%, dressing 86% and transfer 83%). Two additional items that had considerable residual unmet need for assistance were continence (57%) and being alone (83%). It is not clear to what extent home care aides assistants are currently trained and supervised in the provision of personal care to clients with unmet need in these ADLs. However, the need for additional assistance in these basic ADLs is evident. Assistance with specific ADL impairments such as toileting and bathing are very intimate tasks for informal caregivers to perform. Impairment in toileting is a specific risk factor for nursing home admission for this reason (Friedman, Steinwachs, Temkin-Greener & Mukamel, 2006).

B. Develop and analyze a client-level data set to identify IDoA utilization patterns and client-level predictors of utilization and costs.

To answer this question we conducted a hierarchical multivariate analysis. The analysis sample was comprised of CCP clients who receive home care aide service with and without Emergency Home Response services. Using the number of homemaker units provided per month as the dependent variable, we ran a series of regressions that added new variables in a specific theoretical order while keeping previous sets of variables in the equation following Anderson’s predisposing, enabling and need model (Andersen, 1995). The following variables were entered in the following order:

1. Age, gender, race, living alone, service area
2. Total number of chronic diseases
3. Total IADL score Part A of DON
4. Total ADL score Part A of DON
5. MMSE score
6. Total IADL score Part B of DON
7. Total ADL score Part B of DON

Correlations were first examined between all variables in the analysis, followed by an examination of the percent of variance explained in number of homemaker visits by each variable in the model and by all variables included simultaneously in the last step of the analysis.

The results of the regression analysis in **Table 8** (see next page) show that age and gender and living alone versus living with others contribute little to explaining

variance in units of services used. Race, particularly Asian versus White, is a strong predictor of volume of services used, as is geographic residence in the Chicago or Suburban Cook County (Age Options, Inc.) PSAs. Again, there are several possible reasons for regional variation in volume of

**Table 8:
Hierarchical Regression: Predictors of Volume of Home Care Aide Hours**

Variable	% of Variance Explained
1. Age.....	0.55
2. Female vs. male gender.....	0.85
3. Race	8.85
4. Live alone vs. with others.....	9.80
5. PSA (Chicago and Cook Co. vs. Others	18.89
6. Total number of chronic diseases.....	22.12
7. Total IADL Part A	41.53
8. Total ADL Part A.....	44.78
9. Total MMSE Score	45.10
10. Total IADL Part B.....	47.41
11. Total ADL Part B.....	48.27

services used, but these were not addressed in this study. Total number of chronic diseases adds 4% of explained variance to the model but is dwarfed by the contribution of total IADL score on Part A of the DON, which accounts for an additional 19% of variance explained (the largest percent in the entire model). Total ADL Part A score contributes another 3% of variance once the IADL score has been

entered and total MMSE adds another 1%. Finally, the Part B IADL and ADL scores add additional modest amounts of explained variance of 2 and 1 percent, respectively.

Overall these findings indicate that the most substantial contributors to variance in units of home care aide services used are race, PSA and total Part A IADL score.

The percent change in home care aide units that would occur with a one-unit change in these predictor variables in the final model with all variables included is shown in **Table 9** (see next page). As data in this table indicates, the biggest percent increases in visits occur as a function of increases in number of female clients, number of Hispanic vs. White clients, number of Asian vs. White clients, number of other/ American Indian clients vs. White clients, with the greatest amount of increase in homemaker units associated with residence in Chicago or Suburban Cook County vs. all other PSAs. For every additional client enrolled in those geographic areas, a 62% increase in home care aide units utilized per person is seen. In contrast, a one-unit increase in total IADL score on Part A of the DON results in a 5% increase in home care aide units, a one-unit increase in total ADL score on Part A of the DON results in a 2.3% increase and one-unit increases in total Part B IADL and ADL scores are associated with increments of 3.3% and 4.7% in number of units, respectively. The only variable that has a negative relationship with home care aide units is MMSE score. Our results show that as total MMSE score decreases (worsens), the number of home care aide units used increases very slightly by about 1%.

Table 9:
Percent change in Home Care Aide units with a one-unit increase in a Predictor Variable

Predictor Variable	Variable Label	Percent change in Home Care Aid units for one unit increase in predictor variable
age	Age, based on year of birth	-0.43%
sex_r	Gender: 0-male; 1-female	8.18%
race_d2	Black vs White	2.22%
race_d4	Hispanic vs White	8.00%
race_d5	Asian vs White	28.99%
race_d9	Amlnd or other vs White	12.80%
liv_alone	Yes vs No	8.07%
psa_r	PSA: Chicago and Cook Co(1) vs. other(0)	61.99%
chdisease_tot	Total chronic diseases	2.02%
IADL_A	IADL side A - cal from ind items	4.93%
ADL_A	ADL side A - cal from ind items	2.33%
MMSESCORE	Mini-Mental State Examination	-1.13%
IADL_B	IADL side B - cal from ind items	3.27%
ADL_B	ADL side B - cal from ind items	4.68%

Several of the findings in **Tables 8 and 9** are as expected. In particular, the finding in Table 8 that IADL impairment (Column A) accounts for the largest increment in the variance may be explained by the type of services typically provided by home care aide, including assistance in addressing needs for meal preparation housekeeping and laundry. The finding that little added variance is accounted for by basic ADLs suggests that these items are not driving the utilization of services in the current service package. As shown in **Table 9**, IADLs have twice as large an effect on the hours of home care aide services as ADLs. It is not clear why demographic characteristics and PSAs are accounting for the level of variance found, as these factors should have been minimal after accounting for the frailty and unmet needs of the client. Further investigation of these findings is suggested. Finally, the full model in **Table 8** accounts for 48% of the total variance in volume of home care hours used. In terms of health services utilization, the model presented in **Table 8** would be considered very good in terms of the amount of variance in utilization explained.

C. Develop and analyze a sample of CCP clients at the upper end of the DON distribution to consider the adequacy of the current SCM structure for meeting their needs.

Two groups of CCP clients were identified as being in the upper and lower end of the DON distribution. Clients in the top three total DON score categories (68-78, n=3,120; 79-87, n=2,083; and 88-100, n=242) were combined to construct the upper-end group. Those in the two lowest total DON score categories were combined to create the lower end (29-32, n=4,290; 33-36, n=5,999). The low-end (10,289) and high-end (5,445) clients comprise 23% and 12% of the total CCP client base receiving home care aide services with or without EHR services. The first analysis (**Table 9**) examined differences between clients in the upper and lower ends of total DON score categories on individual IADL and ADL items. Impairment scores were examined on Part A (level of impairment) after they were adjusted to reflect the amount of informal care provided (Column B) of the DON. For this analysis, scores of 2 or 3 on impairment (Column A) were combined to indicate substantial degree of impairment with each of the ADL/IADLs. Similarly scores of 2 or 3 on unmet need for assistance (Column B) were combined to indicate substantial residual unmet need among clients with substantial degrees of impairment. Through this analysis specific services were identified to be needed by high-end clients (**Table 10**). Next, Service Cost Maximum was compared to actual use of homemaker services, focusing on high-end clients only. Service Cost Maximum units were converted to maximum hours of service per week. Then the mean home care aide units used by the high-end group were converted to mean hours of home care services used per week. Finally, the mean home care aide hours used per week were compared with level of impairment and unmet need for services for the high-end clients and assessed for the adequacy of service.

Table 10 presents the IADL and ADL distributions of individuals at the upper and lower ends of the Part A total DON score. As expected, clients in the upper and lower ends of the DON score categories have similar high rates of impairment for many instrumental activities of daily living (IADLs), especially with respect to impairments related to

need for home care aide services. Across the lower- and upper-end DON score categories, clients have similar high levels of impairments for meal preparation, laundry and housework. Differences between clients in the upper and lower ends of the DON are more pronounced with respect to basic activities of daily living (ADLs). A considerably higher percentage of older adults with upper-end DON scores have impairments in basic ADLs compared to those in the lower-end DON scores. These items include eating, grooming, dressing, transferring and bathing. Three additional Column A impairment items stand out in terms of upper- and lower-end DON score differences — continence, routine health and being alone. For all three items, over 90% of upper-end clients have scores of 2 or 3, while these scores are considerably less common among clients with lower-end scores. For example, over 90% of those in the upper end of the DON scored a 2 or 3 for continence while less than 1% did so at the lower end of the DON.

**Table 10:
Level of Impairment (Column A) Low End (29-36) and High End (68-114) DON Score ¹**

IADL	Low End		High End		% Difference
Manage Money	3,138	30.30%	5,278	96.94%	66.64
Telephone	1,459	14.18%	5,198	95.46%	81.28
Meal Prep	8,303	80.69%	5,440	99.91%	19.22
Laundry	9,969	96.89%	5,441	99.92%	3.03
Housework	10,198	99.11%	5,445	100.00%	0.89
Outside Home	8,519	82.77%	5,444	100.00%	17.20
Routine Health	1,660	16.13%	5,283	97.02%	80.89
Special Health	2,468	23.98%	3,575	65.65%	41.67
Being Alone	2,346	22.80%	5,379	98.78%	75.98

ADL	Low End		High End		% Difference
Eating	321	3.11%	4,562	83.78%	80.67
Bathing	5,478	53.24%	5,439	99.89%	46.65
Grooming	2,709	26.33%	5,354	98.33%	72.00
Dressing	2,339	22.73%	5,410	99.36%	76.63
Transfer	2,247	21.84%	5,265	96.69%	74.85
Continence	832	0.08%	4,977	91.40%	91.32

¹ Level of impairment is defined as a score of 2 or 3 on each item.

Scores in Column B reflect the level of impairment or need that remains once assistance received from family or friends has been considered. Assistance from family and friends for a specific impairment can range from no assistance at all, in which case the impairment level noted in Column A remains the same, to complete assistance, in which case the impairment is fully compensated for by informal care provided. High- and low-end DON comparisons of the distribution of DON scores on Column B are an important indicator of unmet need for assistance. Persons scoring a 2 or 3 on Column A (indicating need for considerable or total assistance performing an activity) who also score a 2 or 3 in column B (client cannot perform the essential elements or any of the activity and need for assistance is not met most or any of the time) are seriously impaired and have either no or questionably secure help from

family or friends. This combination of high impairment and low informal care assistance causes these clients to be at particularly high risk for continuing to be maintained in the community.

Table 11 presents the number and percent of clients with scores of 2 or 3, indicating unmet or barely met need for assistance for each item. A comparison between Column A (**Table 10**) and B (**Table 11**) shows the significant contribution of informal caregivers and other services and resources outside CCP in reducing the need for assistance by

clients with both low and high DON scores. The percentage of clients with a score of 2 or 3 in Column A is reduced by almost one-half among low-end DON score clients for many of the impairment items, including bathing, grooming and transfer. While considerable informal care assistance is also provided to clients at the high end of DON score, the percentage of these clients with a 2 or 3 in Column B representing residual unmet need for care remains high. This is because a much higher percentage of clients in the high-end group have

impairment scores of 3, indicating that they cannot perform the activity and are totally dependent on assistance from another for the activity. These clients often receive some assistance from family and friends but still need assistance most of the time, thereby having a residual unmet need score of 2.

Even with high levels of informal care assistance provided to high- and low-end DON score clients, differences between the two groups remain. Unmet residual need for assistance for several IADLs is high for both high- and low-end clients (e.g., laundry, housework). Compared to low-end DON score clients, however, considerably more clients at the high end have high levels of unmet need for ADL impairment, including unmet need for assistance for eating, bathing, grooming, dressing, transfer and continence. Finally, another major difference between high-end and low-end DON score clients can be seen in their ability to be left alone for short periods of time and in continence. Over 70% of high-end clients have scores of 2 or 3 in Column B for each of these two critical items. These findings identify clear

Table 11:
Unmet Need for Assistance (Column B)
Low End (29-36) and High End (68-100) DON Score¹

IADL	Low End		High End		% Difference
Manage Money	204	1.98%	1,054	19.36%	17.38
Telephone	597	5.80%	4,042	74.23%	68.43
Meal Prep	4,846	47.10%	4,956	91.02%	43.92
Laundry	8,830	85.82%	5,089	93.47%	7.65
Housework	9,486	92.19%	5,091	93.50%	1.31
Outside Home	4,398	42.74%	4,893	89.86%	47.12
Routine Health	645	6.27%	3,922	72.03%	65.76
Special Health	50	0.49%	730	13.40%	12.91
Being Alone	929	9.03%	4,530	83.19%	74.16

ADL	Low End		High End		% Difference
Eating	158	1.54%	3,496	64.21%	62.67
Bathing	2,810	27.31%	5,183	95.19%	67.88
Grooming	1,512	14.70%	4,887	89.75%	75.05
Dressing	1,564	15.20%	5,008	91.98%	76.78
Transfer	715	6.95%	4,512	82.86%	75.91
Continence	162	1.58%	4,004	73.53%	71.95

¹ Level of unmet need is define as a score of 2 or 3 on each item.

differences between low-end and high-end CCP clients that indicate that these clients have different impairments that translate to needs for different types and level of services. Clearly, clients at the high end of DON scores have considerably more impairment and unmet need for care, especially in basic ADLs. They are also more likely to have special needs as shown by their higher impairment and residual unmet needs on the important items of continence and ability to be left alone.

In order to determine the adequacy of the current SCM structure for meeting the needs of upper-end clients, patterns of impairment and unmet need were compared to services provided. **Table 12** provides a summary of home care aide service units provided for each total DON score category including the three groups comprising the upper end (68-78, 79-87 and 88-100). Included in the table are mean and median units of home care aide services used by DON category, the Service Cost Maximum units and the average weekly hours of home care services utilized by the SCM and actually used. Across all DON categories the mean units used were less than the SCM units. Some clients used more units of service than the SCM.

Table 12:
Home Care Aide by DON Score Category: Service Cost Maximum (SCM) and Use

Category by Total Don Score	N	Mean per month	Median	Min.	Max	SCM max. units per month*	SCM hrs. per wk. per client	Mean hrs. per wk. utilized	Mean hrs. per day utilized**
29-32	4,290	12.17	12.00	1.00	52.00	25	5.0	2.4	.42
33-36	5,999	21.07	20.00	1.00	101.00	41	8.2	4.2	.60
37-45	1,1370	29.88	30.00	1.00	88.00	62	12.4	6.0	.86
46-56	8,534	41.45	44.00	1.00	145.00	77	15.4	8.3	1.19
57-67	8,667	61.36	66.00	1.00	176.00	101	20.2	12.3	1.76
68-78	3,120	75.72	88.00	1.00	221.00	116	23.2	15.1	2.16
79-87	2,083	106.91	111.00	3.00	301.00	158	31.6	21.4	3.06
88-100	242	125.85	132.00	3.00	351.00	184	36.8	25.7	3.67
Total	4,4305	42.73	36.00	1.00	351.00				

*Based on 5 week month, 2006 SCM.

**Based on a 7 day week

However, these clients are the rare exception and are few in number. This might be explained by the policy of temporary service increase that allows additional services for persons coming out of nursing homes and/or hospitals. Upper-end DON score clients used between 15.1 and 25.7 mean hours of home care aide services per week (see **Table 12**). Assuming that home care services are provided seven days per week, this represents an average of 2.16 to 3.67 hours per day for home care services for these upper-end DON score clients. This number of hours may be sufficient to address unmet needs for many IADL tasks that are associated with traditional home care services (e.g., meal preparation, housework, laundry), but may not be sufficient to address the high level of unmet needs experienced by clients with more basic ADL needs such as bathing and continence. These unmet needs are commonly provided by personal care services. There is also a potential for cost savings or cost neutrality if personal care attendant services were to be

provided as part of the Service Cost Maximum, insofar as the current cost for personal care (\$9) is less than homemaker services (\$15).

D. Translate an adequate/flexible service package into an adequate SCM methodology/schedule. Project program costs based on a modified SCM schedule.

Several analyses were conducted to address this task. First, as shown in **Table 13.1**, SCMs were compared to mean costs of visits actually used and the proportion of SCM total cost that is attributable to each DON score interval and the contribution of utilization of home care aide visits by clients within each DON score category to total home care units used. The analyses shown in **Table 13.1** indicate that the mean costs for services *used* are substantially lower for every DON score category than the SCM limits for that category. Mean costs for homemaker services used as a percent of the SCM limit range from a low of 43% of utilized costs for clients with DON scores of 29-32 to highs of 68% of utilized costs for clients with scores of 79-87 and 88-100. The low costs of actual services used becomes even more apparent when total actual service costs are compared to total costs utilized by the SCM. Clients actually use about \$25.7 million of the \$45 million, or 56.9% of what is possible. These findings indicate that the program is very tightly managed at present.

Table 13.1:
Comparison of SCM (2006, 2008) with Actual Home Care Aide Use by DON Score Category¹

Total DON Score	N	Percent of Total Sample	SCM, 2006 per Person per Month	SCM, 2008 per Person per Month	Cost of Average Home Care Aide Used per Client	Total Cost Home Care Aide Used by DON Category
29-32	4,290	9.7%	\$341	\$384	\$165.81	\$711,345
33-36	5,999	13.5%	\$559	\$629	\$286.98	\$1,721,595
37-45	1,1370	25.5%	\$845	\$951	\$406.99	\$4,627,422
46-56	8,534	19.2%	\$1,049	\$1,180	\$564.61	\$4,818,388
57-67	8,667	19.6%	\$1,376	\$1,548	\$835.71	\$7,243,075
68-78	3,120	7.0%	\$1,580	\$1,778	\$1,031.24	\$3,217,480
79-87	2,083	4.7%	\$2,152	\$2,421	\$1,456.12	\$3,033,106
88-100	242	0.5%	\$2,507	\$2,820	\$1,714.09	\$414,811
Total:	44,305	100%	\$45,320,849	\$50,992,980	\$25,787,251	\$25,787,223

Weighted SCM Mean: 2006 = \$1,022.93; 2008 = \$1,150.95

The second part of this analysis, shown in **Table 13.2**, indicates that clients in DON score category 57-67 account for the highest percentage (26.3%) of SCM dollars approved, followed by clients with scores of 37-45 (21.2%) and those with scores of 45-56 (19.7%). All other DON score categories account for 11% or less, with the highest-scoring category accounting for only 1.3% of costs. In terms of actual units of service *used*, a similar pattern is seen.

Table 13.2:
Home Care Aide use as Percent of SCM by DON Score Category¹

Total DON Score	N	% of Total Sample	IDoA SCM 2008 per Person per Month	Monthly Cost Home Care Aide Used	Home Care Aide as % of Total SCM 2006	% of Total SCM 2008	% of Total Home Care Aide Used
29-32	4,290	9.7%	\$384	\$711,345	3.23%	3.23%	2.76%
33-36	5,999	13.5%	\$629	\$1,721,595	7.40%	7.40%	6.68%
37-45	11,370	25.5%	\$951	\$4,627,422	21.20%	21.20%	17.94%
46-56	8,534	19.2%	\$1,180	\$4,818,388	19.75%	19.75%	18.69%
57-67	8,667	19.6%	\$1,548	\$7,243,075	26.31%	26.31%	28.09%
68-78	3,120	7.0%	\$1,778	\$3,217,480	10.88%	10.88%	12.48%
79-87	2,083	4.7%	\$2,421	\$3,033,106	9.89%	9.89%	11.76%
88-100	242	0.5%	\$2,820	\$414,811	1.34%	1.34%	1.61%
Total:	44,305	100%	\$50,992,849	\$25,787,223	100%	100%	100%

Weighted SCM Mean: 2006 = \$1,022.93; 2008 = \$1,150.95

Third, SCM and actual utilization were compared to two Medicaid nursing home reimbursement rates: mean monthly nursing component of the reimbursement rate and 60% of the nursing component of the rate. These analyses are shown in **Table 14**. When the monthly per-person 2008 SCM is compared to the mean nursing component of the reimbursement rate, all clients in all DON categories fall below the nursing component rate, with the exception of the two highest DON categories (79-100), which comprise 5.2% of clients. However, when the actual cost of service use is compared, all clients in all DON score categories have costs that are lower than the nursing component of the reimbursement rate. The total SCM monthly cost of \$45,320,849 was divided by the total number of active clients (44,305) to compute an average per-person monthly SCM of \$1,023. This 2008 SCM per capita cost is less than \$1,064, which is 60% of the average nursing component of the rate. When the total monthly cost of actual home aide service used (\$25,787,251) is divided by 44,305 active users, the monthly per capita CCP cost is \$582 compared to \$1,064, which represents 60% of the nursing home rate. Finally when the monthly per capita cost of services used for CCP (\$582) is compared to the total mean nursing component of the rate (\$1,773), the mean cost of home care aide service use is currently 32.8% of the rate.

Table 14:
SCM and Actual Utilization Expenditures as Percents of Nursing Home Reimbursement Rates
by DON Score Category¹

Total DON Score	N	% of Total Sample	IDoA SCM 2008	% Mean of Monthly Nursing Component Nursing Home Rate: \$1,773.82	2006 Rate Home Care Aide Used Cost per Person	% of Total Home Care Aide Used	% Mean of Monthly Nursing Component Nursing Home Rate: \$1,773.82
29-32	4,290	9.7%	\$384	21.65%	\$165.81	2.76%	9.35%
33-36	5,999	13.5%	\$629	35.46%	\$286.98	6.68%	16.18%
37-45	11,370	25.5%	\$951	53.61%	\$406.99	17.94%	22.94%
46-56	8,534	19.2%	\$1,180	66.52%	\$564.61	18.69%	31.83%
57-67	8,667	19.6%	\$1,548	87.27%	\$835.71	28.09%	47.11%
68-78	3,120	7.0%	\$1,778	100.23%	\$1,031.24	12.48%	58.14%
79-87	2,083	4.7%	\$2,421	136.48%	\$1,456.12	11.76%	82.09%
88-100	242	0.5%	\$2,820	159.90%	\$1,714.09	1.61%	96.63%
Total:	44,305		\$45,320,849		\$25,787,251	100%	

Weighted SCM Mean: 2006 = \$1,022.93; 2008 = \$1,150.95

These analyses demonstrate that there is a considerable gap between levels of service used, SCMs and Medicaid nursing home reimbursement rates. This gap potentially indicates an opportunity to expand the service options that CCP provides while still remaining under the Medicaid nursing home reimbursement rates. Based on our analyses of impairment and residual need for care, services that should be explored include personal care, medication management and short-term respite. As noted earlier, clients in the two highest DON categories (79-100) receive on average 3 to 4 hours of homemaker services per day, seven days per week. If we estimate that this translates on average to 24.5 hours of homemaker services per week at \$15 per hour, it amounts to \$367 per week. If clients had the option to choose personal care services instead, the same \$367 would cover 41.7 hours of service (6 hours per day). Another way to increase the adequacy of services provided, especially for clients in the high DON score categories, would be to enable clients to take advantage of the entire SCM. For example, the SCM in the 88-100 DON range is \$2,507. If that amount is divided by 24.5, it would result in at least 6 hours of homemaker care, seven days per week. Other service option estimations are possible but require more information about unit costs for services like medication management and short-term respite.

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SECTION III: Illinois' Community Care Program and Six Best Practice State Programs

In order to understand how Illinois' approach to determining eligibility and allocating service dollars compares to the best practices in other states, advice was sought from two national experts – Robert Mollica, Senior Program Director at the National Academy for Health Policy in Maine, and Susan Reinhard, Senior Vice President for Public Policy at the American Association of Retired Persons. They were asked to identify states that they consider to have best practices in determining service eligibility for older adults and persons with disabilities, in developing adequate care plans, and in allocating resources to maintain people in their homes and in the community.

Mollica and Reinhard recommended **Vermont, Washington State and Wisconsin**. Both Washington and Vermont have clearly articulated rebalancing intentions, and each has aggressively implemented strategies that enable a person to have equal access either to home and community-based services (HCBS) or to a nursing facility. Over the years, Washington officials continue to evaluate their processes in order to improve access to HCBS. Washington is one of the few states to actually allocate a greater percentage of its Medicaid long-term care spending for older adults and adults with physical disabilities to HCBS than it does to nursing home care. Vermont's Choices for Care program is designed to provide equal access, based on choice, to HCBS and to nursing homes for anyone eligible for Vermont's Choices for Care program. The state is working hard to address barriers to either option, including rapid financial eligibility determination, availability of medical and social services, and an adequate supply of nursing home beds. Mollica and Reinhard suggested Wisconsin because that state is now expanding its pilot managed care program statewide. Known as Family Care, the program offers eligible persons a wide range of service options. The expansion, announced by Governor Jim Doyle in 2006, followed an independent study concluding that the cost of this managed care approach was \$452 per person per month less than for a comparable fee-for-service population receiving care.

As a result of discussions with the Older Adult Services Advisory Committee's Services workgroup, the research team added **Arizona, Minnesota and Ohio**, states that Illinois often looks to for comparisons: Ohio, because it shares population and program similarities with Illinois; Minnesota, for its transition initiative and the evolution of its integrated long-term care system; and Arizona, which – until 1982, when it introduced a Medicaid 1115 Research and Demonstration Waiver – was the only state that did not have a Medicaid program under Title XIX. While the purpose of the states' programs is similar, each takes a different approach in allocating resources to meet the needs of vulnerable citizens. There isn't a single best model to adapt to Illinois, but there are program aspects of these states that can be useful to Illinois government, advocates and policy makers.

HMPRG staff conducted interviews with key informants who were knowledgeable about the programs in each respective state. (See Appendix I for a list of State Contacts) When information was available, questions addressed the differences between programs for the aged and the physically disabled. The informants directed interviewers to documentation on their programs, which further illuminated issues of greatest interest to this study.

While these interviews were limited to the issues in this particular study, many other issues suggested themselves for analysis at a future date. Keeping in mind the differences between aging and disabilities, the following questions were asked:

- How are programs administered?
- How does a person become eligible for the State Waiver Program, and how is eligibility determined?
- How is the plan of care developed and how does this relate to the eligibility determination?
- What services are offered and available?
- How is the program funded, and how do they determine how resources are allocated to individuals?
- How do they measure adequacy of the service package?

One final note: the fact that the selection includes states that have elected to convert to managed care or capitated models does not imply a bias on the part of the research team either for or against this methodology or fee-for-service.

