Long-Term Care in Nevada

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LEGISLATIVE COMMISSION'S SUBCOMMITTEE TO STUDY LONG-TERM CARE IN NEVADA

Senate Concurrent Resolution 4 – 1999 Session

SUBCOMMITTEE MEMBERS

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Senator Terry Care
Senator Raymond Rawson
Assemblywoman Merle Berman
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SUMMARY OF RECOMMENDATIONS

The Legislative Commission's Subcommittee to Study Long-Term Care in Nevada has adopted the following recommendations. The recommendations were based upon:

- Testimony received from subject matter experts on long-term care issues and innovative approaches to avoid institutionalization;
- Testimony presented to the Subcommittee at its public hearings;
- A review of written information and comments provided to the Subcommittee; and
- The experience and knowledge of the members of the Subcommittee.

A. LONG-TERM CARE INSURANCE

1. Implement a long-term care insurance program for state employees and retirees.

The Subcommittee recommended a bill draft request to implement a long-term care insurance program for all state employees and retired state employees. The Subcommittee recommended designating the Public Employees' Benefits Program, under the direction of its Board, as the lead agency responsible for implementing and administering the long-term care insurance program. The Public Employees' Benefits Program has experience with administering the existing voluntary long-term care insurance program available to state employees as well as administering the health insurance program for state employees and retirees. The effective date for implementing the long-term care insurance program is January 1, 2003, which allows an adequate amount of time for planning the program and coincides with the annual enrollment process for the state health insurance program. The estimated annual cost to establish the long-term care insurance program is $7.2 million and is based on the following minimum benefit package:

- Facility benefit - $2,000 per month
- Home care – Total home care 50% of facility
- Elimination period – 90 days
- Duration – Three years facility and six years home

The bill draft request will include a general fund appropriation and highway fund appropriation to cover the annual per-employee premium cost for long-term care insurance coverage. The Subcommittee recommended that, to the extent possible, the annual premium cost for long-term care insurance coverage be allocated against the various revenue sources currently used to fund state employee salary

and fringe benefit costs. Allocating the costs in this manner will ensure that the non-general fund and non-highway fund revenue sources pay a proportionate share of the costs for the long-term care insurance program.

The Subcommittee recommended sending a letter informing the Governor the role that long-term care insurance could play for potentially reducing the anticipated growth in government financing for long-term care in the future. **(BDR 23-299)**

B. SUPPORT SERVICES FOR CAREGIVERS

2. Establish a pilot project that replicates the Caregiver Resource Center (CRC) Model in California.

The Subcommittee recommended a bill draft request with a general fund appropriation in the amount of $782,740 to establish a pilot project that replicates the Caregiver Resource Center (CRC) model in California. The CRC model provides support services to caregivers who are responsible for the care of a brain-impaired adult whose brain impairment has occurred after the age of 18. The CRC model targets middle-income families. The CRC model provides a range of support services designed to defer institutionalization, to allow caregivers to maintain a normal routine and to provide quality care. The services the CRC model typically provides include the following: specialized information, advice and referrals to caregiving families; comprehensive in-home assessments to determine the caregiver's needs and skills, to determine the care recipient's functional and behavioral problem and the impact on the caregiver; family consultation which includes short-term counseling, support groups, psycho-educational groups and legal consultation; and respite care.

The Subcommittee recommended the pilot project include two CRC sites, one site located in an urban area of the state and one site located in a rural area of the state. The Subcommittee recommended designating the Division for Aging Services as the lead agency responsible for implementing the pilot project. The appropriation recommended as part of the bill draft request includes funding to retain a consultant. The consultant support is intended to assist the Division for Aging Services with implementing the pilot project and for issues such as establishing eligibility criteria for program services, training, developing a request for proposal process if non-profit organizations are contracted with to provide CRC services and for developing reporting criteria to measure the