ILLINOIS

Background

The Illinois Department on Aging (IDoA) is the state agency responsible for developing and overseeing programs to enable eligible individuals age 60 and older, which otherwise might need nursing home care, to receive care in their homes and communities. One of the primary programs administered by the Department is the Medicaid Home and Community-based Services waiver program, called the Community Care Program (CCP). To operate the CCP, the Department contracts with private agencies to provide adult day care, homemaker, emergency home response, and case management services. In addition to these core services, several other home and community-based services are offered on a demonstration basis in certain regions of the state.

The programs of the IDoA were originally developed in accordance with the federal Older Americans Act. In the late 1970s and early 1980s, the federal government, which had paid for nursing home care through the Medicaid program for eligible individuals, implemented opportunities for states to 'waive' certain Medicaid requirements and serve specific populations with home and community services as an alternative to nursing home care. Among the requirements of these Home and Community-based Services (HCBS) waivers was the stipulation that the programs

overall do not cost more than the cost of nursing home care for Medicaid-eligible individuals (cost neutrality) and that the functional eligibility requirements for enrollment be the same for community services as they are for nursing home placement. In Illinois, this functional eligibility is defined as a score of 29 or more on the Determination of Need (DON) tool, an assessment of a person's ability to perform essential and instrumental activities of daily living.

In response to the availability of federal funds to augment the state's investment in care programs for Illinois seniors, in the early 1980s IDoA applied through the state Medicaid agency and received a Medicaid 1915(c) waiver to provide home and community-based services through the Community Care Program to eligible seniors over the age of 60. So as not to terminate services for individuals who were already being served, the same services were offered to non-Medicaid-eligible seniors within certain income guidelines. In 1982 a lawsuit resulted in a consent decree that anyone eligible for the Community Care Program, regardless of Medicaid eligibility, had to be provided with services within 30 days, and that no waiting list could be implemented. As a result of various interpretations of this consent decree, the Community Care Program serves both Medicaid and non-Medicaid-eligible individuals with no waiting list, and is considered an entitlement program.

The Community Care Program serves approximately 50,000 individuals annually with home and community-based services, and is well-known throughout the state. While some clients become enrolled in the program as an alternative to nursing home care, many people access the program when they or their families realize they need some help living independently. The Department has had a system for diversion and transition from nursing home care for many years. Since July 1996, the Department has been mandated to provide assessment and screening for all nursing home applicants prior to admission using the DON tool. This includes those seeking Medicaid to cover the nursing home costs, persons using Medicare coverage for skilled nursing or rehabilitation, or those who pay privately for services. This program is known as Choices for Care.

The Department contracts with 55 public and not-for-profit social service agencies that it designates as Case Coordination Units (CCUs). The CCUs serve as entry points to long-term care, including home and community-based services, and employ case managers who are trained and certified by the Department to conduct assessments, develop care plans, act as advocates and provide linkages to services for all Illinois seniors age 60 and older. The CCU may designate the discharge planners at the hospital to perform hospital and community-based screenings if training and certification by the Department has occurred.

In accordance with federal Older Americans Act regulations, the Department has divided Illinois into 13 Planning and Service Areas (PSAs). The PSAs in Illinois are each managed and served by an Area Agency on Aging (AAA). The Department works in partnership with these agencies: 12 not-for-profit corporations and one unit of local government, the City of Chicago. AAAs have the primary task of planning and

coordinating services and programs for older people in their respective areas. The AAAs receive funding from the Department based on a formula that takes into consideration the number of older citizens and minorities in that area, as well as the number living in poverty, in rural areas, and alone. Like the Department, AAAs are not, as a rule, direct service providers. AAAs contract with local agencies that provide services to the older people who live in the same community.

Illinois' Community Care Program is one of the largest home and community-based services programs in the country. Over the past five years participation has grown 55%, due in part to increases in the number of people over the age of 60, as well as changes to the program through a legislative initiative that increased the asset limit for eligible individuals from \$10,000 to \$17,500. As mentioned above, CCP is an entitlement program. Any comparisons to other states must take into account that CCP serves *both* Medicaid and non-Medicaid-eligible seniors.

The State's Division of Rehabilitative Services Home Services Program (HSP), which serves individuals under age 60 with disabilities as an alternative to institutional care, was created at about the same time as the Community Care program.³ This program provides a broader array of services than CCP, and allows participants to hire, supervise and dismiss their personal assistants. Similar to the Department on Aging's Community Care Program, the Home Services Program has a state-funded component and a Medicaid 1915(c) waiver component and serves both Medicaid-eligible and non-eligible persons. The Illinois Department of Human Services is the administrative agency for the disability waiver, as designated by the Illinois Department of Health and Family Services, the state Medicaid agency.

Community Care Program Mission/Vision/Values

"Established in 1979 by Public Act 81-202, the Illinois Department on Aging's Community Care Program helps senior citizens, who might otherwise need nursing home care, to remain in their own homes by providing in-home and community-based services ... aimed at assisting seniors to maintain their independence and providing cost-effective alternatives to nursing home placement. The Community Care Program provides services to any person who applies for the program and meets all current eligibility requirements."⁴

Eligibility Determination

The Community Care Program services individuals who are 60 years old or older; are U.S. citizens or legal aliens; are residents of Illinois; have non-exempt assets of \$17,500 or less (non-exempt assets do not include home, car or personal furnishings); and have an assessed need for long term care (scoring 29 points or higher on the Determination of Need form). Although the level of income does not affect eligibility for the program, an income level indexed to the Federal Poverty

³ Note that HSP also serves persons 60 and older who have aged into the program.

⁴ Illinois Department on Aging website <http://www.cbrx.il.gov/aging/1athome/ccp.htm>, viewed 2/28/09.

Level is established for each client to determine the client's ability to contribute to the cost of care (client co-pay).

Eligibility for the Community Care Program is determined by case managers employed by Case Coordination Units (CCUs), agencies throughout the state with which IDOA contracts to provide assessments and eligibility determination for nursing home eligibility and for home and community-based care.

Case managers must have a BSN, BA or BS in health or social science, social work or health services administration, or be an RN (supervisor) or LPN (case manager). Case managers assess eligibility for services using the Determination of Need (DON) and financial eligibility. A person receiving 29 points on the DON, and whose assets are under \$17,500, is eligible to receive services under the Community Care Program. The DON measures a person's ability to manage basic Activities of Daily Living ADLs and Instrumental Activities of Daily Living (IADLs), as well as unmet needs. An additional 10 points are added to the score for those who score 20 or lower on the MMSE, a screening tool for cognitive impairment. People must be notified of eligibility and receive services with 30 days of being assessed. People who are eligible for CCP are required to apply for Medicaid and enroll if they are eligible, but services may start prior to making application.

Medicaid eligibility determination is addressed by local Human Services offices, administered through the Illinois Department of Human Services. IDoA-funded case managers conduct a financial screening to assess possible eligibility for Medicaid, and then assist the client in completing the application for Medicaid, assembling required documentation, and following the process through to eligibility determination.

Care Plan Development

The number of points scored by the case manager on the DON as a result of a face-to-face interview determines the dollar amount and hours of services that the person is entitled to receive. Home Care Aide Services (previously called Homemaker Services) and Adult Day Services each have a separate schedule that defines dollar amounts, known as Services Cost Maximums (SCMs), for ranges of DON scores. The Service Cost Maximum schedule was initially linked to nursing home and residential care services rates as defined by the state Medicaid agency. However, through years of budget challenges and changes to the rates paid for the services, the current schedule allows for limited variation in plans of care, and may not provide adequate services to support a person at the highest need levels to live independently in the community.

In October 2006, the IDoA began to pilot a new Comprehensive Care Coordination assessment. Based on recommendations from experienced case managers, the new tool assesses the client's needs in several domains and assists the case manager in developing a plan of care, regardless of eligibility for CCP. For example, the comprehensive assessment includes sections that address nutritional needs and the

safety of the client's physical environment, which may be addressed by services under the Older Americans Act and not the Community Care Program. The new tool also has several addenda that are available to the case manager to assess the client's needs related to issues such as depression and caregiver stress, if the overall assessment indicates that these areas may impact the plan of care.

The plan of care is calculated based on a weekly number of hours of care for five weeks in a month. Because this results in more authorized hours of service than days in a month, the amount of service a client utilizes each month is about 75% of what is authorized. Case managers also tend to be conservative in their care plan development, especially for the lower scores in a DON range, so that more service can be provided to a client if it is needed prior to the next reassessment.

The Home Services Program, administered through the Division of Rehabilitative Services, employs nurses and other contractual assessors to administer the DON and determine eligibility for services for persons with disabilities. In general, most clients of the HSP employ their own workers, who are paid directly by the state for hours up to the HSP schedule of Service Cost Maximums. Also based on the client's DON score, the HSP schedule and the CCP schedule for Service Cost Maximums, which started out at similar levels, have become drastically different over time. In 2008, the Service Cost Maximum for the lowest DON range was four times more for HSP than for CCP (\$1,548 vs. \$384). While the disparity is less dramatic at the higher ranges, the CCP amount is still only 84% of the HSP Service Cost Maximum for individuals with DON scores from 79 to 100.

Services Offered Through the Community Care Program

Homemaker/Personal Care Services

Adult Day Services

Emergency Home Response

Case Management

Additional services, including home-delivered and congregate meals, are available through Older Americans Act funds through providers contracted through the regional Area Agencies on Aging; but these are not part of the entitlement program and there may be waiting lists. Respite funds are also available through some Area Agencies on Aging, but these are very limited and AAAs report running out of funds long before the end of the year.

Self-Directed Attendant Care

The Community Care Program provides agency-based care through a care plan that is consumer-centered, but not consumer-directed. Individual clients may request that a family member or friend be their paid caregiver, but the person must be employed by an IDoA-contracted provider agency.

Since 2004, Illinois has participated in the national Cash and Counseling demonstration program. It was implemented in four areas of the state in November

2007, and currently serves 185 seniors who are employers and directors of their own services. All of the clients participating in this program employ their own workers, and some but not all are saving a portion of their monthly Service Cost Maximum (based on the DON ranges and authorized at 100% of the available amount) for one-time services or other ongoing services. IDoA has contracted with an agency to serve as the Fiscal/Employer Agent, with the responsibility of assuring that tax forms required for the clients to serve as employers are submitted on a timely and accurate basis, and to process payroll and maintain client accounts. The program is being evaluated, and there are no plans to expand it in its current form.

For individuals under the age of 60, the Illinois Department of Human Services (IDHS) Home Services Program (HSP) has offered a consumer-directed option for its customers for many years. The purpose of this program is to provide services to individuals with severe disabilities so they can remain in their homes and be as independent as possible. Many of these people are at risk of moving into a nursing home or other facility. Personal Assistants (PAs) provided under the HSP are consumer-directed. The PA provides assistance with household tasks, personal care and, with permission of a doctor, certain health care procedures. PAs are selected, employed and supervised by individual customers and paid directly by the Illinois Department of Human Services.

Budgeting and Resource Allocation

The Medicaid waiver assures that Illinois receives a federal financial match of 50% for every dollar spent on home and community-based services for people who are enrolled in Medicaid. Approximately 50% of the services provided in CCP are received by clients who are enrolled in Medicaid, meaning that approximately 25% of CCP's budget revenue is from the federal government while 75% of the close to \$500 million cost of the care provided comes from state General Revenue Funds.

Each year, the General Assembly reviews the budget projections for all departments, including the Department on Aging, the Department of Human Services, and the Department of Health and Family Services (Medicaid agency), and considers the budget proposals separately. The annual appropriation request for the Community Care Program has increased over the past five years and is approaching \$500 million, reflecting rate increases, increased client loads due to the expansion of the asset level, and increased numbers of people aging into the program. While the program may be effective in enabling older people to remain in their homes for longer periods as they age and delay nursing home placement, the State of Illinois does not yet have a mechanism to consider budget trade-offs between institutional and community care.

Measuring Adequacy

The Illinois Department on Aging has a quality assurance process in place to examine the adequacy and quality of services provided. The state is in the process of completing a reapplication for the Medicaid 1915(c) waiver, and is improving and streamlining its use of data and reports to better monitor the program internally. As

mandated by the federal Centers for Medicare and Medicaid Services, services provided under the waiver must meet certain standards, and the administrative agency (in Illinois, delegated from the Department of Health and Family Services to the Department on Aging) must assure that these standards are communicated and complied with through procurement, contracting and ongoing quality assurance activities. Case Coordination Units play a large role in assuring that care plans are adequate and that services are provided. All clients receive information regarding their rights and ability to complain or challenge any service determinations that may not meet their needs.

The 13 regional Area Agencies on Aging also play a part in assuring that needs of seniors in their areas are met. In the three-year service planning cycles mandated through the federal Older Americans Act, AAAs conduct needs assessments and hold public meetings throughout their service areas, in order to identify areas or individual needs that are not being served within the current service structure. The Department on Aging consolidates these plans into a single state plan.

ARIZONA

Background

In October 1982, Arizona began its Medicaid program, the Arizona Health Care Cost Containment System (AHCCCS), as a Section 1115 Demonstration Waiver. (See Appendix B for Waiver definitions). From October 1982 until December 1988, AHCCCS covered only acute care services, except for 90-day post-hospital skilled nursing facility coverage. In November 1988, CMS granted a five-year extension to allow Arizona to implement a capitated long-term care program for the elderly, physically disabled and developmentally disabled populations. This program, the Arizona Long Term Care System (ALTCS), also operates under an 1115 Research and Demonstration Waiver, but is administered separately from the acute care program.⁵ In 2007, approximately 22,000 people were served under ALTCS (15,562 elderly and 6,435 persons with disabilities).

AHCCCS Mission/Vision/Values

- Mission: Reaching across Arizona to provide comprehensive, quality health care to those in need
- Vision: Shaping tomorrow's managed care ... from today's experience, quality and innovation
- Values: Passion, Community, Quality, Respect, Accountability, Innovation, Teamwork, Leadership
- Credo: Our first care is your health care.

⁵ "Arizona Demonstration Fact Sheet", November 6, 2006
<http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/downloads/Arizona%20Health%20Care%20Cost%20Containment%20System%20Fact%20Sheet.pdf>

Eligibility Determination

The Arizona Long Term Care System (ALTCS) program is for aged (65 and over), blind or disabled individuals who need ongoing services at a nursing facility level of care.

Both financial and medical eligibility are determined by the AHCCCS Division of Member Services. After financial eligibility has been established, a registered nurse or a social worker uses the Elderly and Physically Disabled Pre-Admission Screening (EPD PAS) tool to describe the customer's functional ability, current medical status, nursing and social needs. According to Sandy Alderman, ALTCS Eligibility Manager, the tool does not penalize people for having a support system and does not gather caregiver information as part of eligibility determination. The tool includes a personal interview with the customer and caregiver and a review of pertinent medical records or information.

"Our tool, the EPD PAS, is designed with our own definitions with a focus on orientation to person, place and time," Alderman said. "We tried to pare down the tool to eliminate items not related to what we need ... for managed care eligibility we found that we don't need to know details, only if the person is eligible."

In 2006, recognizing that they were operating a fully capitated program, ALTCS revised the EPD PAS to eliminate items found to be unrelated to eligibility determination. Officials reviewed tools from Wisconsin and other states and convened focus groups to assess what worked and what didn't. Based on the review, they made major revisions that enable the assessor to determine if the person is 'in' or 'out' of the program.⁶ There is no cap on the number of people who can be admitted to ALTCS.

Meeting or exceeding a threshold score on this screening establishes initial eligibility for institutional level services. Weighted functional and medical factors are evaluated and assigned a numerical value. The threshold score, or point at which a customer becomes eligible, is determined by a formula based on those scores. The purpose of the functional/medical threshold is to ensure that customers deemed eligible for ALTCS require a nursing facility level of care – but less than that provided in an acute care setting, and more than that required by a supervisory/personal care setting. Eligible ALTCS customers will have a functional and/or medical condition that impairs functioning to a degree that interferes substantially with their capacity to remain in the community and results in long

⁶ Under Special Terms and Conditions, AHCCCS Medicaid Section 1115 Demonstration, "Effective 10-01-1999, the provision of home- and community-based services (HCBS) to the elderly and physically disabled will no longer be capped. In the absence of a limit, AHCCCS will report annually on current placements and ongoing activities for expanding HCB services and settings. The report will be due by 3-31 of each year."

term limitation of capacity for self-care.⁷ Clients who meet or exceed the score become eligible for long-term care services. The EPD PAS is 22 pages long and includes both Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), but if a person is eligible, the assessor doesn't evaluate IADLs because this information is not relevant for eligibility determination.

By 2003, Arizona officials recognized that the tools being used by ALTCS were no longer sophisticated enough to support the functions of determining financial and medical eligibility for long-term care benefits. So the state rolled out its new interactive interviewing system, AHCCCS Customer Eligibility (ACE). The EPD PAS was entered into ACE, which calculates three scores: a functional score, a medical score and a total score, and compares that to the established thresholds.⁸ Eligibility requires a score of 60 or more. However, if the professional believes that underlying factors may cause risk to the person, a physician review is justified and the determination can be overridden. The form allows ample space for professional judgment and comment.⁹ Medical and financial case documentation on the customer is stored by converting paper documents into an electronic database called Fortis.

Anyone who is financially and medically eligible may receive the services. Alderman pointed out, "The score takes account of multiple minor impairments and allows exceptions based on professional judgment." According to a report from the Alzheimer's Association, the tool assesses factors that are relevant to people with dementia. It provides different threshold scoring requirements for people with and without dementia.¹⁰

Care Plan Development

After a person is deemed eligible, he/she is asked to select a Managed Care Organization (MCO). There are a total of seven MCO program contractors throughout Arizona, but in rural areas people may have only one choice. The MCO assigns a case manager who must see the client and start the assessment process within 10 days of enrollment. Qualifications require that the case manager be a degreed social worker, a licensed registered nurse or a person who has had a minimum of two years experience in providing case management service to persons who are elderly and/or have physical or developmental disabilities. The number and frequency of authorized services received by a member is determined through an assessment of the member's needs by the case manager. The case manager does this with the member and/or the member's family, guardian or representative, in

⁷ Arizona Long Term Care System Appendix 10A: Preadmission Screening Manual for Elderly and Physically Disabled (EPD), Nov. 1, 2006.

http://www.azahcccs.gov/Publications/Eligibility/chapter1000/appendix_10a.pdf

⁸ Arizona Long Term Care System Section 1010.00.

<http://www.ahcccs.state.az.us/Publications/Eligibility/chapter1000/chapter1000.asp>

⁹ EPD2 Revised Tool. Pre-Admission Screening Revised 11-06.

¹⁰ O'Keeffe, Janet, DrPH, RN; Tilley, Jane, DrPH; Lucas, Christopher, "Medicaid Eligibility Criteria for Long Term Care Services: Access for People with Alzheimer's Disease and Other Dementias," Public Policy Issue Brief; Alzheimer's Association. May, 2006.

tandem with the completion of the cost-effectiveness study.¹¹ The process involves a review of the ALTCS member's strengths and needs utilizing a standardized instrument. Its goal is a mutually agreed upon, appropriate and cost-effective service plan that meets the medical, functional, social and behavioral health needs of the member in the most integrated setting. The case manager authorizes all non-skilled services and a physician must authorize any skilled-care services.

The MCO is required to provide an adequate number of qualified and trained case managers to meet the needs of enrolled members. A weighted value, based on a formula that uses a maximum of 96, is used to determine the number of clients per case manager. For example, institutionalized members have a weighted value of 0.8, allowing a maximum caseload of 120 clients, while HCBS members living at home have a weighted value of 2.0, allowing for a maximum caseload of up to 48 members.¹²

Services Offered under the Waiver

Acute Care services include:

- Nursing facility days
- Case management
- Behavioral health services
- Medical care acute services

HCBS includes:

- Home health
- Homemaker services
- Home modification
- Home delivered meals
- Personal care
- Adult day health and hospice care management
- Emergency home response
- Environmental modification/repairs
- Respite care (capped at 750 hours/year)
 - Adult day services
 - In-home
 - Overnight
- Transportation¹³

¹¹ AHCCCS Eligibility Policy Manual, 1201.00 Share of Cost (SOC).

<http://www.azahcccs.gov/Publications/Eligibility/>

¹² AHCCCS Medical Policy Manual, 1630, caseload management. Rev. 02/01/05.

<http://www.azahcccs.gov/Regulations/OSPpolicy/>

¹³ Arizona Demonstration Fact Sheet, November 6, 2006.

<http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/downloads/Arizona%20Health%20Care%20Cost%20Containment%20System%20Fact%20Sheet.pdf>

Self-Directed Attendant Care (SDAC Option)

Beginning in October 2007, Arizona included attendant care services in which the member can employ his/her spouse to provide 'extraordinary care.' This is defined by the federal Medicaid regulations as activities that exceed what a spouse would ordinarily perform in the household on behalf of the member if the member did not have a disability or chronic illness, and which are necessary to assure the health and welfare of the member and to avoid institutionalization. It's too soon to report on how customers have received this option. The state is also attempting to get a transitional care waiver that will enable the state to help people leave nursing homes.

Budgeting and Resource Allocation

The ALTCS is a fully capitated program. The MCO is responsible for providing all needed services including medical, skilled nursing, and home and community-based care to people who are eligible for Medicaid, and to the elderly who are dual-eligible for Medicaid and Medicare. All Medicaid state matching funds are received as appropriations from the legislature or from initiatives enacted by Arizona voters. Sources include the General Fund, Tobacco Settlement Funds, Tobacco Tax Funds and county funds.

AHCCCS pays MCO program contractors an actuarially determined, per-member/per-month amount (capitation rate) for each member in order to contract with providers to deliver ALTCS services. AHCCCS contracts with independent actuaries to develop capitation rates that are actuarially sound. Annually, actuaries review data that support rate increases or decreases. Based on that review, capitation rates are adjusted for each county. The MCO establishes and contracts rates with networks of providers that are adequate to meet the service needs of its members. Customers are not responsible for a co-payment for the services, but may share cost if they have established a trust. Trusts are established for a variety of reasons: to remove certain income or resources from the eligibility determination so as to qualify for medical benefits (a Special Treatment Trust); transfer property to heirs to avoid probate; or to make a relative or other individual the beneficiary of a trust to provide for their future needs. AHCCCS applies different policies and procedures to trusts depending on when the trust was created, whose income or resources were used to fund the trust, who created the trust and whether the trust is revocable or irrevocable.

Measuring Adequacy

According to Alan Schafer, ALTCS Manager, "We do regular annual oversight over our MCOs." In 1995, CMS and AHCCCS entered into a partnership on a Quality Management Initiative designed to measure health care outcomes with quality indicators and encounter data. AHCCCS regularly submits acute and long-term care utilization reports and Quality Indicator reports, and also conducts and publishes member satisfaction and provider satisfaction surveys, adhering to the recommendations from the Centers for Medicare and Medicaid Services. The program is designed to identify and document issues related to assuring that

services provided to members meet or exceed established standards for access to care, clinical quality of care and quality of service.¹⁴

Arizona Highlights

1. Determining eligibility and allocating service dollars for older adults:

- The Arizona Long Term Care System (ALTCS) is targeted to people eligible for Medicaid who are at imminent risk of nursing home placement as identified by the Elderly and Physically Disabled Pre-Admission Screening (EPD PAS). Arizona sets a high bar for eligibility. Those not eligible are referred to the State Unit on Aging.
- The EPD PAS tool is designed *only* to determine who is eligible or not eligible for Medicaid-supported long-term care services. It does not consider caregiver support or needs in the eligibility tool. These are considered in the care planning process. EPD PAS is a weighted tool measuring medical, functional and social factors. It is now computerized as the AHCCCS Customer Eligibility (ACE) tool.
- Assessors can override the ACE tool. They are expected to use professional judgment when a person falls within three points of eligibility cut-off and they can document underlying factors that place the person at risk.
- There is a clear separation of eligibility determination from the assessment and care planning functions.
- Social workers and nurses who assess eligibility for ALTCS are employees of the Arizona Health Care Cost Containment System (AHCCCS). The Department places strong emphasis on the professional skills and judgment of the assessors.
- AHCCCS is creating a Uniform Assessment Instrument (UAI), a web-based tool to determine eligibility for all target populations across all agencies by using a federal grant it received for the purpose of implementing the Arizona Aging and Disability Resource Centers (AzADRC).
- MCO caseloads are calculated on a weighted scale, assuring that the care manager has sufficient time to help clients manage their services.

2. Service cost dollar determination:

- Capitated program averaging \$2,336 per client per month in 2007.
- Managed Care Organizations (MCOs) are at full risk to provide services needed by the client including nursing home care and home and community-based services.
 - Required to provide a panel of providers who can offer a broad range of services.
- Independent actuaries develop the capitation rates and adjust them yearly by geographic area.

¹⁴ Rogers, A.D., "Arizona Health Care Cost Containment System: Quality Assessment and Performance Improvement Strategy," 12/14/2007.
http://asahcccs.gov/Publications/Reports/QualityStrategy/12_07CMS_Final QualityStrategy.pdf

3. Measuring adequacy of the benefit:

- AHCCCS and CMS have entered a partnership to measure health care outcomes with quality indicators and encounter data.
- AHCCCS publishes member and provider satisfaction surveys.

4. Structure of HCBS:

- A managed care, fully capitated system covering older people and people with physical disabilities for medical, health and HCBS.
- Combines Medicaid acute and long-term care services. Medicare reimburses the provider on a fee-for-service basis for any Medicare services provided to an ALTCS member.
- The state contracts with the MCO, which in turn assembles a panel of providers to assure that all mandated services are provided for the members.

5. Other:

In 1999, Hawaii and Arizona entered into an agreement to implement the Prepaid Medical Management Information System (PMMIS), through a joint effort between the Hawaii Department of Human Services and AHCCCS. PMMIS provides extensive information retrieval and reporting capabilities for Acute and ALTCS programs. Both states share the ongoing maintenance and operation of the system.¹⁵

Minnesota

Background

The Elderly Waiver (EW) program funds home and community-based services for people age 65 and older who are eligible for Medical Assistance (MA) and require a nursing home level of care. Under its Aging and Adult Services Division (AASD), the Minnesota Department of Human Services (DHS) operates the Elderly Waiver program under a federal waiver to Minnesota's Medicaid State Plan. Counties, tribal entities and health plan partners administer the program.¹⁶ For the past four years, the DHS has been phasing out its fee-for-service program, replacing it with Minnesota Senior Health Options (MSHO), which is an integrated Medicaid/Medicare health care/long-term care option, and with Minnesota Senior Care Plus (MSC+), a Medicaid health care/long-term care option. Much like Arizona's ALTCS for aged and disabled, acute and long-term care services in Minnesota are delivered as part of a Managed Care Organization (MCO) for dual-eligible people age 65 and older. As of January 1, 2009, anyone 65 and older who is eligible for Medical Assistance and enrolled in Medicare Parts A and B, or who has MA only, must join MSHO or MSC+.

¹⁵ "Administrative Features and Regulatory Controls in a Managed Care System," Chapter 5. http://azahcccs.gov/publications/overview/2005/Chap5_2005.pdf

¹⁶ Elderly Waiver Fact Sheet, February, 2008. <http://edocs.dhs.state.mn.us/lfsrserver/Legacy/DHS-5357-ENG>

In fiscal year 2006, all of Minnesota's managed care organizations (MCOs) were constituted as Special Needs Plans under Minnesota Senior Health Options (MSHO), and were required to provide Elderly Waiver (EW) benefits to recipients. Seniors in the EW and Medicaid program chose, or were passively enrolled into, MSHO. Arrangements were made on a county-by-county basis for interaction between the MSHO and the counties. Currently, all but seven counties provide access to one of these managed care options. As of January 1, 2009, there were MCOs in every part of the state.

There are currently 14 MCOs in Minnesota, nine of which cover people 65 and over. Nine of the MCOs are home-grown, and five are national organizations. Because Minnesota requires the MCOs to be non-profit organizations, some national MCOs have developed non-profit subsidiaries. This represents a major shift from the county unit of government-administered programs that previously characterized Minnesota's Elderly Waiver program. Currently, county units determine financial and functional eligibility and also develop care plans, as described below – but that role, based on information from Jean Wood, Aging and Adult Services Division Director, and Lisa Rotegard, Division Manager, may change. In the future, county units may only determine financial and functional eligibility, while care planning will be left to the MCOs. It is also possible that the county units will continue to conduct functional assessments and/or contract with the MCO as a provider of service. Minnesota is in the midst of a major rebalancing period.

People 64 and younger who are eligible for Minnesota Consumer Support will have the choice of whether or not to join an MCO. The state is developing products for this population, but does not plan to make enrollment mandatory in the foreseeable future. Persons with disabilities under the age of 65 may receive services from the Disability Division Community Alternatives for Disabled Individuals (CADI) Waiver program.

The Minnesota Department of Human Services contracts with three Native American tribes to administer the Minnesota Elderly Waiver (1915(c)) for their members. There is no separate waiver for tribes; they operate under the same contractual obligations as the rest of the state. All the tribes run their own services, which vary. Most tribes struggle to provide transportation services because of geographical restrictions. It was interesting to learn that the Red Lake reservation is the only tribe with a nursing home. Nursing homes are a rarity on federally recognized tribal land. Of the 572 federally recognized Native American tribes, only about 12 have nursing homes.

Purpose/Mission/Eligibility

“The Minnesota Department of Human Services (DHS) operates the Elderly Waiver,” according to the state's DHS Web site. “The Elderly Waiver (EW) Program funds home and community-based services for people age 65 and older who are eligible for Medical Assistance (MA) and require the level of medical care provided in a nursing home, but choose to reside in the community. The program is under a

federal waiver to Minnesota's Medicaid State Plan. Counties administer the program."¹⁷

Eligibility Determination

Today, the 87 county units of government administer the program, but in the future, MCOs will play a role. Currently the county units assess financial and functional eligibility and are the single point of entry for all aging services. The Long Term Care Consultation Intake Worker (a social worker or public health nurse employed by the county, but may also be a qualified worker at the MCO) administers a standardized assessment that was developed 20 years ago and has been modified over time. The assessment tool is used by all waiver programs to determine the level of care and intensity of need. In its 300 items, the tool covers ADL, IADL, behavioral, caregiver supports and MMSE. Seventy of the items are entered into the MIS system and are used to develop an 11-level need score (A through K) indicating the level of service for which a person is eligible, and this then populates a care plan. If the person being assessed is ineligible for state-funded services, the case manager can still help to develop a plan and provide the individual with information, but cannot help the person to manage the plan.

According to Wood, the assessor and client can choose to use the computer generated plan, or they can modify it. Both Wood and Rotegard felt that this part of the eligibility determination needs to be improved, and that the level of expertise and professionalism of the assessors should be reviewed in light of the authority they have. Assessors receive training, but currently are not certified. The state provides video conferences weekly on topics pertaining to care management and assessment.

Care Plan Development

Minnesota uses a computerized comprehensive care planning tool. The assessment tool develops a template of areas to be considered in the care plan and identifies providers in that county that can meet the need. It also identifies the MCO(s) available in that area. The MIS system authorizes the provider to deliver the service and to bill the state. If the person selects an MCO, the client must select services available from the MCO's panel of providers. In the current system, the Long-Term Care Consultant who determined eligibility may also develop the plan. But as all eligible clients move into MCOs, the care planning function will shift to the MCO Long Term Care Consultant.

Services Offered under the Elderly Waiver

- Adult day service
- Chore service
- Consumer-directed community supports

¹⁷ Minnesota Department of Human Services – Elder Waiver Program web page.
http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs16_137092

- Home health aides
- Home delivered meals
- Homemaker services
- Licensed community residential services (customized living services or 24-hour customized living services, family foster care, residential care)
- Home modification
- Personal care
- Respite
- Skilled nursing
- Training for informal caregivers
- Transitional supports
- Transportation

Services Provided by the MCO

- Doctor visits
- Emergency room care
- Hospitalization
- Dental care
- Lab and x-rays
- Durable medical equipment
- Prescription drugs
- Personal care attendants
- Home health services
- Home and community-based services (Elderly Waiver)
- Nursing home care
- Interpreter services
- A Care coordinator

An MSHO health plan has an option to provide additional services.

Consumer Direction

The Minnesota Consumer Directed Consumer Support (CDCS) program is statewide. However, according to Wood and Rotegard, it serves only 200-300 people, primarily in ethnic communities where people hire their family members. They indicated that the LTC Counselors require ongoing training in this option, and it is not a staple in the repertoire of services. Minnesota is one of 11 states to have received a Robert Wood Johnson Grant in 2004 and according to the Cash and Counseling website¹⁸ also received an additional \$100,000 for its “ambitious plans using innovative practices to expand significantly beyond the cash and counseling model.”

Budgeting and Resource Allocation

In FY2007 state law mandated that persons 65 and older be enrolled in managed care. As mentioned above, this enrollment was to have been completed by January 1,

¹⁸ www.cashandcounseling.org

2009. At the end of FY2007, 70 percent of Elderly Waiver clients received services through a managed care organization. The average monthly Elderly Waiver client population for FY 2007 was 17,824, with an average monthly allocation of \$2,336 (DHS forecast) per member per month¹⁹ covering Medicare and Medicaid covered services including home and community-based waiver services. The program allows from \$2,500 to \$6,000 per member per month, but more money is available for people making a transition out of a nursing home.

Nursing homes and HCBS are in the same administrative unit in the Aging and Adult Services Division of the Minnesota Department of Human Services. The EW service cost for an individual cannot be greater than the estimated statewide average medical assistance nursing home cost for that same individual and is limited by the individual's case mix classification.²⁰ Under the MSHO, Medicare and Medicaid payments are combined at the health plan level with the intent of giving care coordinators and care providers maximum flexibility to design treatment plans that will keep beneficiaries more independent, provide alternatives to higher-cost services, and prevent, defer, or reduce lengths of stay in acute and long-term care settings.²¹ The care plan is grouped into 11 levels, which also translate into cost limits. The schedule is the same whether one goes to a nursing home, HCBS or assisted living facility, or any of the other residential settings. In transitioning to the new MCO system, the state will need to mesh nursing home rates that increase based on acuity measured by the MDS and RUGS, and the HCBS rates, which go up based on the average payment rate of the industry. MCOs can cooperate across county lines to obtain services, but the counties are allocated an aggregate amount of money per person based on the county demographics. Up until now, Minnesota's Forecast Division has reviewed a variety of factors to project Elderly Waiver cost.

Measuring Adequacy

In 2006, Minnesota introduced an HCBS Waiver Review Process, which entailed detailed reviews of lead agencies for HCBS in each of Minnesota's counties on a staggered basis. The Improve Group, an outside contractor based in Minnesota, conducted on-site evaluations designed both to review the extent to which the programs meet the standards established in the CMS framework for quality, and to identify barriers to community services.²²

In 2007, the Aging and Adult Services Division (AASD) of the Minnesota Department of Human Services (DHS) implemented a statewide survey of seniors enrolled in the

¹⁹ Elderly Waiver Fact Sheet.

²⁰ Rossett-Brown, L., Elderly Waiver Program Administrator, Aging and Adult Services, (Minnesota Dept. of Human Services) "Mapping Your Way Through the Elderly Waiver: The Minnesota Age and Disabilities Odyssey," PowerPoint. August 18, 2008. libby.Rossett-Brown@state.mn.us

²¹ "Long-Term Care Capitation Models: A Description of Available Program Authorities and Several Program Examples," prepared by: The Centers for Medicare & Medicaid Services, August, 2007.

²² Kane, R.A. , Priester, R., Kane, R.L., Spencer, D., "A Year in State Management Practices for Rebalancing Long-Term Care Systems: Update of Activities in 8 states, July 2005 to July, 2006." Report to CMS, p. 12.

Elderly Waiver (EW) program. The Elderly Waiver Consumer Experience Survey was first developed and conducted through 2003-2004 with assistance from a CMS Real Choice Grant. The survey has been tested and proven to provide statistically significant results. It is conducted as part of the state's larger quality management effort to ensure programs are meeting state and federal requirements, and to identify promising practices and opportunities for improvement. This survey gathers feedback directly from consumers, with accommodations made for non-English-speaking populations.²³

Wood and Rotegard expect that the state audits conducted in the past will change dramatically over the next five years. The Department of Health Services (DHS) is still responsible for the 1915(c) waiver, but MCOs also fall under the plan because they operate under 1915(a) and (b) waivers. AASD is still working on ways to provide oversight. MCOs will contract directly with providers or with the county units of government to provide long-term care services with DHS holding them accountable for developing provider networks. DHS also will work with MCOs, providers and stakeholders to assure that long-term care services are available. QI reports in coming years will tell the story of how successful they are.

Minnesota Highlights

1. Determining eligibility and allocating service dollars for older adults:

- All dual Medicare/Medicaid eligible and Medicaid-only eligible beneficiaries 65 and older are required to enroll in Medicaid managed care as of Jan. 1, 2009, and to select a Managed Care Organization. MCOs cover medical, health and HCBS services.
- The program provides state-funded Alternative Care for people who are not Medicaid-eligible but who meet the functional/clinical standards for the Elderly Waiver (EW) program.

2. Service Cost Dollar determination:

- Minnesota officials defined budget neutrality for the state's waivers and implemented a global budgeting mechanism for all long-term care. They were careful to focus only on LTC costs and only include publicly funded long-term care services covered under Medicaid – not housing, transportation or food stamps. The rate structure includes the Medicaid state plan basic care rates; the average monthly EW payments for HCBS; and 180 days of nursing home care. The State pays nursing home costs on a fee-for-service basis after 180 days for enrollees who initially reside in the community and go to a nursing home. It pays fees for service immediately for enrollees who join MSHO directly from nursing homes.

²³ Myott, S., Research and Evaluation Analyst. "Elderly Waiver Statewide Consumer Experience Survey," Minnesota Department of Human Services, Aging and Adult Services Division, May, 2008. http://www.dhs.state.mn.us/main/groups/aging/documents/pub/dhs16_141251.pdf

3. Adequacy of the benefit was measured by:

- Contracting with the Improve Group to assure that county organizations are meeting CMS quality standards and to identify barriers to community services.
- Using a CMS Real Change Grant to develop the statistically significant Elderly Waiver Consumer Experience Survey.
- Implementing a Quality Assurance Plan for Home and Community-Based Services. Minnesota Department of Human Service (DHS) is working with the lead agencies (MCOs) to develop and implement quality assurance, including stakeholders, and developing provider network maintenance strategies.

4. Structure of HCBS:

- Risk and responsibility for medical, health and HCBS service delivery has been moved to MCOs.

5. Other:

- Minnesota significantly reduced nursing home beds since 2003 through a Voluntary Planned Closure Program, a Bed Layaway Program, and a Single Bed Incentive. The state predicts that 14,000 beds will be offline by 2020. Spending on HCBS more than doubled between FY2001 and FY2006 while spending on nursing homes decreased during this time.

OHIO

Background

In Ohio, Medicaid waiver programs for older adults and for adults with physical disabilities are administered separately, as they are in Illinois and Minnesota. Like Illinois, Ohio uses age 60 as the eligibility standard for its PASSPORT program. Ohio also has a separate Assisted Living Waiver. The state is in the process of combining these two waivers.

The Ohio Home Care Program serves people age 18-59. According to Robert Applebaum, Director of the Ohio Long-Term Care Research Project at Scripps Gerontology Center at Miami University in Ohio, "The Ohio Home Care program has a large waiting list, and there is less money in that program for clients than in the PASSPORT and the Developmental Disabilities waiver."

Ohio's PASSPORT program is one of the largest Medicaid waiver programs for older adults in the country and serves only people who are eligible for Medicaid. In 2007, PASSPORT served about 33,000 participants. In 2007 and 2008, Governor Ted Strickland and the Ohio legislature demonstrated their strong commitment to this program by adding a total of 6,700 slots. At the time of the interview in October 2008, there were no waiting lists, but Applebaum expressed concern that they may reappear, given the current poor economy. As of December 2008, the budget crisis in Ohio necessitated a waiting list.

Unlike Illinois, Ohio does not have a statewide HCBS program for people who are not Medicaid-eligible. Instead, property tax levies are collected in 64 of Ohio's 88 counties, raising amounts ranging from \$15,000 to more than \$20 million to be dedicated to services for seniors. Each county program is different, eligibility for the services varies and the types of services are unique to each area. The services funded by these revenues are administered by the local Area Agencies on Aging. Applebaum argues that the levies are a viable method for Ohio's local areas to fund services for people who need PASSPORT program services, but who are not eligible for Medicaid. "These programs are an essential backbone to the aging network,"²⁴ he said, noting that the levy continues to garner 90 percent support in the counties at each voting cycle.

The PASSPORT Program is administered by the Department on Aging, which contracts with 12 regional Area Agencies on Aging (AAAs) and one private non-profit agency (Catholic Social Services of the Miami Valley in Dayton). These 13 agencies are designated as PASSPORT Administrative Agencies (PAAs). Each PAA has a PASSPORT site director who administers the agency's PASSPORT program.²⁵ Financial eligibility is determined by the local county Department of Job and Family Services.

Finally, The Ohio Department on Aging has a long-standing relationship with the Scripps Gerontology Center. Evaluations of the PASSPORT Program as well as longitudinal studies of clients in the program are regularly conducted. An evaluation of the PASSPORT Assessment and Services was published in May 2007.²⁶

Mission/Vision

Ohio's PASSPORT Medicaid waiver program helps Medicaid-eligible older Ohioans get the long-term services and supports they need to stay in their homes. PASSPORT incorporates two primary functions: a prescreening process to determine eligibility and provide information about long-term care options available, and the development of a plan of care for in-home services by the case manager in collaboration with the consumer and revised as necessary.

Eligibility Determination

"Eligible PASSPORT participants are age 60 or older, financially eligible for Medicaid institutional care, frail enough to require a nursing home level of care and able to remain safely at home with the consent of their physician."

²⁴ Applebaum, R., Roman, S.P., Molea, M., and Burnett, A., "Using Local Tax Levies to Fund Programs for Older People: Good Politics and Good Policy?" Ed. Hudson, R.B. *The New Politics of Old Age Policy*. Baltimore: The Johns Hopkins University Press, 2008. pp. 295-304.

²⁵ McGrew, K., Brothers-McPhail, D., "Passport Assessment and Services," Scripps Gerontology Center, Miami University, Oxford, Ohio. May 31, 2007. p. 1.
http://www.goldenbuckeye.com/_pdf/ppeval2007_assessment_services.pdf

²⁶ Ibid.

Eligibility for the PASSPORT program begins with the participant filling out an application and undergoing a telephone screening from the local PAA. The screening consists of a few basic questions to determine if the individual may be eligible for PASSPORT. If this is the case, a licensed social worker (LSW) or registered nurse, employed by the PAA, conducts an in-home assessment, as required by the waiver. If the person is clinically eligible for services, Medicaid eligibility is verified or applied for through the County Department of Job and Family Services.

Ohio's assessment tool is more than 20 pages long. In a 2007 PASSPORT evaluation,²⁷ Kathryn McGrew and Denise Brothers-McPhail praised the case management and supervision system as being effective and appropriate, stating that "assessment ... is an ongoing and developmental process. Successful initial assessments capture enough information about the consumer's strengths and needs, as well as the level of informal support to institute an initial service plan." They went on to caution that the consumer and caregiver(s) should not be overwhelmed at the initial assessment and that the focus be kept "on the fundamentals." Content of this assessment includes measures of ADL, IADL and cognitive functioning. To be eligible a person:

- must need hands-on assistance with at least 2 ADLs; or
- must need hands-on assistance with at least one ADL and require help of another person to administer medications; or
- must need 24-hour-per-day supervision from another person to prevent harm to self or others because of cognitive impairment; or
- must have an unstable medical condition and require at least one skilled nursing service and/or skilled rehab service.

A Pre-Admission Screening (PAS), used for nursing home eligibility, is also administered. A caregiver assessment section was recently added, based on the 2007 evaluation and recommendations.

The 2007 study of Assessment and Services found that the assessors exhibited strong assessment skills, good professional judgment and discretion in negotiating the care plan with a consumer.²⁸ The assessment can result in several outcomes, including PASSPORT enrollment. If enrollment takes place, an initial service plan can be negotiated and a statement obtained from the consumer's physician to certify need for services. After a person is officially a Medicaid beneficiary, services can begin as soon as a PASSPORT slot is available. As noted above, Ohio eliminated its waiting lists, but PASSPORT is not an entitlement program and Applebaum expressed concerns that in the current economic climate waiting lists may again be

²⁷ McGrew, K., Brothers-McPhail, D. "Program Evaluation of PASSPORT: Ohio's Home and Community-Based Medicaid Waiver Assessment and Services," Scripps Gerontology Center, Miami University, Oxford, Ohio, June 2007.

http://www.goldenbuckeye.com/_pdf/ppeval2007_assessment_services.pdf

http://www.scripps.muohio.edu/research/publications/PASSPORT_Assess_Services.html

²⁸ Ibid.

necessary. In some PAAs, the assessor continues as the case manager. In others, these functions are separated.²⁹

Care Plan Development

Case managers have much flexibility to develop plans based on the assessment. According to Applebaum, “The case managers need training in developing a plan of care, and in assessing how adverse outcomes can occur if people are over-served.” Case managers are required to be a licensed social worker in Ohio or a registered nurse and have a minimum of one year experience in medical social work and/or geriatrics.

The level of need for case manager-consumer contacts — consumer managed, supportive, or intensive — is prescribed based on the assessment. The Department monitors the cost for case management and service plans across PAAs and within PAAs by looking for outliers.

Services Offered under the Waiver

- Adult day service
- Chore service
- Home medical equipment and supplies
- Emergency response systems
- Home delivered meals
- Homemaker
- Independent living assistance
- Minor home modification
- Nutritional consultation
- Personal care
- Social work counseling
- Transportation

Consumer Direction

Ohio has a small consumer choice program that started in 2002. Currently only 400-500 people have opted for this program statewide, many of them in ethnic communities where it is important to have the option to hire culturally competent workers. Based on his evaluation of consumer direction in many states, Applebaum believes that even as consumer choice expands, no more than 10-15 percent of consumers will participate.

Budgeting and Resource Allocation

According to Applebaum, each PAA site limits cases to \$2,500 per client per month, equivalent to 60 percent of the cost of nursing home care in Ohio. Any care plan that goes above 60 percent is flagged. Care managers have flexibility in developing care

²⁹ McGrew, PASSPORT Assessment and Services, p. 3.
http://www.goldenbuckeye.com/_pdf/ppeval2007_assessment_services.pdf

plans. They may stay within or exceed the 60 percent if necessary, but there is a supervisory process with management oversight that reviews outliers. Clients tend to utilize 80 percent of what is authorized.

Ohio allows any willing provider to participate in the program as required by Medicaid. “Case managers are not allowed to guide people’s choice,” according to Applebaum. The PAA contracts directly with providers in the area. The providers bill the PAA, which in turn bills the Department on Aging, which bills the state Medicaid agency. Despite local control, quality control over providers remains problematic.

The state portion of the PASSPORT funds is derived from state General Revenue Funds; a portion of the franchise fee on nursing facility beds; and a small amount from off-track betting. When budgeting, the Department on Aging looks at costs and calculates the Medicaid match. (In 2007 Ohio Federal Medical Assistance Percentage (FMAP) = 59.66 percent. In 2009 FMAP is expected to be 62.14 percent).³⁰

In May 2008, The Unified Long Term Care Budget workgroup submitted recommendations to Governor Strickland, the state legislature and members of the Joint Legislative Committee on Medicaid Technology and Reform. The report offers a strategic framework upon which a comprehensive and cost-effective system can be built, using an effective unified long-term care budget and budgeting process as a tool for achieving policy goals.³¹

The first question that the work group dealt with was this: “Who should be covered by the unified long-term care budget?” The group decided that the budget be “inclusive of all consumers with a chronic or recurring need for services, regardless of age or payer source.” The mission and a vision statement they developed may be worth consideration in Illinois:

Mission: To create a budget for long-term care services and supports that unifies the budgeting process for facility-based and home-based services and that supports Ohio’s ability to accurately forecast expenditures for these services in future years.

Vision: Ohio’s budget for long-term services and supports will be flexible to permit consumers to choose from a wide array of quality services based on their preferences and needs; transparent to policymakers; and a cost-effective solution to budgeting for the future service needs for Ohioans in need of long-term care who may eventually need Medicaid-funded supports.

³⁰ Kaiser Family Foundation Statehealthfacts.org. “Federal Matching Rate (FMAP) for Medicaid and Multiplier,” <http://www.statehealthfacts.org/comparetable.jsp?cat=4&ind=184&typ=2&gsa=1>

³¹ Riley, B. E., “Building a Cost-effective, Consumer-friendly Long-term Services and Supports System. Final Report of the Unified Long-Term Care Budget Workgroup,” Ohio Department of Aging, May 30, 2008.

Measuring Adequacy

In 2006, the Ohio General Assembly called for an independent evaluation of the PASSPORT program. The Ohio Department of Aging, which administers the program pursuant to an agreement with the Ohio Department of Job and Family Services (Ohio's Medicaid agency), and an Advisory Council for the project specified the topics and questions to be addressed in the evaluation conducted by Scripps Gerontology Center. The report, published in May 2007, outlined key findings and stated that the development of the PASSPORT Quality Management and Improvement System is solidly grounded in the principles and functions of the CMS framework and appears to be on track to be fully operational in 2008.^{32 33}

Ohio Highlights

1. Determining eligibility and allocating service dollars for older adults:

- Eligibility is determined by case managers employed by a PASSPORT Administrative Agency (PAA). PAAs are 12 Area Agencies on Aging and one non-profit agency, Catholic Charities.
- During the assessment and care planning process clients are assessed for the level of care management time and intensity they will need: consumer-managed, supportive, or intensive.
- The assessors are well-trained to determine eligibility, and are accountable for their decisions. Their role is differentiated from the care managers (clinical social workers and nurses) who require strong clinical assessment skills and the ability to apply professional judgment to negotiate care plans. The same person may function in both capacities. Applebaum: "Care managers need training in developing a plan of care, and in assessing how adverse outcomes can occur if people are over-served."

2. Service Cost Dollar determination:

- Each PAA site limits cases to \$2,500 per client per month, equivalent to 60 percent of the cost of nursing home care in Ohio. Care plans that go above 60 percent are flagged. Average care plans cost approximately \$1,100.
- PASSPORT incorporates strong supervisory management of caseloads that identify outliers to manage costs and identify training issues.

³² • The people getting PASSPORT services need them and are financially eligible for the program.
 • The initial and ongoing PASSPORT assessment process adequately captures consumer needs and contributes to an appropriate service plan.
 • Consumers seek a level of services that best meets their needs and do not demand excessive services.
 • ODA has undertaken a concerted effort to fully operationalize and implement the CMS Quality Framework with its emphasis on participant-centered planning, delivery, and outcomes.
 • The fiscal accountability of the PASSPORT program is ensured through multiple levels of monitoring and audits.

Overall, this evaluation found that PASSPORT is a cost-neutral, effectively targeted, quality-oriented, thoroughly monitored, consumer-responsive home care program.

³³ <http://www.goldenbuckeye.com/infocenter/publications/ppeval2007.html>

3. Measuring adequacy of the benefit:

- In order to obtain independent evaluations, the Ohio Department on Aging has formed an ongoing relationship with Miami of Ohio's Scripps Gerontology Center to evaluate the PASSPORT program. Scripps conducts longitudinal studies on clients, and has conducted extensive evaluation surveys enabling the Department to improve the program and to demonstrate its effectiveness.

4. Structure of HCBS:

- The AAAs (and one non-profit agency) are the PASSPORT Administrative Agencies and have the responsibility to administer the program. There is not a separate structure for eligibility determination and care planning.

5. Other:

- Local tax/levies rather than General Revenue Funds are raised to pay for some non-Medicaid services. Ohio citizens show their strong support for aging services at the county and local levels by providing 90 percent support at each funding cycle.
- In May 2008, the Unified Long Term Care Budget work group worked through the issue of global budgeting with the help of a conflict resolution mediator. The group issued recommendations to the Governor and legislature. The vision of this workgroup: "Ohio's budget for long-term services and supports will be: flexible to permit consumers to choose from a wide array of quality services based on their preferences and needs; transparent to policymakers; and a cost-effective solution to budgeting for the future service needs for Ohioans in need of long-term care who may eventually need Medicaid-funded supports."
- Ohio is in the process of combining its HCBS and Supportive Living Waivers.

VERMONT**Background**

In 2005, Vermont, through its Department of Disabilities, Aging and Independent Living (DAIL), contracted with CMS for a Medicaid Section 1115 five-year renewable Research and Demonstration Waiver designed to eliminate the institutional bias in Medicaid coverage of long-term care.³⁴

The goals of the waiver program, Choices for Care (CFC), are to increase the total number of people served and to create a balanced system of long-term care by increasing the capacity of HCBS while monitoring the number of quality nursing facility beds. The driving factor for Vermont to convert from a 1915(c) waiver was

³⁴ O'Conner, D., E. Quach, J. Ingle, "Vermont Choices for Care Policy Brief: Eligibility." University of Massachusetts Medical School and Center for Health Policy and Research. January, 2008.

to manage the cost of long-term care.³⁵ According to Joan Senecal, Commissioner of DAIL, the 1115 waiver allows much flexibility to bring nursing home and HCBS resources together in one global pool. At the same time, the program targets its Medicaid dollars to those with the highest need and provides the resources for them to choose between a nursing home and HCBS. Choices for Care covers people who are aging and people with disabilities. DAIL contracts with five AAAs, 110 residential care homes, 16 adult day programs, 39 nursing homes, 16 DD providers and 12 home health agencies.

Mission/Vision

Choices for Care is a Medicaid-funded, long-term care program to pay for care and support for older Vermonters and people with physical disabilities. The program assists people three different ways: with everyday activities at home, in an enhanced residential care setting or in a nursing facility.

Eligibility Determination

To be eligible for Choices for Care the person must be a Vermont resident, be 65 years of age or older, or 18 years of age or older with a physical disability, must meet specific clinical criteria, and meet financial criteria for Vermont Long-Term Care Medicaid.

DAIL employs 13 RNs, state employees who conduct eligibility determinations. In the past, DAIL used contracted workers to conduct the determinations, but found that the state needed more control over the outcomes. In the Choices for Care program the RN administers the clinical assessment face-to-face with the client. This two-page clinical tool is designed only to determine eligibility for the program. The RN then turns to a decision tree, which identifies if the person is 'highest' need, 'high' need or 'moderate' need.

Highest Need: Individuals are placed in this group if they need extensive or total assistance with at least one of the following: toileting, bed mobility, eating or transferring; if they have a severe impairment with decision-making, or have a moderate impairment and exhibit certain other behaviors; or if they meet certain other criteria. Participants have *equal entitlement* to home and community-based services and nursing facility services.³⁶ Persons with this category of need are assumed to require skilled nursing home care and are entitled to receive services. They may select where these services are to be delivered – nursing home or in the community. The program is designed so that access to either in-home care and services or nursing home care is available to the applicant, including rapid eligibility determination and a full range of in-home services and settings.

³⁵“Choices for Care: Where have we come from? Where are we? Where are we going?” September, 2008. <http://www.ddas.vermont.gov/ddas-publications/publications-idu/publications-idu-documents/choices-for-care-status-powerpoint-september-2008>

³⁶ O’Conner, op. cit.

High Need: This group consists of individuals who do not meet the criteria for the 'highest need' group, but have extensive needs for personal care and rehabilitation services. Many of the persons in the "high need" group were previously receiving services through the home and community-based services waiver program. These individuals were grandfathered into the program and are not at risk of losing services if resources are not available to the state. For beneficiaries in the 'high need' group who become eligible for long-term services after the demonstration starts, however, the services they receive are subject to adequate resources being available to serve them.³⁷ As of July, 2008, there were 45 people on the 'high need' waiting list.³⁸

Moderate Need: This group is an expansion population in the waiver, not previously receiving Medicaid long-term services. It consists of persons who do not yet meet the functional eligibility requirements for nursing home care, but who may be eligible to receive limited resources (as state resources permit). The 'moderate' program was designed to test the theory that early interventions can be cost-effective for the state by helping to prevent increased disability and maintain people in community settings. Individuals in this group are served with a specific set-aside of state funds.³⁹ "Participants have limited access to case management, adult day care, homemaker and Housing and Supportive Services (HASS), but only if funds are available. The Centers for Medicare and Medicaid Services (CMS) require that enrollment not dip below 250 individuals."⁴⁰ In October 2008 DAIL reported serving 1,100 clients, with a waiting list of 215.

The amount of time it takes to determine eligibility for Choices for Care is a barrier to the notion of equal access. While DAIL eligibility can be determined retroactively, in practice most people are admitted to nursing facilities from hospitals with initial Medicaid coverage while awaiting Medicaid clinical and financial review. DAIL currently requires that retroactive eligibility be only available to people "when an individual's circumstances present a clear emergency and Department staff is unavailable." (CFC regulations, 10/05). In non-emergency situations the process can take up to a month, even when a case is expedited. According to Senecal, "this process takes far too long. We are looking to streamline it by allowing people who are on SSI to receive services and let the paperwork follow." She cited University of Massachusetts research that outlines remedies and recommendations to enable DAIL to initiate presumptive eligibility in much the same way a nursing facility can conduct its own preliminary screening and admit the individual on the same day if a bed is available.

³⁷ Kaiser Commission on Medicaid Facts: "Medicaid and the Uninsured." 7/2006.
<http://www.kff.org/medicaid/upload/7540.pdf>

³⁸ Kaiser Commission on Medicaid and the Uninsured, "Vermont's Choices for Care Medicaid Long-Term Services Waiver: Progress and Challenges as the Program Concluded its Third Year." November, 2008. <http://www.kff.org/medical/upload/7838.pdf>

³⁹ Kaiser Commission on Medicaid Facts: Medicaid and the Uninsured. 7/2006.
<http://www.kff.org/medicaid/upload/7540.pdf>

⁴⁰ O'Conner, op. cit.

Care Plan Development

Eligible clients select a Choices for Care (CFC) case management agency (one of the AAAs or home health agencies that contract with Vermont), and a case manager is assigned. The case manager then completes a full assessment and provides options counseling. A plan is developed collaboratively by the case manager and the client. The case manager helps the client to fill out the financial eligibility forms and sends these to the Department for Children and Families (the Vermont Medicaid agency). The plan they agree upon is reviewed by the RN who administered the original eligibility determination. At any point in the process, the client may choose to go into a nursing home.

There are currently 120 case managers in the CFC agencies. Vermont developed case management standards and created a certification exam, which is required for anyone providing care management in their OAA or Choices for Care programs. Senecal indicated that the case managers are expected to know the benefits available to clients “inside out” and to counsel people very carefully. She stressed the importance of the case manager’s role in being able to see and understand chronic illness in order to prevent unnecessary hospitalizations. However, she commented that reducing hospitalizations was not the goal and that it was important that people go to the hospital when necessary.

Services Offered under the Waiver

Highest and High categories:

- Case management (48 hours/year)
- Personal care*
- Respite (including companion care – 750 hours/year)
- Companion care (including respite care – 750 hours/year)
- Adult day services (maximum 12 hours/day)
- Assistive devices (\$750 maximum/year)
- Emergency home response
- Intermediary service organizations
- Enhanced residential care
- Nursing home
- Flexible dollars (approved by the case manager and with authorization by a Choices for Care RN if the request is out of the ordinary)

Moderate Need:

- Case management
- Adult day care
- Homemaker services

*According to Joan Senecal ADL needs are covered with the caveat that Choices for Care doesn’t provide 24/7 care and supervision. In addition, it covers up to 4.5 hours/week of IADL services for specific IADLs: phone use, money management, household maintenance, housekeeping, laundry, shopping, transportation and care of assistive devices. People may request a variance if they can prove that they need more time for health and safety reasons.

Consumer Direction

According to Senecal, Vermont's consumer direction program is relatively small — 70 people total. They thought that younger people would take advantage, but that has not been the case. Only 15% of the Choices for Care caseload are comprised of people under age 65 and it doesn't appear that consumer direction has enabled the state to attract significant numbers of younger people with disabilities. In this option, a client can take his or her budget and work with a counselor to purchase services. Vermont contracts with a non-profit agency that provides consumer counseling, and has established a fiscal intermediary to pay workers based on time sheet submissions. Vermont received a Robert Wood Johnson three-year Cash and Counseling demonstration grant in the summer of 2006 for a statewide program to cover elderly, people with disabilities and eligible children.

Budgeting and Resource Allocation

In 1996, legislation was passed allowing budgeted money not spent on nursing home care to be used and transferred to HCBS. According to Senecal, the legislation was introduced by a legislator/nursing home owner who recognized that Vermont's long-term care budget was "not sustainable," and that the state needed to control costs by reducing the use of institutional services and increase the access to HCBS. This set the stage for a decline of power of their nursing home industry and the passage of legislation to shift money from nursing homes to HCBS, and ultimately for the application to CMS for a Section 1115 Research and Demonstration Waiver.

The waiver operates under a five-year global budget cap. Vermont's funding for all long-term services, including nursing facility and HCBS services, are subject to an aggregate cap set at \$1.236 billion. This amount is based on projections regarding the demand for, and cost of, long-term services by low-income elderly and individuals with disabilities in Vermont. If actual costs exceed this level, the state will have to limit services provided in order to stay under this cap, or it is responsible for any additional costs. Under the waiver, the state hopes to save \$61 million on existing populations through greater use of HCBS, and would use \$56 million of that for spending on the 'high' and 'moderate' need groups.⁴¹

Vermont has contracted with the University of Massachusetts and the Center for Health Policy and Research to address the question of whether Vermont's incentives to use community services are sufficiently balanced by safeguards to protect access to care in the most appropriate setting that is needed, whether in the community or in a nursing home. The following policy reviews of Vermont's CFC initiative are planned: 1) Eligibility (issued January 2008); 2) Enrollment; 3) Service Authorization; 4) Service Delivery; 5) Quality Management.

⁴¹The Henry J. Kaiser Family Foundation. Kaiser Commission on Medicaid Facts: Medicaid and the Uninsured. *The Vermont Choices for Care Long-term Care Plan: Key Program Changes and Questions*. July 2006.

Measuring Adequacy

Built into Vermont's 1115 waiver are the following quality measures:

- Long-term care ombudsman role expanded to include HCBS
- LTC Consumer Survey (Macro)
- Gold Star Employers (Home Health, Nursing Homes)
- Nursing Home Quality Awards
- Nursing Home Quality Improvement Council
- HCBS Quality Management Plan
- HCBS Provider Reviews
- Examination of HCBS Provider Review process
- University of Massachusetts for an independent evaluation of CFC

Vermont Highlights

1. Determining eligibility and allocating service dollars for older adults:

- A defining goal of Vermont's program is to equalize nursing home and HCBS access and resource allocation by targeting people who are likely to go into a nursing home. They focus on addressing access barriers to HCBS.
 - Determining Medicaid eligibility: Vermont's Department of Disabilities, Aging and Independent Living (DAIL) is attempting to speed up the process for Medicaid eligibility determination, particularly for people in hospitals, to enable people to receive HCBS quickly. This means making presumptive eligibility as possible for accessing HCBS as it is for accessing nursing homes. Studies have shown that people on SSI may be a 'safe' category of potentially eligible people to allow for presumptive eligibility.
 - People eligible for Choices for Care have equal access to either nursing home or HCBS.
- Eligibility is determined by registered nurses employed by DAIL.
- One tool is used to determine eligibility. A decision tree is then used to determine level of need. Those with the 'highest' level of need are entitled to receive service. 'High' and 'moderate' levels receive services as resources are available.
- The caregiver role is not included in eligibility determination. It is only a factor in care planning.

2. Service Cost Dollar determination:

- Global budget cap based on projections of need in the targeted populations. In 2006 they averaged \$3,386 per client per month for HCBS and \$1,861 in their enhanced residential centers.

3. Measuring adequacy of the benefit:

- Independent contracting for program evaluation: University of Massachusetts and the National Academy for State Health Care Policy collaborated on an independent evaluation of the program.

4. Structure of HCBS:

- Vermont worked closely with CMS to convert from a 1915(c) waiver to 1115, allowing it to manage global budgeting and administration of HCBS and nursing homes.
- Program is administered by the Department of Disabilities, Aging and Independent Living, which contracts with providers.

5. Other:

- Disease management is a key factor in the program design.
- Reduced hospitalizations or ER visits are not viewed as a measure of success. The goal of the program is to encourage adults to utilize health care when necessary.

WASHINGTON

Background

Washington's 1915(c) Medicaid waiver program, Community Options Program Entry System (COPEs), is administered by the state's Aging and Disability Services Administration, HCS Division (ADSA). COPEs covers people who are 65 and over and people 18-64 with physical disabilities. Washington and its neighbor Oregon have been leaders in aggressively promoting community-living options.

In 1993, the Washington state legislature established the state's vision for providing a broad array of services that "support persons who need such service at home or in the community whenever practicable and that promote individual autonomy and dignity and choice."⁴² Legislators assumed that as community options became available, the relative need for nursing home beds would likely decline. They also recognized that there would always be a critical need for nursing home care as part of the state's long-term care options, and specified "that such services should promote individual dignity, autonomy, and a homelike environment."⁴³

In 1995 the state set an aggressive target of June 30, 1997, to reduce Medicaid nursing home bed census by at least 1,600 by offering HCBS, enhanced residential facilities and assisted living. According to Bill Moss, director of Home and Community Services, Washington has eliminated the bias between nursing homes and HCBS in income and in functional eligibility, as well as spousal rules and income transfer. He currently is concerned about whether the personal needs allowance is

⁴² Department of Social and Health Services Fact Sheet: "A Successful Vision." 1993.
<http://www.aasa.dshs.wa.gov/about/factsheets/a%20successful%20vision%20fact%20sheet%2012-07.doc>

⁴³ Ibid.

sufficient for a community dweller. There are discussions in the state about whether it should be raised.

Washington's commitment to access to HCBS is featured in a July 2005 Issue Brief by Robert Mollica, senior program director at the National Academy for Health Policy in Maine, and Susan Reinhard, AARP's senior vice president for public policy. Citing Washington as a model state, they identified three areas that facilitate access:

- One agency manages all state-supported long-term support services for older adults and people with physical disabilities.
- The eligibility tool (CARE) assesses functional, health, cognitive and behavioral status. It's used to determine eligibility for long-term support services, develop a care plan, and determine the maximum number of hours of service that may be authorized for in-home services.
- Medicaid financial and functional eligibility determinations are closely coordinated. Financial eligibility workers are located in the same offices as the people who determine functional eligibility.⁴⁴

Washington continues to enhance its HCBS commitment by implementing programs and services including a range of affordable housing with service options and nurse delegation. Known as the Boarding Home Service Packages, the state has four tiered options, moving from the most minimal, Adult Residential Care, which provides personal care and medication reminders, up to Assisted Living, which provides personal care, medication management and periodic nursing service. Some nursing homes have converted their bedrooms to participate in this program.

Washington State began efforts to rebalance its long-term care system in 1989, and immediately recognized that people who required a nursing home level of care would have nursing needs in the home. However, if provided by an RN these services would be cost-prohibitive. In 1994 the state legislature passed a nurse delegation act allowing nursing assistants to perform six nursing tasks. A subsequent evaluation of the program by the University of Washington School of Nursing demonstrated that with proper training and supervision from a licensed nurse, nursing assistants could perform certain nursing tasks such as administration of prescription medications or blood glucose testing, normally performed only by licensed nurses. A registered nurse must teach and supervise the nursing assistant, as well as provide nursing assessments of the patient's condition. The protocol, entitled "Delegation of Nursing Care Tasks in Community-Based and In-Home Care Settings,"⁴⁵ spells out what the RN delegates can do, and also allows RNs to decline participation in the program. The RN delegation makes cost-effective nursing services available to people regardless of the setting in which they live.

⁴⁴ Gillespie, J., Mollica, R. "Streamlining Access to Home and Community-Based Services: Lessons from Washington." Issue Brief. Community Living Exchange. Rutgers Center for State Health Policy and National Academy for State Health Policy. June 2005.

⁴⁵ "Delegation of Nursing Care Tasks in Community-Based and In-Home Care Settings."
<http://www.aasa.dshs.wa.gov/professional/nursedel/documents/ND%20WAC%202004.doc>

COPES serves approximately 35,000 people per year, two-thirds of whom are 65 or older. Almost all of the people served in this program are Medicaid-eligible. Approximately 300 people receive services funded by the state.

Moss said that more state money is spent on younger than on older people. Young people tend to have a higher level of need for ADLs and cognitive performance because of the nature of their illness or disease, such as traumatic brain injuries. He also said that his research shows that the higher the need, the more cost effective it is for clients to be served to be in a residential program.

Mission Statement

The mission of the Home and Community Services (HCS) Division is to promote, plan, develop and provide long-term care services responsive to the needs of persons with disabilities and the elderly, with priority attention to low-income individuals and families. The program helps people with disabilities and their families obtain appropriate quality services to maximize independence, dignity and quality of life.

Eligibility Determination

Persons of any age must meet functional ability based on unmet needs for personal care, tasks not being provided by informal caregivers or a community resource. An eligible person's income and resources must be within limits set by law.

An Aging and Disability Services Administration Home and Community Services (HCS) financial worker determines financial eligibility. An HCS social worker or nurse, in a home visit, uses the Comprehensive Assessment Reporting Evaluation (CARE) tool to document a client's functional ability and determine eligibility for long-term care services, and then evaluate the assistance a client will receive. All of the questions factor into a payment algorithm that produces 17 different classification groups, which determine the base number of hours for which a person is eligible, ranging from 20 hours up to 420 hours per month. A Resource Use Classification Model algorithm converts the categories into hours of service reflecting unmet needs. CARE, developed by Deloitte and Touche in 2003, is Web-linked and is valid across populations and settings. HCS social workers have laptop computers with them at the home visit to complete the assessment and care plan. Assessors then upload the completed assessments to ADSA's central computer. Assessors receive extensive technical training to use the CARE system and they complete 15-20 assessments each month.⁴⁶

Care Plan Development

Prior to CARE, the number of service hours was authorized based on varying program or policy limits, not on unmet need. The limits have been standardized under CARE. Consumers receive more or fewer services based on their clinical and functional characteristics. Payment levels are also established if the consumer

⁴⁶ Gillespie, J., and Mollica, R. op. cit.

chooses to live in an adult home or assisted living facility.⁴⁷ The CARE tool can trigger medically related referrals for shots, exams, a nurse evaluation, etc. A skin observation protocol was developed, for example, because skin breakdowns are triggers for nursing home placement. If a client has skin breakdown, the case management entry automatically generates an RN referral. Moss stressed that professional judgment continues to play a significant role in the assessment. The case manager has authority to change the plan's services based on circumstances.

Upon completion of the assessment, CARE generates a report on the computer screen identifying programs for which the consumer is eligible. The social worker/assessor describes the advantages of the programs to the consumer. Both can view the screen simultaneously and work together to develop a plan, which the consumer must then approve.

The HCS social worker develops and sets up initial services based on the CARE assessment. Once the assessor has determined that the services have begun, responsibility for the consumer is transferred to a case manager, who monitors service delivery and provides ongoing case management. This service is provided by the local Aging and Disabilities Service Administration (ADSA) staff for beneficiaries in nursing homes, adult family homes and assisted living settings, and by case managers at Area Agencies on Aging for HCBS participants. Case managers hold a master's degree in social work, or a bachelor's degree with three years of experience. Caseloads average 80 consumers per case manager, but vary based on complexity. A Community RN is consulted if the assessment triggers a need for nursing. The assessor, case manager, agency-based providers and other approved department representative can enter notes and changes regarding the consumer into the CARE system, thus enhancing communication among the service providers for the same consumer.

Services Offered under the Waiver

- Personal care
- Adult day services
- Home modification
- Home health
- Meals
- Emergency home response
- Medical equipment and supplies
- Transportation
- Training for therapeutic goals
- Boarding Home Service Packages
 - Adult Residential Care (ARC)
 - Enhanced Adult Residential Care (EARC)
 - Enhanced Adult Residential Care – Specialized Dementia Care Services
 - Assisted Living

⁴⁷ Ibid.

Consumer Direction

According to Moss, Washington has a relatively new consumer direction program that is not yet well integrated. The program is limited to King County, the county in which Seattle is located, and currently approximately 200 people participate. Like Vermont and Arizona, Washington is a recipient of a Robert Wood Johnson three-year Cash and Counseling demonstration grant. Moss said people universally want choice, but that younger people play a larger role and are relatively more assertive in their desire to control their services. Older people usually don't strongly manage or feel the need to manage their services. On the other hand, Gillespie and Mollica report that most HCBS in Washington is provided by independent providers who must pass a background check and take a state-certified training course to become licensed home care providers. The assessor must assure that the independent provider is licensed before the plan can be approved. Thus despite the fact that the Cash and Counseling program has been slow to start, Washington, as a state, has historically built consumer-directed elements into its program.

Budgeting and Resource Allocation

In 2001 and 2002, Aging and Disabilities Service Administration conducted a time study in boarding homes, adult family homes and in consumers' homes in several areas throughout the state to determine resource use when specific care needs were identified. Researchers followed consumers for three days and recorded all interventions. The ADSA staff combined the time study results with the assessment information and determined the characteristics that were associated with the cost of care. These interventions were factored into the Resource Use Classification Model algorithm that is built into the CARE system. Mental illness and depression were identified as cost drivers and included in the algorithm, as were certain diagnoses related to occupational and physical therapy, ADLs and IADLs. The results were used to develop the new payment methodology that ties client characteristics to resource use.⁴⁸

Washington applies global budgeting for all of its Medicaid long-term care services. Officials assume no waiting lists for people who are eligible for Medicaid services and forecast the budget based on their projections.

Measuring Adequacy

CARE standardizes documentation for CMS waiver reviews and state quality assurance functions. Five percent of assessments are reviewed by staff members from the ADSA quality assurance unit annually. State agency field office supervisors conduct a monthly quality review of all cases by case managers employed for six months or less. Quality assessments are performed by field managers for all case managers. The system allows managers to generate reports from the data to

⁴⁸ Washington Department of Social and Health Services: Aging and Disabilities Services Administration *Care Eligibility and Rates for Long-Term Care Services*. Rev. 1/30/04. http://www.nashp.org/Files/WA_Care_eligibility_manual.doc

monitor and measure performance of individual workers, reporting units and regions. Management reports can identify:

- Total number of assessments completed
- Consumer-specific care plan details
- Various clinical scores
- Intake totals and outcomes of intakes
- Consumers preparing for nursing facility discharge and the barriers to discharge
- Nursing referrals
- Response time from initial intake

ADSA has convened a change board, a group of representatives from the field and the state, to determine what other functional enhancements can be made to CARE.

Washington Highlights

1. Determining eligibility and allocating service dollars for older adults:

- The Comprehensive Assessment Reporting Evaluation (CARE) tool and system was developed to assure accuracy, quality, equity and fairness in the assessment process. It eliminated subjectivity. CARE combines assessment, eligibility and service authorization information and links with the state's payment system. It reduces duplication of data entry and allows verification of the bill against authorized services. Data from CARE can support quality assurance and monitoring activities. The software is available to other states because it was developed with federal funding.
- While the CARE system eliminates subjectivity, care managers are expected to exercise professional judgment and have the authority to override plans.
- CARE produces reports and enables care managers, field supervisors and managers to monitor and measure performance of individual workers and reporting units. A competency/consistency rating can also be generated for individual case managers and additional staff training is provided when ratings are low.
- The assessment is administered by social workers and nurses employed by the state and located in the Aging and Disability Services Administration field offices. They complete the assessment on a laptop computer and upload completed assessments to ADSA's central computer.
- The Resource Use Classification Model algorithm converts categories of clinical complexity to hours of service and assigns a base number of hours, which is modified by the availability of informal supports and other adjustments such as off-site laundry.

2. Service Cost Dollar determination:

- The Aging and Disability Services Administration (ASDA) conducted a time study of interventions to develop a payment method tied to client characteristics and resource use. These interventions were factored into the

Resource Use Classification Model algorithm that is built into the CARE system.

- CARE authorizes the number of in-home hours consumers can receive per month, with a maximum authorization of 420 hours per month. Payment levels vary based on where a person chooses to live: home, adult home or assisted living facility. Average cost per month is \$1,304 per client per month.

3. Measuring adequacy of the benefit:

- See above regarding use of the CARE tool.

4. Structure of HCBS:

- Washington offers a variety of residential options that include services that are a part of the CARE system.
- One agency – Aging and Disability Services Administration – manages all state-supported long-term support services for older adults and adults with physical disabilities.

5. Other:

- Washington instituted the nurse delegation 10 years ago as a means to provide cost-effective nursing procedures in HCBS. It outlined clear regulations defining what the designee can and can't do, as well as what the nurse can choose to do. Nurse delegation enables personal care attendants, with training from a nurse, to perform nursing functions such as passing medications, wound care, etc., for persons with disabilities in whatever non-institutional setting that person chooses to live.

WISCONSIN

Background

In 2006, Governor Jim Doyle announced a five-year plan expanding the Family Care program to achieve the state's goal of promoting the integration of long-term care and health care services. Under this plan, Family Care will be available to everyone in the State who is eligible for the Medicaid Waiver program. In 1999 Wisconsin contracted with the Lewin Group to conduct an evaluation of the Family Care pilot program. The final report concluded that the program has substantially met the goals of increasing choice and access and improving quality in social outcomes as well as cost savings and user satisfaction among older and younger people for services in the home. This report influenced the governor's decision to expand Family Care state wide. Family Care is a capitated program Wisconsin operates under Medicaid 1915(b) and (c) combined demonstration waivers.

County units of government, which historically have been responsible for administering and delivering HCBS services in Wisconsin, are now forming partnerships with neighboring counties to create Case Management Organizations (CMOs). These CMOs will balance fiscal responsibility with care planning and

services that enable individuals to remain in the community. At the end of 2008, almost 50 percent of the eligible population in Wisconsin had access to Family Care.

The program covers older adults and adults with physical and/or developmental disabilities. People apply through Aging and Disability Resource Centers (ADRCs), units of county government that provide a centralized location where people can receive information about services and eligibility determination. People can come into the ADRC, call, or request an in-home visit. When an eligible person selects Family Care, he or she is assigned to a CMO in the area. The state pays the CMO a capitated rate per client per month and the CMO pays for the client's HCBS services. The Family Care Program is administered by the Wisconsin Department of Health and Family Services, and an individual's financial eligibility is determined by County Fiscal Support Units.

Mission/Goals

"Family Care is a long-term care program ... As a comprehensive and flexible long-term care service system, Family Care strives to foster people's independence and quality of life, while recognizing the need for interdependence and support. Its goals:

- Choice – Give people better choices about the services and supports available to meet their needs.
- Access – Improve people's access to services.
- Quality – Improve the overall quality of the long-term care system by focusing on achieving people's health and social outcomes.
- Cost-effectiveness – Create a cost-effective long-term care system for the future."⁴⁹

Eligibility Determination

Family Care MCOs serve people in three primary target groups:

- Frail Older Adults (65 and older)
- People with Physical Disabilities (17 years, 9 months and older)
- People with Developmental Disabilities (17 years, 9 months and older)

Financial Eligibility: The County Economic Support Units are often located in the ADRC, speeding up the process of determining a person's financial eligibility for Medicaid.

Functional Eligibility: A functional screen is used to assess functional eligibility. Included in the screen are measures for ADL, IADL, cognitive functioning, behavior, medical, mental health, substance abuse, and an Adult Protective Service risk assessment. According to Kathleen Luedtke, Planning & Analysis Administrator in the ADS Division of Long-Term Care, "The person who performs the functional screening is a certified screener who, through experience, should be able to estimate whether the potential member meets the eligibility criteria. However, the screen is

⁴⁹ Wisconsin Department of Health Services, "Who Does Family Care Serve?" <http://dhs.wisconsin.gov/lcicare/generalinfo/Serve.htm>

not just a data base; it is a computer application that contains programming logic that evaluates each data element entered and determines eligibility. All data gathered by the initial and all subsequent screens are stored in the system for later comparisons, rate setting and quality assurance purposes. This eligibility is then passed to the state information system and financial eligibility determination system.”

Screeners are trained and certified by the state before they conduct assessments. Screening can take place at the ADRC or in a person’s home. When a person is found to be eligible for Medicaid and agrees to participate in Family Care, the ADRC refers that person to a CMO for assessment and care planning. According to Donna McDowell, director of Wisconsin’s Bureau of Health Services and statewide director of the ADRC OAA Program, the screener at the ADRC tells the applicant that “Family Care can pay for everything you may need.” She mentioned that much like the Illinois experience, older people remain wary of the standard barriers for applying for Medicaid, including estate recovery.

Care Planning

The functional screen conducted by the ADRC does not drive the care plan. When consumers elect to participate in the Family Care Program the MCO assigns an Interdisciplinary Team (IDT) to work with them. The team consists of a social worker (this may be someone with a related degree or five years of experience) and a nurse. When asked if a doctor’s authorization was necessary, McDowell responded, “Absolutely not,” in striking contrast to the programs in other states.

The goal of the program is to identify and achieve the outcomes consumers identify as important. The nurse and social worker team facilitate a discussion with the consumer, and the outcomes drive the plan of care. The nurse and social worker are then charged with using the Resource Allocation Decision (RAD)⁵⁰ method to allocate services and design a care plan using services on the list below. This question-and-answer process is designed to determine the most effective services and supports for each individual member. The RAD method is employed as a cost control and universal procedure for choosing services and service amounts. The member’s outcomes represent what is valued or important to him or her, or are things he or she wishes were different in his or her life. The method uses a seven-question framework to guide the Interdisciplinary Team (IDT) in locating the most

⁵⁰ “Using the Resource Allocation Decision Method,” May 2008.
<http://dhs.wisconsin.gov/LTCare/pdf/RADinformational.pdf>
The RAD Method

1. What is the need, goal, or problem?
2. Does it relate to the member’s assessment, service plan and desired outcomes?
3. How could the need or goal be met?
4. Are there policy guidelines to guide the choice of option?
5. Which option does the member (and/or family) prefer?
6. Which option is the most effective and cost-effective in meeting the desired outcome?
7. Explain, DIALOGue, Negotiate

cost-effective way to achieve the members' desired outcomes. Training materials and program evaluations are quick to point out that cost-effective does not always translate to cheapest services.

Services Offered under the Waiver⁵¹

- Adaptive aids, communication aids, medical supplies, home modifications
- Home health, therapies, nursing, personal care, supportive home care
- Residential services, nursing home care
- Transportation, daily living skills training, supportive employment
- Nutrition services including home delivered meals
- Emergency response system services
- Respite care, adult day care, day services
- Case management

Consumer Direction

The Self-Directed Supports Waiver is a new component of long-term care in Wisconsin. The program Include, Respect, ISelf-Direct (IRIS) has been operational since July 2008.⁵² The eligibility process is identical to Family Care; consumers are screened at ADRCs and by County Economic Support Units. The one difference is that once eligibility is determined, the functional screen will calculate a budget. This is an automatic dollar amount based on data entered to determine eligibility, as described above. Consumers may use IRIS for some services and Family Care for others. The same model of outcomes (RAD) is used to help the consumers develop their plan of care. The Wisconsin Department of Health and Family Services, Division of Disability and Elder Services, has ultimate responsibility for the program but contracts with two agencies that administer the operational side. The Management Group is the Independent Consulting Agency (ICA) responsible for providing consultants, service and support information, intake and orientation to IRIS policies and procedures. The Milwaukee Center for Independence provides fiscal oversight as the Financial Service Agency, processing payments, payroll and taxes, and collecting cost shares from those consumers who pay a portion of their income.

Budgeting and Resource Allocation

According to Kathleen Luedtke, "the cap rate paid is not an individual rate. If rates were individual you wouldn't really have managed care. In Family Care an MCO receives the same dollar amount for each of its enrollees. The information captured about each member, plus Medicaid card service costs, and much more information, are used by our actuaries to develop a capitation rate for each managed care organization." Capitation rates average \$2,809 per member per month. The CMOs contract with local providers or directly provide services with CMO staff. Counties

⁵¹ Items Covered in the Family Care Benefit Package.

<http://dhs.wisconsin.gov/lc/lcinfo/Generalinfo/Benpackage.htm>

⁵² IRIS Wisconsin's Self Directed Waiver Program Participant Handbook. http://www.wisconsin-iris.com/handbook_002.pdf

are at full risk financially in the Family Care model. It is interesting to note that while the Nursing Home Bureau and Health Care and Family Care both operate under the umbrella of the long-term care division, the budgets are not combined.

Measuring Adequacy

Wisconsin uses an aggressive array of measures to measure quality and adequacy of long-term care services, and particularly the Family Care Program. External reports were prepared by the Lewin Group in 2003,⁵³ demonstrating the cost-effectiveness of the Family Care model. MetaStar Inc., a Madison-based non-profit organization, is the External Quality Review Organization authorized by the Wisconsin Department of Health and Family Services, Division of Disability & Elder Services, Center for Delivery System Development, to conduct external quality review activities for the Family Care Program in the state.⁵⁴

Wisconsin DHFS recently contracted with the University of Wisconsin to measure and use Personal Experience Outcomes for people receiving long-term care services in the community. The PEONIES project – an acronym for Personal Experience Outcomes integrated Interview Evaluation System – is developing a tool for interviewing consumers about outcomes and quality. The tool is currently undergoing testing for validity.⁵⁵ Other measures include regular site visits to ADRCs and CMOs, care plan reviews, and quarterly reports.

Wisconsin Highlights

1. Determining eligibility and allocating service dollars for older adults:

- Aging and Disability Resource Centers (ADRCs) provide one-stop access to services and information for older people and people with disabilities.
- County Economic Support Units are co-located at ADRCs to expedite Medicaid eligibility determinations for HCBS.
- Operation of a Web-based assessment tool automatically assigns levels of care as data is entered.
- Screeners for the ADRC are trained and state-certified to conduct the assessment and help people consider their options when deciding if they want to enroll in Family Care.

2. Service Cost Dollar determination:

- Family Care is a capitated program covering health and social services (excluding medical care and hospitalization).
- Enrollees join a Case Management Organization, which receives a capitated rate for each member. The CMO contracts with local providers or may directly provide services.

⁵³ The Lewin Group. "Wisconsin Family Care Final Evaluation Report." June 30, 2003. <http://www.legis.state.wi.us/LAB/reports/03-0FamilyCare.pdf>

⁵⁴ MetaStar Web site: <http://www.metastar.com/web/Services/tabid/55/Default.aspx>

⁵⁵ The Board of Regents of the University of Wisconsin System. Last updated 8/18/08. Copyright © 2008. http://www.chsra.wisc.edu/peonies/PEONIES_Index.html

- Interdisciplinary teams (IDTs) consisting of a nurse and social worker are assigned to each client/family who enrolls in Family Care. They all work together to develop a plan that defines the client's goals and puts services and resources in place to achieve them. Care planning is outcome-based using the Resource and Allocation Decision Method (RAD), which considers client need/preference and resource allocation.
 - The RAD questions are designed to assist IDT in negotiating the plan with clients.
 - The RAD method is employed as a cost control and universal procedure for choosing services and service amounts based on what is valued or important to the client.
- Family Care is a capitated program. The CMOs receive the same dollar amount for each enrollee. Actuarially sound projection of costs and benefits based on past expenditures trended forward. Costs are associated with functioning using the Long-term Care Functional screen. Individual MCO rates are built from these projected costs of actual enrollees (the actual case mix), and are adjusted at year end for cost share, case mix, high-cost ICF-MR relocations and high-cost ventilator-dependent enrollees.⁵⁶

3. Measuring Adequacy of the Benefit:

- Use of outside evaluators:
 - The Lewin Group demonstrated cost-effectiveness of the Family Care Model, enabling advocates to convince the Governor and legislature to invest in HCBS.
 - MetaStar, Inc., to conduct external quality review activities.
- Wisconsin DHFS contracted with the University of Wisconsin to develop a method of measuring and using personal experience outcomes for people receiving long-term care services in the community.
- Regular site visits to ADRCs and CMOs, care plan reviews and quarterly reports.

4. Structure of HCBS:

- Family Care is a managed care model that integrates funding, health and social services through the ADRC.

5. Other:

- A strong advocacy movement provided research and data to demonstrate to the Governor and legislature that Family Care Demonstration is cost-effective. The research effort provided by the advocates was so compelling that the Governor mandated statewide expansion of the program.

⁵⁶ Leudtke, Kathleen, "Managed Long-Term Care in Wisconsin," PowerPoint, 2008.

SECTION IV: Responses to the Legislative Mandate Study Questions

This study was designed to respond to mandates to the Department on Aging in PA 95-065. Following are the three areas of inquiry at the beginning of this study, which served as guideposts to the research, followed by a discussion of how the study sheds light on these important questions.

1. Why is the DON-based Service Cost Maximum schedule different for the elderly and disabled populations? To what extent can these differences be explained by differences in the characteristics of the populations served?

The current study provides some insight and historical perspective into the disparities between the SCMs in the Illinois programs that serve these two populations. Unfortunately client-level data for the program that serves people with disabilities in Illinois was not available in time for the analysis to be included in this study.

The two programs are very similar in that they both must adhere to standards defined by the federal Centers for Medicare and Medicaid Services (CMS) in providing home and community-based services as an alternative to nursing home care. All of the states examined for this study had either Medicaid 1915(c) waivers or 1115 waivers to provide services for their elderly and disabled populations. Illinois, unlike most states, administers the programs through different government agencies – the Illinois Department on Aging and the Illinois Department of Human Services, respectively – and does not have global budgeting. This results in the Illinois programs being administered somewhat differently. While the rates for the individual services must be the same, since CMS does not allow two rates to be paid for the same service in one state, the administrative processes and services for the programs differ.

For example, the Community Care Program, administered by the Department on Aging for Illinois seniors, provides case management and only three services – home care aide, adult day services, personal emergency response systems – while the Home Services Program, administered by the Division of Rehabilitative Services in the Department of Human Services, provides many services, including homemaker, personal assistant, adult day services, assistive technology, home modifications, meals and personal emergency response systems. Personal assistant services are the most-utilized HSP services, while seniors tend to utilize home care aides.

Another difference between the programs involves the obvious differences between the populations and the services available to them outside of Medicaid. The CCP provides services to Illinois residents age 60 and over, while the HSP serves people under 60 with a disability. Participants in both programs must have a comparable level of impairment, as documented through the Determination of Need assessment. Both populations may have access to services through Medicare as well as Medicaid, but only

seniors may have access to services provided regionally through Older Americans Act funds. In Illinois, these funds support an extensive network of home-delivered and congregate meal sites, transportation, and supports for family care givers. These services are available with regional variation, and may have waiting lists.

Since the Determination of Need score provides the basis on which the client's Service Cost Maximum and resulting plan of care is developed in both programs, the fact that CCP and HSP administer the DON slightly differently may be a factor. For seniors, the same case manager who administers the DON also develops the plan of care, so that eligibility and service planning are the responsibility of the same person. For people with disabilities, the DON is administered by state staff or contractual workers (including in some cases CCP case managers) and the service planning is done by other workers in the community. Most of the best practice states separate eligibility determination and service planning in their programs, similar to the HSP. In Illinois, the fact that the CCP case managers determine both eligibility and plan services may affect the scoring of the DON and the utilization of the Service Cost Maximums.

The best explanation for the disparity between the Service Cost Maximums in the Community Care Program and the Home Services Program was identified in interviews with individuals who had been involved in the programs over time. While the rates in both programs originally were indexed to nursing home and residential care costs in Medicaid, this logic became disconnected in times of state budget crisis when each department had to offer solutions for trimming their respective programs. In 1992, for example, the Department on Aging chose to cut the SCMs in half for CCP clients with the lowest DON scores, while the Department of Human Services closed intake and tightened eligibility determinations for HSP applicants. This resulted in the existing situation in which the CCP Service Cost Maximums are 24% of those in the HSP at the lowest DON score levels.

2. How will the legislatively mandated changes in the Community Care Program's service package – in particular, the addition of medication management, personal care/assistance and consumer direction — affect service utilization and cost? What are the implications of these changes for the current DON-based system of service dollar allocation?

The Illinois Department on Aging has been mandated in PA 95-065 to add certain services to the Community Care Program, including medication management (subject to appropriation) and personal assistant/consumer-directed services (following an evaluation of the Cash and Counseling demonstration program). In addition, the Act directs the Department to provide enhancements that include greater flexibility in the existing program to serve seniors on evenings and weekends, and to allow for the ease of employment of a family member or friend to be the provider of care to the client. Finally, the Department has determined that the addition of flexible funding for services, home modifications, and assistive

technology are important additions to the program that will be incorporated in an amendment to the Medicaid waiver in 2010.

The implementation of all of these new services may increase the overall cost of the program, especially if the services are available without regard to the existing Service Cost Maximums. This study examined the SCMs and service utilization for home care aide (homemaker) services only. Given the unmet needs of the clients examined in the study, it is recommended that medication management be added as a service in addition to personal care. The study also found that the amounts of service for personal care activities for persons at the highest need levels were inadequate. Further study is needed to determine how people at this level of need manage to remain in the community, but based on the researchers' knowledge of community-dwelling people with significant ADL deficits, additional hours of service as well as flexible respite and family support services are recommended for those at the highest DON levels.

The implications of both the legislative mandates and the findings of this study could serve as justification and incentive to redefine the use of Service Cost Maximums in the Community Care Program. First, a system of proscriptive dollar amounts that translate to hours of services will no longer be a viable method for determining plans of care if additional services are provided. Most states provide guidelines for service authorization that are some percentage of the nursing home rate, and some states may also prioritize the population served based on varying levels of need as determined by the functional assessment. Service plans in these states are guided by the limits, and program effectiveness is considered overall — is the overall cost of Medicaid home and community care for these individuals less than the care for them would be if they were in a nursing home?

Second, the addition of these new services redefines the nature of the CCP, and may warrant a reexamination of the applicability of the *Benson v. Blaser* consent decree. All states examined in this study provide a richer and more flexible service package than Illinois and limit their home and community-based services for the elderly and people with disabilities to the Medicaid enrolled population; and most of the states target people who are most likely to require skilled nursing home care. These states also provide additional services to non-Medicaid-eligible seniors through other funding sources. Ohio is notable in its use of specific county levies for senior services.

If the services mandated by recent legislation and suggested by this study are simply added to the Community Care Program, and the Service Cost Maximum structure is changed to simply be equivalent to the Home Services Program, then CCP may continue to serve seniors at the middle range of need and provide what appears to be inadequate services to those at the higher DON scores. The need for funding will increase, without cost controls to assure that the services will be available for those who most need it. This study recommends that the overall CCP be evaluated to determine whether it meets its goal, which is defined as providing

support to seniors in living safely at home and delaying or reducing nursing home placements.

Most states have addressed these challenges through some consideration of the overall Medicaid expense for long-term care, including both residential and skilled care as well as home and community-based services. The initiation of the Money Follows the Person federal demonstration project in Illinois may provide some insight as to how such a budgeting process could be implemented.

3. How does Illinois' approach to determining eligibility and need and allocating service dollars for older adults compare to best practices in other states?

In general, the interviews with other state Medicaid waiver programs indicate that if you have seen one state's program, you have seen one state's program!

Through this limited review of state home and community-based services programs for older adults and people with disabilities who are enrolled in Medicaid, this study found that all states, including Illinois, use a functional assessment tool as part of the determination of eligibility. However, the administration and scoring of the tool are used differently state to state. Nearly all states differentiate the eligibility assessment from the care planning process, which is different from the CCP, but similar to the process utilized by the Illinois HSP. Most states also do not consider the 'B-side' of the Determination of Need tool in setting the service levels, so eligibility for the program and levels of service available tend to reflect a client's actual functional deficiencies, without taking into account the family support available to the client.

The study also identified that all of the best practice states *except* Illinois provide the full range of services only to people who meet Medicaid financial eligibility. The Community Care Program serves seniors who have up to \$17,500 in individual assets, and doesn't consider income as an eligibility factor. This allows the Illinois program to serve many more people than other states, with the possibility of preventing both nursing home placement and spend-down to Medicaid. Because all of the states that were examined for this study have implemented their home and community-based services programs as alternatives to Medicaid-funded nursing home care, their service packages are more extensive and are designed to provide adequate services as a complete alternative to nursing homes. The Illinois program for seniors serves primarily older people at the middle range of unmet need, as defined by the DON (68% of those served have a DON score less than 56 out of a possible 100 points), in contrast for example with Vermont where only people designated as 'highest' need are entitled to receive services. Service Cost Maximums for clients at the very highest DON scores permit a little over five hours of service a day, seven days a week, but actual utilization shows that people at this level are receiving about 25.7 hours each week – much less than the 24/7 care needed by a person with incontinence, cognitive impairments or other difficulty in living alone.

In terms of setting guidelines for the cost of service for each client, states have various approaches. While the average authorized amount of service allowed for Illinois seniors is less than \$1,000, other states range from a low of \$1,300/month for clients in Vermont to over \$3,000/month in Arizona.

Arizona and Minnesota use a managed care approach, and provide a specific per-member/per-month payment to providers that manage care across their member populations. As long as the overall cost of the program is less than the cost of nursing home care for the same population, and the client outcomes and access to services are not compromised, then the providers work with clients and families to assure that the client needs are met. Illinois has examined the per-member/per-month concept through its Managed Community Care Project (MCCP) administered for Chicago participants through CJE Senior Life. Although the program has demonstrated good outcomes for its participants, replication of its success statewide would require substantial additional evaluation, and necessitate an application for a new Medicaid waiver.

States that have not implemented a managed care approach still have implemented guidelines for the amount of money that can be spent for each client for home and community-based services, and in some cases have also prioritized the amount of service available for clients at various levels of need. In Vermont, for example, the individuals who are determined to have the 'highest' need are always entitled to receive the greatest amount of funds/services, up to the cost of nursing home care. Seniors and people with disabilities in Vermont who have 'high' needs are entitled to the maximum services as funds are available. Ohio sets a limit that is based on 60% of its nursing home costs, and Washington based its rates on utilization for the same needs levels in the nursing homes. All of the states that were examined for this study used some type of monitoring process to examine plans of care that are out of the ordinary, and to assure that no one receives substandard care.

While the Community Care Program serving Illinois seniors has several things in common with the other states examined in this study – including the Determination of Need tool, the goal of providing an alternative to nursing home care, and a methodology for controlling costs – it falls short in meeting the unmet needs for activities of daily living at the highest DON ranges, and is substantially less generous in funding at the lower levels than the Illinois Home Services Program. What Illinois does not have that forms the foundation for home and community-based services programs in other states is a uniform philosophy that home and community services are a one-for-one alternative to nursing home care. Wisconsin has made this very clear in its use of Aging and Disability Resource Centers as a point of central intake for all individuals seeking any long-term care who have any type of disability. Both Vermont and Washington are aggressively working to eliminate barriers and enable people who are eligible for long-term care to make a choice of where they wish to live and receive services.

If Illinois took the approach that every person eligible for CCP (or HSP) must be otherwise eligible for nursing home care, and redeveloped its services and Service Cost Maximums to meet the needs of those individuals, both the Community Care Program and the Home Services Programs might be substantially different in the services offered, service plans, Service Cost Maximums, and levels of utilization. In the Community Care Program, while most participants average a 47 DON score, most new clients come in at a 29, indicating that new clients have a very low level of need. Clients screened through Choices for Care, the nursing home screening process, have an average DON score of 53.

Illinois instead has chosen to help many people with limited individual funds, and has included older people and people with disabilities who are not eligible for Medicaid. This may allow the state to serve more individuals and prevent the need for Medicaid nursing home care for some of them. A comprehensive evaluation of the CCP program is recommended to answer these and other questions regarding the effectiveness of the program.

SECTION V: Recommendations for Illinois

These recommendations are based on the major points gleaned from the literature, written materials, interviews with best practices states, key informant interviews in Illinois and an analysis of the Community Care Program data set. This study is the first systematic, independent analysis of the Community Care Program in its 30-year history, albeit addressing a limited scope of questions. CCP is the centerpiece of the state's home and community-based care program for Illinois seniors. Serving 50,000 people each year, it is one of the largest programs in the country. Demands to expand the program will continue to grow at the same time that budget constraints force rational stewardship of public resources. There is growing concern that anticipated growth in the program in its current form is unsustainable. The study team strongly recommends to the Department that it develop a process to evaluate the Program in order to make internal adjustments and improvements, and to provide decision makers with the knowledge and tools they need to justify systemwide changes to meet the needs of older people. In addition, the findings from the data analyses indicate that specific services – including personal care attendants, medication management and respite — are needed and can immediately address gaps for persons with high levels of need.

Recommendation 1 – Expand the CCP service mix to include increased hours for Personal Care Assistance, Medication Management and Short-Term Respite to address needs/gaps for people with unmet needs for these services.

- *Personal Care Services:* Personal care is currently available from home care aides. Our recommendation is to allow consumer direction for personal care assistants, enabling clients to select and hire their own workers as they do in the Illinois Home Care Services program, and as is common for both aged and disabled in most of the best practice states. Findings in Table 11 show that there is a considerable unmet need for assistance among high-end DON score clients, especially with respect to basic Activities of Daily Living (ADLs). Also, the findings in Table 12 show that persons in the high DON score range of 68 to 100 receive approximately 2 to 3.67 hours of home care aide per day in a 7-day week. Table 6 shows that the majority of these clients have significant cognitive impairment. The current 2 to 4 hours per day may be sufficient to address unmet need for Instrumental Activities of Daily Living (IADL) impairment but is considerably less than what is needed by clients who have considerable cognitive impairment in addition to high unmet IADL and ADL needs. The number of units of service needed per day for significant ADLs such as bathing and continence may be as high as a full day for a small percentage of the high-end DON score clients who are both physically and cognitively impaired and need supervision. Personal care can be part of the Service Cost Maximum schedule.

- *Medication Management:* Based on the number of chronic conditions that clients have and responses to item 13, “is the applicant able to follow the directions of physicians, nurses or therapists, as needed, for routine health care,” it appears that 27% of clients could benefit from the addition of medication management as another new optional service. As shown in Table 11, need for medication management is most frequent among clients with high-end DON scores (range 68-100), of whom 72% have an unmet need for this service. It is difficult to determine the percentage of clients for whom medication management will be an ongoing as opposed to a one-time service. We recommend that medication management be added as a new cost outside the existing SCM schedule.
- *Short-term respite:* Based on the number of clients with impairment on the MMSE and the number that scored a 2 or 3 on item 15, “can the applicant be left alone (e.g., able to recognize, avoid and respond to danger and or emergencies),” we recommend that family caregivers be offered the option of short-term respite. Overall 28% of total clients met the cut-off score indicating moderate to severe cognitive impairment on the MMSE. An even greater proportion (66%) had scores of 2 or 3 on being alone. This percent is reduced to 36% after factoring in informal care. However, persons providing this informal care are likely to be in great need of this service. Short-term respite may be an intermittent service and not provided on a regular basis. We recommend that it not be part of the existing SCM but be provided as an additional service for those clients in need of it.

Recommendation 2 – Link Community Care Program Service Cost Maximums with the Nursing Home Rates.

- The authors strongly recommend that CCP SCMs be more closely linked with Medicaid nursing home reimbursement rates. All best practice states indicated that their home and community-based program budget is based on or tied to their nursing home rate. Services in Ohio are set at 60% of Medicaid nursing home costs. In Minnesota’s managed care program, the cost for an individual cannot be greater than the medical assistance nursing home cost for that same individual. Illinois’ Community Care Program, as demonstrated by the Service Cost Maximum analysis in this study, is a very economical alternative to nursing home placement with no apparent fiscal waste. On the other hand, it does not offer some important services for people with high needs who are at greatest risk of nursing home admission. The SCM in Illinois should be linked to a percentage of the nursing component of the Medicaid nursing home care rate. As noted in the interviews, the CCP and HSP SCMs were initially linked to nursing home costs. HSP continues to maintain this linkage, but CCP does not. A basic premise of CCP is that it is designed to provide an alternative to those eligible for nursing home placement who prefer to remain in the community as long as the mean cost of the program does not exceed that of the nursing

component of nursing home care. Linking the SCM to the Medicaid per diem reimbursement for the nursing component of nursing home care would accomplish this goal of cost neutrality while also enabling these high risk clients to have their service needs met.

Recommendation 3 – The analysis of the distribution of services shows that the Community Care Program reaches many thousands of people and supports the informal caregiving structure for those who technically qualify, but who are not at immediate risk of nursing home placement based on measures of their functional capacity. The data raises questions, however, about whether the Community Care Program is well-suited to accomplish its stated goal of keeping people out of nursing homes. At the higher DON levels, very few people find the Community Care Program adequate to meet their needs. These clients represent those most at risk of nursing home utilization, and for whom additional expenditures in the community would be offset by savings in nursing home spending. Therefore, it is recommended that the Department conduct an independent evaluation of the Community Care Program to address questions that IDoA and policy makers must ask of a program that is intended to provide older people with an alternative to institutionalization while maintaining budget neutrality.

- What benefits/outcomes should participants achieve through receipt of services from the Community Care Program (this includes older people, family caregivers and paid caregivers)?
- Do individuals and families have different benefits/outcomes according to different levels of need (DON scores or some other means of identifying needs) that would call for a different CCP service package – e.g., the highest-risk person would need a stronger medical component and nurse case managers?
- Should CCP targeting be based on level of need (for example, Vermont’s ‘highest,’ ‘high’ and ‘moderate’)? If so, how?
 - From the perspective of cost effectiveness, do we achieve greater cost efficiency by serving high need/high risk individuals who, based on identified indicators, are at the highest risk for nursing home placement?
 - Or should CCP serve those of mid-level or modest needs so that the time they will need more intense services can be postponed? Is it likely that earlier intervention will delay or prevent people from needing a higher level of care?
 - Should CCP have contained within it a more intensive program for high-need/high-risk individuals who are at the greatest risk for institutionalization? This could be a Medicaid-only population, while General Revenue Funds would be targeted at those with higher assets as a preventative strategy.
 1. What range of services is necessary to achieve these benefits? What can be learned from other states? Have any states determined that some services are essential while others are nice to have, but not essential?

2. Can the necessary range of services be translated into estimated costs? Can level of need and benefits/outcomes be linked with specific services?
3. How would a broader consumer direction program influence these decisions about targeting? Or a personal assistance model of help?

While not based on Illinois CCP data, the following are points to consider based on analysis of the literature and best practice states:

Suggestion 1: Illinois' waiver program serves people with resources above the level for Medicaid eligibility, thus enabling CCP participants to slow the Medicaid spend-down and retain assets, and to potentially remain in the community longer. Each of the six states serves only Medicaid-eligible clients in their programs and, with the exception of Illinois and Ohio, sets 65 as the age of eligibility for aging services. Given concerns about the potential growth and sustainability of the program, Illinois may want to revisit its eligibility criteria.

Suggestion 2: To meet the needs of people who require nursing home levels of care, nurses along with social workers (in most states this means BA or MSW social workers) provide assessment and care coordination. In some states, nurses consult with social workers who do the care planning; in others nurses do the eligibility determination. As Illinois moves toward targeting clients who are at risk of nursing home placement, reintegrating nursing home residents and introducing medication management to its service mix, there will be more people in the program with complex health and psychosocial needs. Many of the best practice states have standards for caseloads based on the complexity of the clients situations. Illinois should consider the professional qualifications of the people who do the assessments and provide the care coordination, and should develop caseload standards.

Suggestion 3: Illinois needs to consider a more flexible, robust array of services as an alternative to nursing home placement. In addition to CCP's core services of homemaker, adult day services and emergency home response, most best practice states offer, among their array of services, meals, respite, transportation, mental health services, home modifications, medication management and personal care attendants.

Suggestion 4: Much like Illinois' HSP for people with disabilities, most of the states separate the eligibility determination function from the care planning function, giving the state more control over who is determined eligible for the program, and the ability to allocate and manage the care coordination function.

Suggestion 5: Illinois needs to effectively harness technology to mesh the clinical, budgetary and management aspects of their programs. Best practice states use technology to improve outcomes, achieve fairness in allocation of resources and

meet the complex needs of people. For example, Washington State's CARE tool, upon which Illinois' Comprehensive Care Coordination tool is based, is computerized. As the care coordinator fills in answers to the questions, the tool may trigger a nursing visit, a TB test, and the care plan. Several years ago they conducted a statewide study of how long it takes to do tasks and imbedded the information in an algorithm that populates the care plan. CARE authorizes billing, provides management information at the local and state levels, and enables the state to monitor and evaluate the program. The CARE system is in the public domain.

Suggestion 6: Global budgeting enables the best practice states to shift resources to where a person is being served. Each state has a different model that has been adapted to the culture and history of that state. Illinois should research and evaluate global budgeting models in other states and develop a method that works for Illinois to enable money to follow the person.

Appendix A Key Features of State Programs

	Illinois	Arizona	Minnesota
Administrative Agency			
Aging	The Department of Healthcare and Family Services Department on Aging: Community Care Program (CCP)	Arizona Health Care Cost Containment System (AHCCCS) Arizona Long Term Care System (ALTCS)	Minnesota Department of Human Services Aging and Adult Services Division: Elderly Waiver Program (EW)
Disabilities	The Department of Rehabilitative Services	Aging and Disabilities under same Waiver	Disability Division: Community Alternatives for Disabled Individuals (CADI) Waiver
Waivers			
Aging <i>Ages Covered Programs</i>	Age 60+ 1915c (2 waivers, HCBS and SLF)	Age 65+ 1115 Applying for transitional care waiver. Recently enacted consumer direction.	Age 65+ 1915c As of 1/1/09 all eligible people 65+ required to enroll in an MCO.
Disabilities <i>Ages Covered Programs</i>	Age 18-60 1915c (3 different waivers) a. Brain Injury b. AIDS c. Physical Disabilities	Age 18-65 Same as above	Age 18-65 CADI. Under 65 not required to enroll in an MCO, but may enroll voluntarily. No long range strategy to require managed care
FMAP Federal Matching Rate for Medicaid and Multiplier - 2009			
	50%	66%	62%
Census Estimates - US Census Bureau 2007			
Total Population	12,852,548	6,338,755	5,197,621
Persons 65 and older	1,548,781 (8.6%)	820,391 (8.6%)	636,216 (8.1%)
Number of People Served Under the Medicaid Waiver			
Aging	43,975 (FY07 projected) Community Care Program. 43% are on Medicaid or approximately 18,909 people	15,562 (2007) Medicaid only. Home - 5,837; Assisted Living Facility - 3,286; Nursing Home - 6,439	17,824 (2007)
Disabilities	FY06 33,000 served under the three 1915c waivers in FY04 25,412 served under the Physical Disability 1915c	6,435 (2007) Home - 4,039; Assisted Living Facility - 878; Nursing home - 1,518	XXXXX
Average Cost of HCBS Per Client/Consumer Per Year			
Aging	Projected FY07 \$628 per month	In 2005, weighted cap rate was \$3,171 per member per month.	FY07 Allowable range \$2,500-\$6,000/month. Average actual cost \$2,336
Disabilities	2006 Average of all three waivers \$1,080 physical disability average generally lower	Same as above	XXXX
Average Cost Per Client/Consumer Per Year (Nursing Facility)			
Aging & Disabilities	<ul style="list-style-type: none"> FY'08 yearly average \$41,040.60 \$24,970-\$72,295 yearly range daily range from \$68.41-\$198.07 	FY'08 yearly averages <ul style="list-style-type: none"> Level 1 -- Urban \$54,863-Rural \$53,155 Level 2 -- Urban \$59,980-Rural \$57,922 Level 3 -- Urban \$71,138-Rural \$68,865 	FY'07 \$52,824 yearly average
Eligibility Tool			
Aging <i>Instrument</i>	Determination of Need (DON) The DON scores three areas: 1) MMSE; 2) Part A - ADL and IADL; and 3) Part B - extent to which need is unmet from sources other than the CCP. A minimum score of 29 qualifies for CCP. Score determines amount of services/resources for which applicant is eligible. Eligible clients are required to apply for Medicaid. Co-payment established if client income/assets is above Medicaid eligibility level.	Pre-Admission Screen (PAS) ADL, IADL, Cognitive Functioning, Medical. Tool designed to determine person's orientation to person/place/time. In 2006 pared down tool to focus exclusively on items related to eligibility determination. Tool assesses need assuming no support system which is factored into care plan later. Must establish financial eligible to receive services.	Long-Term Care Consultation Assessment Form (LTCC) ADL, IADL, Medical, Behavioral, caregiver support, MMSE. Tool consists of 300 questions. 60-70 of these are used to populate the MIS system and used to develop a need scale ranging from A-K (11 levels), also populates care plan that client and/or assessor may choose to use. Clinical judgement may be applied in addition to the tool. Universal assessment tool has been developed but not yet been introduced. Must establish financial eligibility to receive services.
Disabilities	Same as above	Same as above	LTCC - Same

Ohio	Vermont	Washington	Wisconsin
Ohio Department of Job and Family Services (ODJFS)	Vermont Agency of Human Services	Department of Social and Health Services	Department of Health and Family Services
Ohio Department on Aging (PASSPORT)	Department of Disabilities, Aging and Independent Living: Choices for Care	Aging and Disability Services Administration HCBS Division Community Options Program Entry System (COPEs)	Family Care Program
Ohio Department of Job and Family Services: Bureau of HCBS Ohio Home Care	Aging and Disabilities under same Waiver	Aging and Disabilities under same Waiver	Aging and Disabilities under same Waiver
Age 60+ 1915c	Age 65+ 1115 (5 year renewable demonstration waiver)	Age 65+ 1915c	Age 65+ 1915c and 1915b – Family Care Demonstration Waiver
Age 18-60 1915c	Age 18-65 Same as above	Age 18-65 Same as above	Age 18-65 Same as above
50%	51%	59%	59%
11,466,917 1,545,085 (8.1%)	6,468,424 84,425 (7.3%)	5,601,640 757,852 (7.5%)	5,641,581 736,301 (8.3%)
33,000 (2007) Medicaid only. Includes 6,70 additional slots added in '07-'08 to eliminate waitlists.	4800 (approximately 85% >65) 2,200 in nursing home; 1,300 in HCBS (Highest and High need); 1,300 people are moderate need	23838 (FY 2007)	8,677 (2008)
XXXXX	See above		3,464
\$23,702/year \$1,975/month	FY 06 HCBS = \$3,386 Enhanced Residential Center = \$1,861	FY '07\$1,304.61 average per client per month	FY09 average capitation rate \$2,809. Range is \$2,375-\$3,450
XXXX	Same as above	Same as above	Same as above
FY'07 \$55,751 yearly average	FY'07 \$56,575 yearly average	FY'07 \$49,092 yearly average	FY '07 \$47,450 yearly average Range from \$46,800-\$48,360
Pre-Admission phone screen, In-Home Assessment and PAS ADL, IADL, Cognitive Functioning. Requirements include 1) Hand's-on assistance with at least 2 ADL; or 2) Needs hands-on assistance with at least one ADL and requires help of another person to administer medications; or 3) need 24-hour-per-day supervision from another person to prevent harm to self or others due to cognitive impairment; 4) Have unstable medical condition and require at least one skilled nursing service and/or skilled rehab service. PAS is also administered. CDJFS must approve Medicaid application prior to service initiation	Clinical Eligibility Worksheet; High/Highest Need Decision Tree ADL, IADL, Cognitive Functioning. Caregivers role only considered if living together. Administered face to face also using hospital records and MDS when appropriate. Decision tree used to determine Highest Need/High Need. Financial eligibility determined by Dept of Children and Families, Economic Service Division (ECF-ESD). Must be financially eligible to receive services. Presumptive eligibility is being explored.	Community Assessment Reporting Evaluation (CARE) Functional, medical, cognitive, substance abuse, suicidality, caregiver stress. Takes up to 3 hours to administer. Eliminated bias in the tool between nursing home and community. All questions factor into a payment algorithm. Web-linked tool. 17 different classification groups form basis for number of hours from 20-500 per month. Tool developed by Deloitte and Touche 2003. Prior to that used the Oregon tool	Long-Term Care Functional Screen (LTCFS) ADL and IADL, cognition, behavior, diagnoses, medically-oriented tasks, transportation, employment; indicators for mental health problems, substance abuse problems, and other conditions that put a person at-risk of institutionalization. County Economic Support Units co-located at ADRC. They establish financial eligibility prior to service delivery.
Ohio Home Care Waiver Ohio Dept. of Job and Family Service	Same as above	Same as above. Tool is used across settings and populations	Same as above

(Continued on next page.)

	Illinois	Arizona	Minnesota
How is Eligibility Determination Administered?			
Aging			
<i>Administrator</i>	Case Manager administers Comprehensive Needs Assmt. Form. The Determination of Need (DON) is one of the screens in the Form. If client is eligible, the case manager develops a plan based on what client is eligible to receive based on the DON and can also initiate or refer clients to other services they need based on the Comprehensive Needs Assessment Form.	EI Eligibility Interviewer uses weighted scores to determine medical eligibility. 60 or higher is eligible. Person is either "in" or "out". Physician review required for 57-59 and may override.	Financial eligibility determination made by the county unit of government. LTC consultants then administer standardized screening and assessment. If eligible, case manager can help to develop an initial care plan, but does not help to manage the plan.
<i>Qualifications</i>	BA level case manager certified by IDoA. Physician approval required.	Social Worker or Nurse	Licensed social workers, RN or PHRN's. A state statute defines the assessors.
<i>Employer</i>	Case Coordination Units, under contract with IDOA	Arizona Long Term Care System (ALTCS)	County unit of government. MCO's also have people qualified to do assessment. MN going through a transition period
Disabilities			
<i>Administrator</i>	Home Services Counselor conducts face to face interview with customer. HSC authorizes plan.	Same as above	Providers contracted through Case Management agency CareStar
<i>Qualifications</i>			Public Health Nurse, Registered Nurse, Social Worker (not licensed)
<i>Employer</i>	DORS		

How is Plan of Care Developed?			
Aging	CCU case manager who determines eligibility develops care plan based on DON score. Score determines service cost maximums for which the person is eligible: Homemaker, ADS, Em. Home Res. May help arrange additional services that are not available through CCP, but available thru AAA or their local community such as HDM, respite	Eligible clients enroll with MCO, assigned case manager. In Phoenix area, choice of 3 MCO providers. All other areas of the state, one provider available. Care plan developed by client, case manager, and PCP from MCO panel of providers. Plan based on assessment of what the client needs. Care is provided up to the amount person is eligible to receive in nursing home.	Comprehensive care planning tool based on the assessment results identifies a template of areas to address in the care plan, the providers in the area, or an MCO. MIS authorizes provider to render service and to bill the state. Services can include 24 hour AL, foster care or board and lodge settings. Plan based on score which fall into 11 groups/limits allowing from \$2,500 to \$6,000 per month.
Disabilities	Service Cost Maximums are yearly costs. Left over monthly costs are annualized so that home modification can be planned for and paid up front. "Customer" hires PA. Customer/PA agreement is completed annually by the customer establishing the standards for the PA. Customer assures that PA meets established standards.	Same as above	County units of government receives a pool of money based on county demographics. They allocate an aggregate amount of money per person to be spent flexibly

Ohio	Vermont	Washington	Wisconsin
<p>In-home assessment required by RN or LCSW who may start process toward PASSPORT enrollment. Assmt. takes approximately 2 hours to complete. The assessor determines level of care.</p> <p>Licensed Social Worker or Registered Nurse. Physician approval required.</p> <p>13 AAA's and one non-profit agency</p>	<p>Face to face assessment administered by RN, often in hospital or nursing home.</p> <p>Registered Nurse (13 in the state)</p> <p>Department of Disabilities, Aging and Independent Living: Choices for Care</p>	<p>Social workers have laptops. Tool is used to determine number of hours authorized. Algorithm codes for eligibility. Social Worker makes ultimate decision.</p> <p>BSW w/ experience. Tool triggers RN if necessary</p> <p>Aging and Disability Services Administration HCBS Division</p>	<p>Administered to all people at ADRC who have prospective LTC need, and to all prospective NH, DD, CBRF pre-admission counseling process. Automated form so that upon completion, assessor can instantly see the applicants level of care, eligibility for Family Care and other HCBS waiver programs.</p> <p>Experienced professionals, usually social workers or registered nurses, who have taken an on-line training course and passed a certification exam and are able to access and administer the screen.</p> <p>Physician approval NOT required</p> <p>Aging and Disabilities Resource Centers (ADRC's)</p>
<p>XXXX</p> <p>XXXX</p>	<p>Same as above</p>	<p>Same as above</p>	<p>Same as above</p>

<p>Assessors determine amount of services and level of case management. Assessor may become case manager or refer to case manager.</p> <p>Three levels of case management:</p> <ol style="list-style-type: none"> 1) consumer managed 2) Supportive 3) Intensive <p>Case manager negotiates plan of care with client and responsible others. Cost of plan must be below 50% of cost of Medicaid funded nursing home.</p>	<p>Highest Need entitled to receive services: NH or HCBS. Eligible person selects CMO. Case manager assesses at home visits. Tool is 25 pages and includes options counseling. Tool drives plan of care: One ADL allows 5.5 hours per week. CM can seek individual waivers if person needs more. The maximum amount of service based on ADLs depends on the assessed needs of the individual. Plan considers what family can do and what needs to be substituted for areas in which family can not participate. Plan of care must be approved by the original assessing RN. Once plan in place, case manager visits monthly to handle complaints and modify plan due to changes in function. **NOTE qualifications of the case manager: There are not enough MSW's in VT so they developed case management standards for their contracted agencies, and applicants must pass a test by 80% in order to work in Choices for Care or Older American's Act programs.</p>	<p>Assessor provides initial assessment and sets up initial services. Transfers the client to AAA case manager who is an MSW or BSW with 3 years of experience and who works with client (and support system) to develop plan. Community RN consulted if RN had been called for in the assessment. They have developed a skin observation protocol which automatically generates an RN referral</p>	<p>Client enrolls in a Family Care Care Management Organization (CMO). Assigned to an interdisciplinary management team - RN and Social Worker who work with consumer to identify core issues and desired outcomes using the Resource Allocation Decision (RAD) Method:</p> <ol style="list-style-type: none"> 1) What is the need, goal, problem?; 2) Does it relate to the person's assessment, service plan and desired outcomes?; 3) How could the need be met?; 4) Are there policy guidelines to guide the choice of option?; 5) Which option does the member (or family) prefer?; 6) Which option(s) is/are the most effective and cost-effective in meeting the desired outcomes(s)?; 7) Explain, Dialogue, Negotiate (consumer can appeal CMO's decision.)
	<p>Same as above</p>	<p>Same as above</p>	<p>Same as above.</p>

(Continued on next page.)

	Illinois	Arizona	Minnesota
What Services are Available? (List and/or Describe)			
Aging	<ul style="list-style-type: none"> • Adult Day, • Homemaker, • Case Management • Emergency Home Response Flexible Dollars 	<p>Services include acute medical services (doctors, hospitalization, prescriptions, etc), nursing home care in licensed nursing facility, psychiatric hospitalization, • Home Health</p> <ul style="list-style-type: none"> • Habitation • Adult Day • Personal Care • Transportation • Mental Health • Homemaker • Attendant Care • Respite • Meals • Hospice HCBS may also be provided in supervised alternative residential settings such as Adult foster care, Assisted Living, Group Homes (ALTCs does not pay for room and board in alternative settings) 	<ul style="list-style-type: none"> • Adult day • chore service • companion services • consumer directed community supports • home health aids • meals • homemaker • home modifications • personal care • respite • specialized supplies and equipment • training for informal caregivers • transitional supports • transportation.
Disabilities	<ul style="list-style-type: none"> • Personal Assistant • Homemaker • Maintenance Home Health • Emergency Home Response • Meals • Adult Day • Assistive Equipment • Home Modification • Respite Services 	<p>Same as for aging</p>	<ul style="list-style-type: none"> • Adult Day • Assisted Living • Case Management • Case Aid • Home Health and Nursing • Health Therapies • Personal Care • Family Counseling and Training • Foster Care • Meals • Home Maker • Independent Living Skills • Home and Vehicle Modifications • Prevocational Services • Residential Care • Respite • Supplies and Equipment • Supported Employment • Transitional Services • Transportation

Ohio	Vermont	Washington	Wisconsin
<p>Passport:</p> <ul style="list-style-type: none"> • Homemaker • Personal Care • Emergency Response • Chore Services • Social Work Counseling • Nutrition;Meals • Adult Day • Medical Equipment • Transportation • Home Modifications <p>Choices:</p> <ul style="list-style-type: none"> • Home Care • Adult Day • Meals • Emergency Response • Home Modifications • Medical Equipment and Supplies • Pest Control • Alternative Meals 	<p>Highest and High (only as resources are available)</p> <ul style="list-style-type: none"> • Nursing Home •Adult Day Services • Personal Care • Companion Services • Respite • \$750 per yr. Assistive Technology or Home Modification • Personal Emergency Response • Enhanced Residential Care Home Services (in Res. Care Home, or AL) • Nursing Facility Services in Lic. Nursing Facility • Case Management • Homemaker Services • HDM <p>Other living arrangements</p> <p>Moderate:(only as resources are available)</p> <ul style="list-style-type: none"> • Case Management • Adult Day • Homemaker 	<ul style="list-style-type: none"> • Personal Care • Adult Day • Home Modification • Home Health • Meals • Emergency Home Response • Medical Equipment and Supplies • Transportation • Training for Therapeutic Goals 	<ul style="list-style-type: none"> • Adaptive Aids (general and vehicle) • Adult Day Care • Alcohol and Other Drug Abuse Day Treatment Services (in all settings) • Alcohol and Other Drug Abuse Services (except those provided by a physician or on an inpatient basis) • Care/Case Management (including Assessment and Case Planning) • Communication Aids/Interpreter Services • Community Support Program • Consumer-Directed Supports/Self-Directed Supports • Consumer Education and Training • Counseling and Therapeutic Resources • Daily Living Skills Training • Day Services/Treatment • Durable Medical Equipment, except for hearing aids and prosthetics (in all settings) • Home Health • Home Modifications • Housing Counseling • Meals: home delivered • Medical Supplies • Mental Health Day Treatment Services (in all settings) • Mental Health Services, except those provided by a physician or on an inpatient basis <ul style="list-style-type: none"> • Nursing Facility (all stays) including Intermediate Care Facility for People with Mental Retardation (ICF/MR) and for people under age 21 or 65 and older Institution for Mental Disease (IMD) • Nursing Services (including respiratory care, intermittent and private duty nursing) and Nursing Services • Occupational Therapy (in all settings except for inpatient hospital) • Personal Care • Personal Emergency Response System Services • Physical Therapy (in all settings except for inpatient hospital) • Prevocational Services • Relocation Services • Residential Services: Certified Residential Care Apartment Complex (RCAC) • Community-Based Residential Facility (CBRF) • Adult Family Home • Respite Care (for care givers and members in non-institutional and institutional settings) • Specialized Medical Supplies • Speech and Language Pathology Services (in all settings except for inpatient hospital) • Supported Employment • Supportive Home Care • Transportation: Select Medicaid covered (i.e., Medicaid covered Transportation Services except Ambulance and transportation by common carrier) and non-Medicaid covered • Vocational Futures Planning
<p>XXXX</p>	<p>Same as for aging</p>	<p>Same as for aging</p>	<p>Same as for aging</p>

	Illinois	Arizona	Minnesota
Consumer Direction			
Aging	Cash and Counseling program started May, 2007. Available in 4 locations around state. 150 people are in the program as of 3-09. People can use up to 100% of SCM less \$75 to cover fiscal administration.	Self Direction Attendant Care (SDAL) Option. Enabling legislation passed 4/21/08 SB1329. Report on participation due to legislature 01/01/11	Consumer Directed Community Supports Program. Currently 200-300 people in program, primarily in ethnic communities where people prefer to hire family members. Program is state wide and care mgrs require on-going training.
Disabilities	Program is consumer directed.	Same as above	XXXX
Waiting Lists or Targeting Strategies?			
Aging	Entitlement program - no wait lists due to court order.	Effective 10/01/1999, HCBS to the elderly and physically disabled no longer be capped. Utilize strict eligibility criteria.	Allocated resources are based on case mix. They are not as concerned about inappropriate NH placement, but are concerned about the growth and use of Assisted Living which is considered to be HCBS for EW clients. They project the # of people who access the services based on need and preference. As of 1/1/09, all clients will be in MCO's which may have their own targeting strategies.
Disabilities	Same		XXX
How Does the Program Assure That the Client/Consumer is Receiving Adequate Services?			
Aging		AHCCS developed and implemented Quality Management program tailored for managed care. In 1995 AHCCS entered into partnership with CMS on a QMI designed to measure health care outcomes with quality indicators and encounter data. AHCCCS regularly submits acute and LTC utilization reports and Quality Indicator reports and conducts and publishes member satisfaction and provider satisfaction surveys	Waiver Review Project. Quality framework used for evaluation plus new focus on client level outcomes. 7 key areas for framework: participant access and participant centered service plan and delivery; provider capacity and capability; participant safeguards, rights and responsibilities, outcomes/satisfaction; system performance. They face challenges around specific performance of providers. Over the next 5 years audits will change dramatically as the MCO operates under a different set of waivers - 1915 b/c
Disabilities			XXXX
How Does the State Pay for the Services			
Aging	State contracts with Case Coordination Units, Homemaker, ADS and EHR provider agencies. State establishes unit rates for each service - 73% of rate is dedicated to direct service worker, 27% is for agency/administrative costs.	Mandatory Medicaid managed care MCO contracts with providers. MCO is paid a capitated rate per member, per month. Rate is 60% of Medicaid nursing home rate in AZ.	Fiscal Support entities function as financial intermediary. Fee for Service being phased out. 1/1/09 all Medicaid eligible clients for EW are required to enroll in MCO.
Disabilities	<ul style="list-style-type: none"> Current PA rate is \$9.35 per hour. PA's are paid through a payroll system at the comptrollers office twice a month. State takes out union dues for all PA's. 	Same as above	Costs are much higher per person and there is no cap on individuals or services. There are plans to change this.
How Does the State Budget for the Services/Programs?			
Aging			Forecast Division considers time, services, numbers, etc to project the cost of the elderly waiver. With Managed Care becoming universal, MCO's are at risk for HCBS, Nursing homes and hospitalizations.
Disabilities			

Ohio	Vermont	Washington	Wisconsin
<p>Money Follows the Person – in FY07 5 year plan to implement statewide</p> <p>Consumer directed program, Choices, in effect since 2002. Currently in 5 locations around the state serving between 400-500 people. Plans to expand statewide.</p>	<p>Flexible Choices: Person can use budget, work with their counselor to develop plan and hire workers. All independent providers providing Medicaid-funded participant directed services must complete a two-hour orientation, four-hour safety training, and a 28-hour introductory training course within 120 days of employment. Fiscal Intermediary pays independent providers.</p>	<p>Program in effect 18 mos. It is not well integrated as yet. They find that younger people prefer to play a larger role in control of their services - more assertive. Older people tend not to complain often and don't strongly manage their service.</p>	<p>IRIS, a separate SDS waiver, is a self directed option for publically funded community care supports and services using natural supports and creativity with budgeting to achieve "hopes and dreams". Available in all counties where Family Care is offered. FC members choosing IRIS can still benefit from advice and support of their interdisciplinary care team.</p>
XXXX	Same as above	Same as above	Same as above
<p>Eliminated waiting lists by providing additional 'slots' in 2007 and 2008, but waiting lists are a possibility.</p>	<p>"Highest Need" entitled to receive services. May have waiting list for "High Need". Waiting list exists for "Moderate Need"</p>	<p>No Waiting lists. They plan to develop chronic care management and an employment program for younger people</p>	<p>WI does not have a risk sharing agreement with MCO's on high cost people. They have pay-for-performance agreements such as targeted disease prevention by care teams to reduce certain costs such as con-compliance with diabetes care protocols. They offer state support to MCO's with behavioral or disability-specific expert consultation to effect community integration and safe care plans for high cost individuals.</p>
XXXX	Same as above	Same as above	Same as above
<p>Utilize CMS framework for Quality Management and Improvement System (QMIS). During care plan reviews, case managers review actual utilization. Established a Quality Management Assurance Subcommittee. Scripps Gerontology Center has been evaluating the program for 16 years. In most recent evaluation they found that clients used 80% of services they were eligible to receive.</p>	<ul style="list-style-type: none"> • Long-term care Ombudsman role expanded to include HCBS • LTC Consumer Survey (Macro) • Gold Star Employers (Home Health, Nursing Homes) • Nursing Home Quality Awards • Nursing Home Quality Improvement Council • HCBS Quality Management Plan • HCBS Provider Reviews • Examination of HCBS Provider Review process • University of Massachusetts- independent evaluation of CFC 	<p>Lewin Group provided an external evaluation and cost analysis of the program. MetaStar has contracted to do external quality reviews. The University of WI is developing measurement of Personal Experience Outcomes. The Department also conducts site visits to ADRC's, and CMO's, care plan reviews and quarterly reports.</p>	<p>Wisconsin Family Care Final Evaluation Report for the WI Legislative Audit Bureau, by the Lewin Group 6/30/03</p> <p>H62Evaluation project funded by the Wisconsin Department of Health and Family Services for the purpose of developing a way to measure and use Personal Experience Outcomes for people receiving long-term care services in the community. Initiating PEONIES project: Personal Experience Outcomes iNtegrated Interview and Evaluation System.</p>
XXXX	Same as above	Same as above	Same as above
<p>State contracts with PAA (Area Agencies on Aging). Any willing provider can participate. State pays the PAA. Providers bill the PAA. Each site limited to 60% of the cost of nursing home placement. Anyone with a care plan of over 60% is flagged for review.</p>	<p>Programs must stay within aggregate Global Budget Cap of \$1..326 Billion (2006), or state is liable for cost overruns.</p>	<p>Caseload Budget Counsel projects trends and forecasts. Global budget for HCBS and nursing home care.</p>	<p>CMOs manage and deliver care RAD – Resource Allocation Decision Method CMOs receive a monthly per capita amount per member.</p>
XXXX	Same as above	Same as above	Same as above
<p>Legislation enacted in 2008 that authorizes the state to create a global budget, ensuring consumer choice in how and where they receive service.</p>	<p>VT contracts with providers including nursing homes</p>	<p>Older adults use consumer directed program as much as younger people with disabilities. New Freedom consumer directed program Global budget - all LTC under same administrative unit.</p>	<p>ADRC function as global budget funnel for Waiver and HCBS funds. Care Management Organizations receive capitated rate to provide HCBS</p>
		<p>Younger people with disabilities tend to have a higher levels of need due to functional and cognitive disabilities.</p>	

Appendix B Literature Review

To determine best practices in home and community-based service design and delivery, it's crucial to look at state-specific models as well as a sample of recent literature. We reviewed literature that addresses eligibility determination, service cost formulas, program expansion and measures of service quality, all of which are shifting components of state long-term care policy. To assess the role of each of these components in informing the study questions, we found that studies on care coordination, program evaluation, service flexibility, cost containment and evaluation methodology offered useful perspectives for this report.

The literature on state-specific long-term care configuration and service delivery is diverse in topic and scope. Studies reflect the fact that HCBS systems are in constant flux and difficult to compare. Adding to the difficulties in comparing states is the fact that both Medicaid and the Older Americans Act permit considerable state and local control, and hence variation, in how states organize long-term care. While investigators do not agree about successful models of administrative structure, finance and service quality, they agree about the complexities that characterize each state's long-term care system. Given the array of state designs, the most useful studies highlight lessons applicable for systems operating at various implementation levels of home and community-based service delivery.

This summary reviews trends in home and community-based services, including increased use of technology, complexity in assessments, rigorous quality and adequacy measures, consumer direction, flexible budgeting and enhanced care coordination training.

Illinois has made progress in HCBS delivery. The number of participants receiving HCBS has increased, and the state has introduced a Cash and Counseling Demonstration.⁵⁷ However, it does not currently employ key design elements noted in the literature as features of successful HCBS programs: adequacy, use of technology, service delivery, cost containment and consumer direction.

Technology

Technology is a critical component of long-term care system design and implementation. Increased use of automated systems improves the ability to measure quality, coordinate services, capture service utilization, and improve communication across program silos.⁵⁸ In addition, technology can speed up eligibility determination and provide a structure for increased complexity in

⁵⁷ AARP Public Policy Institute. 2008. *A Balancing Act: State Long-Term Care Reform*. Washington, D.C.: AARP.

⁵⁸ Miller, Edward Allan and Mor, Vincent. 2006 *Out of the Shadows: Envisioning a Brighter Future for Long-Term Care in America*. A Brown University Report for the National Commission on Long-Term Care.

assessments. Researchers agree that expanding technological platforms is a necessary investment for states – but caution against relying exclusively on automation. For example, in the case of eligibility determination, research indicates that professionals must have the authority to override a web-based system if necessary.⁵⁹ Suggestions about an automated universal eligibility tool, much like the MDS used in nursing facilities, also appear in the literature.⁶⁰ While there is some discussion of using a core tool such as the MDS with added measures designed to be state-specific, this has not been thoroughly studied.

The ability to generate and manage data using technology for quality measurement has helped many states develop a balanced LTC system. Technology has allowed states to modify their services in order to provide equal access to both HCBS and nursing facilities through single points of entry and expedited eligibility. Technology can provide the data necessary to target services, control costs, provide people what they need, and measure quality. For example, lists of high-cost consumers can be generated to better target services. Also, outlier patterns in scoring assessments can be tracked within and across geographic locations. In a report on Washington's HCBS system, Gillespie and Mollica note the utility of sophisticated technology, stating, "A competency/consistency rating can be generated for individual case managers. Additional staff training is provided when this rating is low. These reports assist in internal monitoring and analysis of quality service delivery, risk management, and budgetary forecasting. The system is designed to allow managers to generate reports from the data to monitor and measure performance of individual workers, reporting units, regions, assessment status, and date."⁶¹ But a cautionary note here: reliance on data measures of quality can undermine recent trends towards person-centered outcomes that are not always easily quantified.

The use of mobile technology, such as laptop computers and printers, reduces home visits and paperwork. This can minimize costs, especially in rural areas. Care coordinators can print out resource information for clients in real time and upload client information immediately. In Washington, for example, clients sit beside an assessor so that both can look at the computer screen instead of across from each other, as is traditional in a paper evaluation. Consumers and assessors alike note the increase in trust and understanding of the assessment process.⁶²

Not surprisingly, funding for technological advances remains a barrier in many systems, but an investment in technology now is a key to future cost reductions. The

⁵⁹ Real Systems Change Grant Functional Assessment Report. Prepared by Johnson-Lamarche, Heather. Contract with the University of Massachusetts Medical School for Health Policy and Research. November 2006.

⁶⁰ Ibid.

⁶¹ Gillespie, J., Mollica, R. "Streamlining Access to Home and Community-Based Services: Lessons from Washington." Issue Brief. Community Living Exchange. Rutgers Center for State Health Policy and National Academy for State Health Policy. June 2005.

⁶² Acosta, Paula, and Leslie Hendrickson. *Advancing Medicaid HCBS Policy: From Capped Consumer to Consumer Directed*. New Brunswick, N.J.: Rutgers Center for State Health Policy. 2008.

increasing use of technology intersects with virtually all best-practice components of home and community-based long-term care, including assessment and care management. Currently, however, technology is introduced incrementally. This is to be expected in a time of budget tightening, but it elicits concern about the long-term consequences of piecemeal projects. Systems developed separately as funding is available often lack the tools to communicate with each other electronically.⁶³

Technological sophistication can also enhance care and policy discussions, especially because non-electronic data does not easily follow consumers from one setting to another.”⁶⁴ Technology can, for example, facilitate transfer of information among different providers who are responsible for clients with complex chronic conditions and disabilities. Assessment data, data elements, and phrasing of interview questions can be made more easily available via technology⁶⁵. Although the use of technology raises questions about how to protect consumer information, HIPAA protocols have shifted to recognize the utility of electronic records. The National Association of State Units on Aging published a brief in which it noted, “With broader adoption of information technology (IT), protocols to protect privacy and confidentiality have changed to accommodate a new and evolving IT infrastructure,”⁶⁶ thus paving the way to incorporate technology in LTC planning and design.

Care Coordination

Multiple definitions and terms are used in literature and practice to describe care coordination. Historically, case management was the accepted term and more recently, care management. The language again has shifted to ‘care coordination.’ For consistency, we will use ‘care coordination’ throughout this section. We also use ‘care coordination’ because the philosophy driving this phrase aligns with the increasingly broad definition of the coordinator role found in the literature. Also, the term conveys the shift towards consumer-directed models. In quotes and the section on state long-term care systems, the terminology will differ based on state definition and terminology. We use care coordination broadly, as there is no universally accepted definition that accounts for the diversity of this work and the professionals who carry it out.

Assessments

Experts^{67 68} generally support, as a best practice, the trend toward complex assessments during the period of enrollment in home and community-based care.

⁶³ *From Isolation to Integration: Recommendations to Improve Quality in Long-Term Care*. Final Report for National Commission on Long-Term Care. December 2007.

⁶⁴ Ibid.

⁶⁵ Ibid.

⁶⁶ NASUA Issue Brief: *Aging and Disability Resource Centers and the Health Insurance Portability and Accountability Act of 1996*. September 2004.

⁶⁷ Gillespie, Jennifer. *Assessment Instruments in 12 States*. Washington, D.C.: National Academy for State Health Policy. 2005.

⁶⁸ Wiener, Joshua M., and Steven M. Lutzky. *Home and Community-Based Services for Older People and Younger Persons with Physical Disabilities in Washington*. Report for U.S. Department of Health and Human Services Health Care Financing Administration. Washington D.C.: Urban Institute. 2001.

Opinions diverge, however, about what measures to include in the assessments. There are many reasons why states use different strategies to assess consumers. While assessments are designed to determine the supports consumers need to remain in their homes, the political and fiscal landscape drives modifications in assessment protocol and procedure. States may, for example, restrict service allocation and eligibility or offer care in only certain geographic locations. Geron notes that this landscape “has transformed the rationale and methods of assessment.”⁶⁹ Several other states have separated eligibility determination from care planning and assessment, thus dividing the ‘gate-keeping’ function from the service plan in order to closely monitor entry into programs.

A difference in how the assessments are used is another factor leading to divergent measures. Some tools are meant to drive care plans while others simply capture necessary scores and biographical data about consumers. Assessment tools more frequently include caregiver assessments, recognizing the correlation between the stress and loss experienced by caregivers and institutionalization. Because many states now offer supportive services for caregivers through Older Americans Act funding, this initial measure can assist in determining a plan of care, which includes both consumer and caregiver needs.

Levels of Care

Some states use gradations in levels of care. Hendrickson and Reinhard note, “It is not sufficient to conclude they [potential clients] are or are not eligible for services.”⁷⁰ Investigators who champion “different sets of criteria for different levels of care believe that it gives states the opportunity to provide services to more people at different levels of intensity. Many believe that if some community-based services are made available to individuals who do not meet criteria for nursing home level of care, more costly services can be delayed or avoided.”⁷¹ While eligibility criteria for different levels of care are not widespread, the issue is gaining more attention as states struggle to manage tight budgets. Another practice in levels of care is a formal gradation of case management. In Ohio, the state designed a system that offers levels of care management according to the population’s diverse needs. This practice may be especially useful for states that cover groups with more moderate needs who are not nursing home-eligible, such as Vermont. Policy makers and service providers continue to discuss the coverage of consumers with more moderate needs in terms of both preventative programming and cost.

⁶⁹ Geron, Scott Miyake. *Taking the Measure of Assessment*. Generations at www.asaging.org, retrieved October 10, 2008.

⁷⁰ Hendrickson, Leslie, and Susan Reinhard. *Global Budgeting: Promoting Flexible Funding to Support Long-Term Care Choices*. New Brunswick, N.J.: Rutgers Center for State Health Policy. 2004.

⁷¹ Summer, Laura. *Community-Based Long-Term Services Financed by Medicaid: Managing Resources to Provide Appropriate Medicaid Services*. Georgetown Long-Term Care Financing Project. June 2007. Retrieved at www.ltc.georgetown.edu on September 17, 2008.

Predicting Nursing Home Placement

The inclusion of nursing home predictors can enhance the capability to target service planning. Research and policy literature have long studied predictors of nursing facility admission. Researchers agree that reliable predictors of nursing home admission include the number of ADL and IADL assists, frequency of in-patient stays 12 months prior to admission, availability and stability of caregiver support, and HCBS state policy.⁷² Layers of variables affect an individual's admission, but these variables have been consistent predictors across studies over a long period of time. Caregiver availability and stability, or lack thereof, is a primary factor in predicting when someone will go into a nursing home. Gibson and Houser note, "The cost of funding services and supports [for caregivers] is minute compared to the value of their contributions."⁷³

Thus, HCBS planning must include resources allocated for caregiver support. While researchers agree about nursing home predictors, the key informants we interviewed for our best practices states reported that they did not specifically examine nursing home predictors in the data they collect for their programs. Instead, states compared similar populations in nursing facilities with those in the community. This disconnect between academic evaluations and state policy is important to note. Those states with strong ties to academic institutions – Ohio, Vermont and Minnesota (see state programs) – have access to expert statistical analysis, which is used to demonstrate the need for changes in LTC policy. Supporting caregivers in ways that respond to both their immediate needs for support and their longer-term needs calls for structural reforms in long-term care policymaking that are far more dramatic than the very important respite and other support programs that now exist. Such changes would include allowances for out-of-pocket costs, free 'vacation' respite, attribution of social security credits for drop-out years and other such structural changes.

Assessments and Cognitive Impairments

There is a debate about how best to use cognitive measures in eligibility determination and care planning. The trend at this time is away from the *exclusive* use of the Mini Mental State Exam (MMSE).⁷⁴ Researchers are quick to point out that the MMSE was not constructed to be used to determine service eligibility or care planning. Despite the fact that the MMSE and other such screens have been rigorously tested for reliability and validity, additional screening is necessary. The reason for this is that the items in the MMSE measure left brain function, which potentially misses major 'right brain' cognitive damage.⁷⁵ In a report on eligibility

⁷² Gaugler, Joseph and Sue Duval, Keith Anderson, Robert Kane. "Predicting nursing home admission in the U.S.: A Meta-Analysis. *BMC Geriatrics*, 2007. 7:13. Retrieved from www.biomedcentral.com October 3, 2008.

⁷³ Gibson, Mary Jo and Ari Houser. "Valuing the Invaluable: A New Look at the Value of Caregiving." AARP issue brief. June 2007. Retrieved from www.thecaregiver.org/pdfs on November 1, 2008.

⁷⁴ O'Keeffe, Janet, DrPH, RN; Tilley, Jane DrPH; Lucas, Christopher. *Medicaid Eligibility Criteria for Long Term Care Services: Access for People with Alzheimer's Disease and Other Dementias*. Public Policy Issue Brief; Alzheimer's Association. May, 2006

⁷⁵ *Ibid.*

criteria for people with Alzheimer's disease, Fox et al. noted that "advocates and experts in Alzheimer's disagree about what criteria best identifies people with dementia who need services."⁷⁶ Yet, there is no agreement on an alternative tool. For example, a caregiver's report that the client's needs require greater levels of supervision may be more vital than the use of scoring mechanisms in determining service allocation, eligibility and planning. While reports will vary, "average caregiving time is a rough indicator of long-term care resources expended to maintain the person with dementia in the community, the primary goal of the community-based long-term care benefit."⁷⁷

Similarly, mental health assessment continues to be a topic of discussion for home and community-based assessments and planning. Hendrickson and Kyzr-Sheely note that mental health problems, such as depression, are underreported using most assessment tools. A potential consequence is a care plan that does not include services responsive to mental health needs, increasing the risk of early and unnecessary institutionalization.⁷⁸ Practically, however, many systems lack the capability to offer mental health services; thus, some practitioners see little utility in assessing a problem that the service system cannot address. Laura Summer of the Georgetown Long-Term Care Financing Project explains, "A study of the care planning process in Michigan concluded that care planners were less likely to identify and respond to some problems than others. Depression was often overlooked, perhaps in part because the case managers were not trained to recognize it or perhaps because they knew that they did not have the resources to address the problems."⁷⁹ It is up to policy makers to address this gap in community-based services.

Although there is general agreement about the importance of complex assessments, some researchers^{80 81} call into question the exclusive reliance on scoring to determine eligibility. Scores offer guidance – but as Geron notes, "The assessment should not include simplistic scoring schemes that tie the hands of the assessors and force assessors to 'game' the scoring in order to confirm their professional judgment."⁸² Instead, the weight of a professional's comments and recommendations can be incorporated and used as the main authority in an

⁷⁶ Fox, Patrick and Katie Maslow, Xiulan Zhang. *Long-Term Care Eligibility Criteria for People with Alzheimer's Disease*. Health Care Financing Review. Summer 1999. Retrieved October 22, 1008. www.springerlink.com

⁷⁷ Ibid.

⁷⁸ Hendrickson, Leslie, and Gary Kyzr-Sheeley. *Determining Medicaid State Home Eligibility: A Survey of State Level of Care Assessment*. New Brunswick, NJ: Rutgers Center for State Health Policy. 2008.

⁷⁹ Summer, Laura. op. cit.

⁸⁰ Fox, Patrick and Katie Maslow, Xiulan Zhang. *Long-Term Care Eligibility Criteria for People with Alzheimer's Disease*. Health Care Financing Review. Summer 1999. Retrieved October 22, 1008. www.springerlink.com

⁸¹ Real Systems Change Grant Functional Assessment Report. Prepared by Johnson-Lamarche, Heather. Contract with the University of Massachusetts Medical School for Health Policy and Research. November 2006.

⁸² Geron, Scott Miyake. *Taking the Measure of Assessment*. Generations at www.asaging.org; retrieved October 10, 2008.

assessment with the support of scores as opposed to using scores that override professional evaluation.

The Role of Care Coordinator

The care coordinator is vital to the structure of HCBS. However, the role of the care coordinator is defined by state, and sometimes regional, expectations. There continues to be variety in the ways care coordination is structured, managed and practiced across states. However, literature indicates a trend towards the professionalization of the role and a greater responsibility assigned to individual care coordinators. In the expanded role of care coordinator, core services such as assessment and referral become basic, and the negotiation of complex and competing additional tasks becomes highlighted. These additional components include evaluation tracking, clinical intervention, advocacy, marketing, an understanding of medical conditions, budgeting expertise, and crisis management. Further evidence of professionalization is prevalent on the national level as organizations have developed care coordination certification based on experience, licensing and academic preparation. Golden and White explain that these activities have expanded since the 1990s, when “professional organizations and associations developed standards for the practice of case management specifically in health and aging.”⁸³

Care Coordination Training

The shift towards assessment complexity reinforces the need for a high level of training and a greater reliance on professional judgment, a quality that tends to be downplayed as the focus on professionalism moves toward technocratic expertise. Training is most successful when a variety of tools are used and specific content is included. According to Geron,⁸⁴ extensive training should include the role of coordination within the larger LTC system, the accepted level of professional authority, manuals, and shadowing experienced professionals.

In a recent report, the Government Accountability Office (GAO) used hypothetical elder profiles to distinguish state variability in case management and care planning in Medicaid waiver services. Using Kansas, Louisiana, New York and Oregon as examples, the GAO report found variability between, as well as within, states in service availability and allocation of resources. In some scenarios the identical consumer was allotted 14 hours by one case manager and 42 hours by another – coordinated care does vary for each individual. The GAO report underscores the need for training, certification and continual updating of curriculum materials.

⁸³ Golden, Robyn and Monika White. Credentialing Opportunities for Social Workers in Aging. In Berkman (Ed.), *Handbook of Social Work in Health & Aging* (1065-1073). New York: Oxford Press. 2006.

⁸⁴ Geron, Scott Miyake. Comprehensive and multidimensional geriatric assessment In Berkman (Ed.) *Handbook of Social Work in Health & Aging* (721-729). New York: Oxford Press. 2006.

Social Work and Nursing in Care Coordination

The literature recommends using both nursing and social work professionals in tandem to adequately assess clients and, in some cases, to develop care plans.⁸⁵ People are living longer with complex chronic conditions. Effective care coordination must address a variety of medical and social conditions presented by older people. While both professionals may not be required for care planning, access to a nurse or a social worker has been demonstrated to produce more effective care plans. A 2007 study designed for community-dwelling older adults found that emergency room visits and hospital utilization were reduced by using an interdisciplinary approach.⁸⁶

Consumer Direction

Consumer-directed care for the elderly, based on the values of consumer control and flexibility, emerged out of the disabilities community. This concept has gained support from organizations such as The National Association of State Units on Aging.⁸⁷ Consumer direction can be at odds with the traditional structure of aging services, which is characterized by person-centered care, care coordination and care planning. Flexibility is paramount; it permeates all areas of a consumer-directed system including evaluation and benefit design.

While there is great variation in consumer-directed models, two structures are common: Employer Agent and Agency-Based. In the Employer Agent structure, the consumer acts as employer, with responsibilities that include purchasing services, setting hours and wages, and completing necessary paperwork. In the Agency-Based structure, the agency is the employer and is responsible for paperwork and some purchasing of services. These models incorporate different worker qualifications and different regularity of needs assessments. Agency models tend to focus on satisfaction with services while employer-based models may focus on consumer decision-making, managing services and access to information. A training program for case managers in Cash and Counseling demonstrations was developed at Boston College.⁸⁸ This curriculum is designed for support brokers because their role as monitor combined with advocacy is unique.⁸⁹

Managing risk is an issue that is particularly problematic. Policy makers such as the Commission on Long-Term Care Quality argue that finance systems should include consumer direction as a central feature. Too much regulation can undermine the consumer-directed process. Balancing risk and safety is thus an important tension

⁸⁵ Counsell, Steven R., and Christopher M. Callahan, Daniel O. Clark, Wanzhu Tu, Anna B. Buttar, Timothy E. Stump, Gretchen D. Ricketts. Geriatric Care Management for Low-Income Seniors. *The Journal of the American Medical Association*. Vol. 298 (22). 2007.

⁸⁶ Ibid.

⁸⁷ *The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities*. National Council on Disability Report. December 2005.

⁸⁸ www.cashandcounseling.org/resources/consultanttraining

⁸⁹ Ibid.

point in consumer-directed care, advocates of which believe can best be handled through a continued commitment to flexibility in benefit design.

Washington's consumer-directed programming included an 'other' category to be used for services deemed necessary to support life in the community. Minnesota assigns a support broker to manage risk. If the consumer refuses to address a safety concern identified by a support broker, this refusal can be documented. Consumer direction remains intact, but the safety issue is addressed formally as a part of the larger risk management procedure. Other issues addressed in states' consumer direction programs include availability of emergency back-up plans and advanced planning for consumers.

Flexible Budgeting

Most studies of the fiscal implications of eligibility determination and program planning focus on eligibility and assessment tools. This research is useful to those interested in tool modification, but it doesn't provide much help in determining how to allocate dollars among individuals. In state budgeting, moving from measurement to dollar allocation is generally done in three ways: use of an automated algorithm, the use of professional discretion, or some combination of both. These mechanisms are not easily dissected.

As states re-allocate resources to rebalance long-term care, they are facing budget cuts and the need to contain costs for increased numbers of people needing to be served. While there is no agreement on a prescriptive strategy to respond to these fiscal constraints, trends towards budget consolidation, levels of care, "money follows the person," consumer co-pays, flexible funding, capitation, strategic care, and disease management initiatives continue to gain ground. According to a 2008 Kaiser report,⁹⁰ most states have expanded or will expand home and community-based services between FY08 and FY09; yet, given budget realities, states have developed numerous approaches to cost containment while simultaneously expanding programs.

States use a variety of approaches to pay for long-term care. Long-term care insurance partnership programs were authorized by the Deficit Reduction Act of 2005.⁹¹ In 2008, 32 states had a Partnership Program.⁹² However, a person receiving policy benefits through a Partnership Program may only have the option of nursing home care, depending on state-specific service design, policy, and delivery.⁹³ Other methods include:

⁹⁰ Kasper, Judith, Barbara Lyons, and Molly O'Malley. *Long-Term Services and Supports: The Future Role and Challenges for Medicaid*. Report for Kaiser Commission on Medicaid and the Uninsured. Washington, D.C.: The Henry J. Kaiser Family Foundation. 2007.

⁹¹ See www.cms.hhs.gov

⁹² Kaiser Commission on Medicaid and the Uninsured. *Headed for a Crunch: An Update on Medicaid Spending, Coverage, and Policy Heading into an Economic Downturn*. September 2008.

⁹³ Kassner, Enid. AARP Public Policy Institute. *Long-Term Care Insurance 2006*. Retrieved from www.aarp.org/research/longtermcare/insurance on October 30, 2008.

- Tax levies, which are collected in two-thirds of the counties of Ohio (see state programs).
- Managed long-term care approaches, such as Wisconsin's Family Care and Arizona's ALTCS, which put financial risk and responsibility on counties and managed care organizations.⁹⁴
- Disease and care management strategies, which are also commanding greater national attention. These targeted programs can act as a vehicle for savings, especially when predictive modeling is employed.⁹⁵
- Capitation rates and the use of independent financial teams to forecast budgeting changes have also helped states manage fiscal challenges.

Other approaches hinge on the ability to move dollars between institutional care and home and community-based care using a form of consolidated or global budgeting. This model supports a key CMS policy: a person's needed services should not depend on where money is budgeted.⁹⁶ Experts agree that this budget system is conducive to expanding services for those who live in the community.⁹⁷ While shifts in financing strategies are possible without consolidated or global budgets, they tend to be incremental because of barriers in a fragmented system.⁹⁸ An incremental approach often requires legislative action for each change. A consolidated approach in which money can be moved flexibly allows states to manage their long-term care system more effectively.

The high cost of institutional care is well-documented.⁹⁹ Reinhard notes that "on average, Medicaid dollars can support nearly three older people and adults with physical disabilities in HCBS for every person in a nursing home."¹⁰⁰ Some states have reduced costs through an increase in home and community-based services. However, few states have shown savings over time across geography and population. This lack of data is due, in part, to only recent attention and limited resources devoted to evaluation.

Evaluation

The current literature on measuring quality and adequacy reflects recent efforts to improve evaluation of home and community-based services. State contracts for waivers must meet CMS regulations; however, best practices point to measures that

⁹⁴ Wisconsin Department of Health and Family Services. *Family Care for Long-Term Care Service Providers*. Madison, Wis. 2007. Retrieved October 7, 2008 from World Wide Web: <http://dhs.wisconsin.gov/lcicare/>

⁹⁵ Kaiser Commission on Medicaid and the Uninsured. op. cit.

⁹⁶ Hendrickson, Leslie, and Susan Reinhard. *Global Budgeting: Promoting Flexible Funding to Support Long-Term Care Choices*. New Brunswick, N.J.: Rutgers Center for State Health Policy. 2004.

⁹⁷ Grage, Wendy Fox. Pulling Together: Administrative and Budget Consolidation of State Long-Term Care Systems. AARP Public Policy Institute. 2006. #05 at www.aarp.org/ppi

⁹⁸ Hendrickson, Leslie, and Susan Reinhard. op. cit.

⁹⁹ Morris, Michael. Reducing Nursing Home Utilization and Expenditures and Expanding Community-Based Options. New Brunswick, N.J.: Rutgers Center for State Health Policy. 2007.

¹⁰⁰ Reinhard, Susan. A Balancing Act: State Long-Term Care Reform. Presented at Annual NASHP meeting October 6, 2008. Retrieved from: www.nashp.org/files/reinhard/nashp2008.Pdf

go far beyond the required reporting. Because quality and adequacy are relatively subjective in nature, policy discussions have recently debated the definition of each measure. Do measures examining quality of services rely on an approach associated with a traditional institutional model? Are indicators measuring quality of life outcomes as determined by consumers? Do administrative personnel determine these quality indicators?

These questions can be addressed in several ways, but there are common components across debates. In McGaffigan's discussion of consumer direction,¹⁰¹ she argues that a strong program incorporates the individual consumer into quality management. Traditionally, providers and policy makers define quality and then construct the evaluation around that definition. More states are now measuring client outcomes with assistance from The Home and Community-Based Services Clearing House,¹⁰² an exchange of information for states implementing home and community-based programs. Reports provide technical models and tools for identifying high quality HCBS programs and are available for states to use on a broader scale and for system-wide application.

Many states are also now using the CMS quality framework,¹⁰³ which is based in part on CMS assurances required under HCBS waiver contracts. Experts agree¹⁰⁴ that this framework is highly beneficial in enabling states to develop in-depth quality assessments. The framework is a comprehensive tool that clearly indicates the need to measure outcomes on multiple levels as opposed to one or two simplified measures of success. State investments in external evaluations are common – especially states further along in the implementation of home and community-based services. Best quality measures are developed, monitored and refined, with consumers playing key roles in the process. Best practices also point to the use of diverse methods of data collection using a combination of qualitative and quantitative data.

Younger Adults with Disabilities in HCBS

While the range of literature on long-term care for younger adults with disabilities is diverse, most studies concentrate on the DD/MR population.¹⁰⁵ Research on long-term care for people with physical disabilities is limited. This is partly the result of a proclivity toward studying those with a disability as a homogeneous group. That, in turn, ignores variations within the disability population. Because data on physical disabilities is severely limited, it is difficult to address questions about older adults

¹⁰¹ McGaffigan, Erin. *Redefining Quality: Participant-Directed Services*. Rutgers Center for State Health Policy. March 2008

¹⁰² www.hcbs.org

¹⁰³ www.cms.hhs.gov/HCBS/qualityframework

¹⁰⁴ National Quality Inventory Survey of HCBS Waiver Programs. Prepared by Gary Smith and Beth Jackson for CMS. January 2004. Retrieved from: www.cms.hhs.gov/hcbs/downloads on November 14, 2008.

¹⁰⁵ *The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities*. National Council on Disability Report. December 2005.

and adults with disabilities under state waiver programs. Many experts point out that a comparison between groups is problematic and difficult to achieve.¹⁰⁶ While fiscal considerations drive the need to compare distinct consumer groups in order to guide budget forecasts, service parity between populations is often not included in these budget discussions. Furthermore, many states include aging and disability populations under the same waivers and concentrate on evaluations linked to quality indicators across populations. The National Council on Disability and National Disability Institute issued a comprehensive report, “The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities,”¹⁰⁷ in an effort to fill a gap in policy addressing challenges of long-term care for people with disabilities. The report cautions against research resting on common definitions and highlights the limited research available that has effectively evaluated outcome cost data for consumer-directed services across populations.

Conclusion

The literature offers an emerging landscape of home and community-based service strategies relevant for Illinois. These studies address eligibility determination, allocation of resources and program expansion. Trends in the research and evaluation of programs in other states provide Illinois with useful information:

- Systematic components such as increased use of technology and flexible budgeting can expand access to HCBS.
- States that invest in interdisciplinary assessment and care coordination strategies find that clients receive the services they need to live in the community, they’re satisfied with the quality, and their plans are fiscally sound.
- Quality measures are shifting towards outcomes and quality of life measures as determined by the user of the services.
- Outside, independent quality evaluations have proven to be effective in helping states reform their systems and improve program effectiveness.

¹⁰⁶ Ibid.

¹⁰⁷ Ibid.

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Washington Department of Social & Health Services. 2007. *Comprehensive Assessment and Reporting Evaluation System*. Olympia, Wash..

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Appendix C

Illinois Department on Aging Historic Timeline

- 1979 – CCP established to provide cost-effective alternative to nursing homes.
- 1983 – *Benson vs. Blaser*, a class action law suit ruling that persons on a wait list were entitled to timely determination of eligibility and service. In 1983, the Department on Aging (DoA) effectively closed intake for the Community Care Program (CCP) by creating a waiting list of applicants determined eligible for the program and limited the delivery of services to those persons already receiving them. As a result, IDoA was found to be in violation of Medicaid law requirements regarding reasonable prompt services to eligible persons. It should also be noted that Medicaid further proscribes limitations on the provision of program services unless this limitation is described in an approved Medicaid State Plan or waiver. Consequently, this lawsuit forced IDoA to process applications for all clients who applied and to provide services to all who were eligible. Thereafter, the Home Services Program (HSP) began to operate similarly.
- 1983 – 1915(c) Waivers granted to IDOA for people over age 60 and to DRS to provide services to disabled people aged 18-50.
 - IDoA provided core services: Homemaker, Adult Day Services and Care Management.
- Early 1980s – first DON tool developed, using ADL and IADL measures establishing a foundation for the range of categories, scoring and allocation of Service Cost Maximums (SCMs) based on nursing home rates at that time. Case managers designed plans of care based on resources within the SCMs.
- 1989 – Federal request for state agencies to study the DON tool. IDoA expanded study to include dementia and added the MMSE to ADL and IADL measures.
- 1990 – Americans with Disabilities Act passed.
- 1992 – A Budget crisis resulted in mandates to trim waiver program expenditures.
 - Department of Rehabilitative Services temporarily stopped intake and serving some of its lower-scoring clients in their HSP.
 - IDoA kept CCP intake open, but reduced SCMs for clients with lower DON scores, ultimately divorcing its cost structure from the nursing home reimbursement.

- 1992 – *McMillan vs. McCrimon* – In response to the Emergency Budget Act of 1992, the Home Services Program stopped taking applications. Within 21 days, a suit was filed challenging the actions as a violation of the Medicaid statute. Ten days later a federal court ruling found that the Medicaid Act includes detailed requirements that a State Plan for Medical Assistance must “provide that all individuals wishing to make application for medical assistance under the plan shall have the opportunity to do so, and that such assistance shall be furnished with reasonable promptness to all individuals (42 U.S.C. Section 1396a(a)(8)). As a result of this finding, the federal court prohibited the program from refusing to accept and process applications.
- 1999 – Olmstead Supreme Court decision handed down.
- 2006-7 – Asset limit for CCP and HSP raised to \$17,500, and EHR added to CCP’s core services.

Appendix D Medicaid Waiver Definitions

Medicaid State Waiver Program Demonstration Projects¹⁰⁸

Section 1115 Research and Demonstration Projects

This section provides the Secretary of Health and Human Services broad authority to approve projects that test policy innovations likely to further the objectives of the Medicaid program.

Section 1915(b) Managed Care/Freedom of Choice Waivers

This section provides the Secretary authority to grant waivers that allow states to implement managed care delivery systems, or otherwise limit individuals' choice of provider under Medicaid.

Section 1915(c) Home and Community-Based Services Waivers

This section provides the Secretary authority to waive Medicaid provisions in order to allow long-term care services to be delivered in community settings. This program is the Medicaid alternative to providing comprehensive long-term services in institutional settings.

States may opt to simultaneously use Sections 1915(b) and 1915(c) program authorities to provide a continuum of services to disabled and/or elderly populations. In essence, states use the 1915(b) authority to limit freedom of choice, and 1915(c) authority to target eligibility for the program and provide home and community-based services. By doing this, states can provide long-term care services in a managed care environment or use a limited pool of providers.

In addition to providing traditional long-term care state plan services (such as home health, personal care and institutional services,) states may propose to include non-traditional home and community-based '1915(c)-like' services (such as homemaker services, adult day health services and respite care) in their managed care programs.

States can implement concurrent Section 1915(b) and 1915(c) waivers *as long as all federal requirements for both programs are met*. Therefore, when submitting applications for concurrent 1915(b)/(c) programs, states must submit a separate application for each waiver type and satisfy all of the applicable requirements. For example, states must demonstrate cost neutrality in the 1915(c) waiver and cost effectiveness in the 1915(b) waiver. States must also comply with the separate reporting requirements for each waiver. Because the waivers are approved for different time periods, renewal requests must be prepared separately and submitted at different points in time. Meeting these separate requirements can be a

¹⁰⁸<http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/>
http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/06_Combined1915bc.asp

potential barrier for states that are considering going forward with such a program. However, the ability to develop an innovative managed care program that integrates home and community-based services with traditional state plan services is appealing enough to some states to outweigh the potential barriers.

Section 1915(i) Home and Community-Based Services State Plan Option: Section 6086 of the Deficit Reduction Act¹⁰⁹

Section 6086 of the Deficit Reduction Act of 2005 (DRA, P.L. 109-171) authorized a new optional benefit that allows states to cover limited HCBS without waivers. The requirements of this optional benefit, Section 1915(i) of SSA, differ from other Medicaid state plans (e.g., home health and personal care) and the Section 1915(c) HCBS waivers. Section 1915(i) authorizes states to offer HCBS without a waiver beginning in January 2007. States can define beneficiary needs, and do not have to require that beneficiaries meet institutional levels of care to qualify for services. (The program may not target population by characteristic such as age or disease/condition.) Under this waiver, states may amend their Medicaid plans without demonstrating budget neutrality as they do under 1915(c) waivers. Section 1915(i) permits states to offer fewer HCBS services than are permitted under 1915(c) waivers and to restrict eligibility to beneficiaries whose incomes fall below 150 percent of the Federal Poverty Level. States also may offer self-direction under the 1915(i) option and may cap enrollment.

Possible challenges for states considering 1915(i) include: Regulations are not yet final, eligibility is determined by needs-based criteria, and only one HCBS benefit is available per state making it challenging for states to decide how to best use the option among competing priorities.¹¹⁰

Section 1915(j) Self-Directed Personal Assistance Services State Plan Option¹¹¹

Enacted as Section 6087 of the Deficit Reduction Act of 2005, effective January 1, 2007, states may elect to provide self-directed personal assistance services (PAS) in

¹⁰⁹ Binder, Cliff. *Medicaid's Home and Community-Based Services State Plan Option: Section 6086 of the Deficit Reduction Act*, CRS Report for Congress. Updated January 31, 2008.

¹¹⁰ Galbraith, Suellen, Director for Government Relations. *Understanding the Medicaid Deficit Reduction Act and Moratoria on CMS Rules*, American Network of Community Options and Resources (ANCOR). PowerPoint. September 18, 2008.

Note: As of September 2008, one state, Iowa, has added the 1915(i) State Plan HCBS benefit (April 5, 2007). Nevada and Georgia are under review and Colorado has submitted a draft. North Dakota withdrew its application.

Note: As of September 2008, five states have approved 1915(j) State Plan Amendments: Alabama, Oregon, Arkansas, Florida and New Jersey.

¹¹¹ Schervish, Marguerite, *Section 1915(j) of the Social Security Act: Self-Directed Personal Assistance Services State Plan Option*, Center for Medicare & Medicaid Services. PowerPoint presented September 8, 2008.

the State Plan so demonstrations and waivers would not be necessary. Self-directed PAS includes Personal care and related services under the Medicaid State plan, and/or home and community-based services under Section 1915(c) waiver that the State *already* has in place. Section 1915(j) does *not* offer new services, but introduces the self-directed care model. States that select to offer PAS may also include 'permissible purchases.' Individuals have employer authority to hire, fire, supervise and manage workers, and have budget authority to purchase personal assistance and related services from their budget allocation. States that elect the Section 1915(j) option could target the population using Section 1915(c) waiver services, limit the number of individuals who will self-direct their PAS, and limit the option to certain areas of the state, or offer it statewide.

Appendix E Interview Guides

University of Illinois at Chicago

DON SCM Key Informant Interview Guide

Date _____

Name _____ Title: _____

Organization: _____ Address: _____

Phone: _____ Email Address: _____

Thank you for participating in the interview, which is part of the Determination of Need/ Service Cost Maximum Study. We would like to learn more about why DON-based SCM differs for the elderly and disabled HCBS waiver populations.

As part of this study we are conducting key informant interviews with key developers of the Determination of Need methodology, to discuss rationale for DON cut-off scores and SCM assignment, determination of “authorized” expenditures and the reasons for lower actual use.

We are also interviewing key informants from the Department of Human Services, Division of Rehabilitative Services (DRS) and/or others to determine how the SCMs were set for the DRS’ Home Services Program for younger adults with disabilities.

Background

1. What agency/group do you represent and for how long? What is your position and role with agency/group?

DON Instrument

2. Are you or have you been involved in the development, revision or use of the Illinois Determination of Need instrument? If yes describe your role?
3. Column A: What is your understanding as to how a client is scored for a specific disability on the Illinois DON?
4. Column B: What is your understanding as to how a client is scored for unmet need for informal care assistance on the Illinois DON?

5. Why are met needs that are provided by family caregivers subtracted from the overall score on the CCP version of the DON? Is the same scoring system used for DORS?

Service Cost Maximum (SCM)

6. How are the SCMs for the CCP program set? What analyses were performed to derive the caps? What other method was used to derive them? What percent of clients are under/at the cap limit?
7. Are the SCMs useful?
8. Have there been changes in SCMs? What were the changes and the justification for changing these?
9. Should IDoA use some other method to determine the cost of a service package? Please describe.
10. Have there been changes in DON scores for determining SCM? If so, what were these changes and why were these changes made?

Services and SCM

11. How frequently is eligibility/service need re-assessed?
12. Should elderly clients with similar DON scores receive similar service cost caps to those received by persons served under the disability waiver? Why? Why not? Is there a better way to handle this in your experience?

Closing Questions

13. What advice do you have for Illinois in terms of changing SCM levels and cutoffs scores for SCM?
14. In your opinion, is there an inequity in current SCM and current services offered to clients? If so what changes would you recommend?
15. Are there any other questions that you think I should ask you about the infrastructure and cost maximum in caps under the CCP?
16. Are there other persons you feel who we should interview concerning SCM?

Finally, are you aware of any documents or files that would help us understand these issues and would help us document the history of SCM funding and structure Interview Guides?

**Health and Medicine Policy Research Group
Center for Long-Term Care Reform
Determination of Need/Service Cost Maximum Study
State Interview Guide**

Introduction

Thank you for taking the time to speak with us today.

Health and Medicine has agreed to evaluate aspects of the Illinois Medicaid Waiver program for older adults and younger people with disabilities — which in Illinois are comparable, but quite different. They both use the same tool to determine eligibility and to allocate service dollars, but the Service Cost Maximum for people with disabilities under age 59 is significantly higher, leading to concerns about equity and adequacy of the benefit provided to people 60 and older. In addition, as part of the state's reform efforts it is understood that we need to expand the types of services available to older people if they are to remain in the community. Currently, once a person is determined to be eligible for services, four are available under the program: Homemaker, Adult Day, Emergency Home Response, and Case Management. Part of the evaluation we will submit to the Department on Aging will include a section on best practices from other states, which we expect will be useful to Illinois.

The interview will take 30-45 minutes. For the purpose of analysis, we would like to ask if we can tape record this interview. The recordings will only be reviewed by Health and Medicine's research team in the process of analysis.

Questions

Eligibility:

1. Who does your program cover?
 - Medicaid-eligible only?
 - People with disabilities?
 - Aged people with disabilities?
 - Other?
2. Do you use a tool to determine eligibility? What does the eligibility tool measure? What indicators do you use to determine if a person is eligible for the program?
3. Who conducts the eligibility determination? What are their qualifications? Who employs them?
4. Is there any difference in the eligibility tool and process for people who are younger or older?

5. How many people are served in your program? Aged? Disabled?
6. What are your predictors for nursing home placement?

Plan of Care:

1. Once someone is eligible to receive help, what is the next step? How is a plan of care developed? How is the plan implemented? Monitored? How do you determine if the services a person receives are adequate to meet their needs?
2. Are there differences in how a plan is developed for older and younger people? Is there a difference in how older and younger people use the services?
3. Do you have a consumer-directed program? If so, how do you determine how much a person is entitled to receive? How do you monitor the program?

Services:

1. How do you determine which services and how much service a person is to receive?
2. Who are the service providers and how are they paid?

Funding the program:

1. What is the average cost per client served in your program?
2. How does the state pay for services that are received by your eligible clients? How do you budget for these services?

III. BEHAVIORAL HEALTH (CONTINUED): MINI-MENTAL STATE EXAMINATION

Case manager is to administer all 11 questions equivalent to a score of 30.

- (5) 1. What is the (year) (season) (day) (date) (month)?
 - (5) 2. Where are we: (state) (county) (town) (nursing facility/hospital) (floor)?
 - (3) 3. Name 3 objects. Allow 1 second to say each. Ask the client all 3 after you have said them. Give 1 point for each CORRECT answer in the first trial only. Then repeat the 3 objects until the client learns all 3. Count trials and repeat the 3 objects until the client learns all 3. Count trials and record. Trials _____
 - (5) 4. Spell "WORLD" backwards. Score 1 point for each letter in the CORRECT order. _____
 - (3) 5. Ask for the 3 objects repeated in question 3. Give 1 point for each CORRECT answer. _____
 - (2) 6. Identify a pencil and a watch. _____
 - (1) 7. Repeat the following: "No ifs, ands or buts." _____
 - (3) 8. Follow a 3-stage command: "Take a paper in your right hand, fold it in half and put it in your lap."
 - (1) 9. Read and obey the following: CLOSE YOUR EYES.
 - (1) 10. Write a sentence.
 - (1) 11. Copy a design.
- Maximum score is 30. Enter TOTAL correct answers for MMSE score. → → →
1. For MMSE box below: If score is equal or more than "21," enter "0"; if score is "20" or less—enter "10"
2. For the MMSE Plus score: Add an additional 10 points to the total MMSE Box below, if appropriate documentation is provided for all three listed below. (Rule 240.715, d) 1) C)
- Court adjudication as incompetent or disabled; Physician/Psychiatrist certifies need for 24 hour supervision; and, Physician/Psychiatrist certifies presence of Alzheimer's disease, ODS, or dementia.

A NON-COGNITIVE PROBLEM is affecting the MMSE score: YES NO If yes, check the correct non-cognitive problem below:
 Vision/Hearing Problem Language Barrier Low Education/Can't Read Physical Impairment Other: _____

If Mini-Mental State Examination score total is: 21–30, proceed with the DON; informant not needed. 20 points or less: An informant may be needed. 4. Relationship: _____

DETERMINATION OF NEED (Functional Status – Activities of Daily Living/Instrumental Activities of Daily Living)

FUNCTION	A. LEVEL OF IMPAIRMENT	B. UNMET NEED FOR CARE	Service by CCP	Service by Other	FREQUENCY—for specific needs only	Notes:
1. Eating	0 1 2 3	0 1 2 3				
2. Bathing	0 1 2 3	0 1 2 3				
3. Grooming	0 1 2 3	0 1 2 3				
4. Dressing	0 1 2 3	0 1 2 3				
5. Transferring	0 1 2 3	0 1 2 3				
6. Continence	0 1 2 3	0 1 2 3				
7. Managing Money	0 1 2 3	0 1 2 3				
8. Telephoning	0 1 2 3	0 1 2 3				
9. Preparing Meals	0 1 2 3	0 1 2 3				
10. Laundry	0 1 2 3	0 1 2 3				
11. Housework	0 1 2 3	0 1 2 3				
12. Outside Home	0 1 2 3	0 1 2 3				
13. Routine Health	0 1 2 3	0 1 2 3				
14. Special Health	0 1 2 3	0 1 2 3				
15. Being Alone	0 1 2 3	0 1 2 3				
TOTAL	0	0				
MMSE	A	MMSE/A TOTAL	B	TOTAL DON SCORE	IL-402-1230 (Rev 3/08)	

Appendix G Acronym List

AAA	Area Agency on Aging
ADL	Activities of Daily Living
BOB	Bureau of Budget
CCC	Comprehensive Care Coordination Tool
CCP	Community Care Program (Illinois Department on Aging)
CMS	Centers for Medicare and Medicaid Services
DD/MR	Developmentally Disabled/Mentally Retarded
DON	Determination of Need
DHS	Illinois Department of Human Services
DRS	Division of Rehabilitation Services
EHR	Emergency Home Response
GAO	United States Government Accountability Office
HCBS	Home and Community-Based Services
HFS	Illinois Department of Healthcare and Family Services
HMPRG	Health and Medicine Policy Research Group
HSP	Home Services Program (Illinois Department of Human Services)
IADL	Instrumental Activities of Daily Living
IDoA	Illinois Department on Aging
IDPA	Illinois Department of Public Aid, now Healthcare and Family Services
MDS	Minimum Data Set
MMSE	Mini Mental State Examination
PSA	(regional) Planning and Service Areas
SCM	Service Cost Maximum
SPMSQ	Short Portable Mental Status Questionnaire

Appendix H Key Informants

1. Carol Aronson Director, Shawnee Alliance for Seniors
2. Jean Blaser Retired, former Deputy Director, IDoA/CCP
3. Kelly Cunningham Chief, Bureau of Long-Term Care, Health Care and Family Services
4. Ann Ford Executive Director, Illinois Network for Centers for Independent Living
5. Donna Ginther Consultant, former AARP Illinois Legislative Director
6. Jonathan Janska Program Director, Progress Center for Independent Living
7. Jody Martin Supervisor of CCP, CCC Training, IDoA
8. Nancy Nelson Manager for Advocacy and Outreach for AARP
9. Greg Paveza Dean, School of Health and Human Services, Southern Connecticut State University
10. Randi Tomlin Assistant Bureau Chief of Home Assistance Program, Illinois Department of Human Services, (originally Rehabilitation Services)

Appendix I State Contacts

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Determination of Need, Service Cost Maximum Study

**State of Illinois
Department on Aging**


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Springfield, Illinois 62701-1789
www.state.il.us/aging

Senior HelpLine: 1-800-252-8966
1-888-206-1327 (TTY)

Elder Abuse Hotline: 1-866-800-1409
1-888-206-1327 (TTY)

The Illinois Department on Aging does not discriminate in admission to programs or treatment of employment programs or activities in compliance with appropriate State and Federal statutes. If you feel you have been discriminated against, call the Senior HelpLine at 1-800-252-8966, 1-888-206-1327 (TTY).

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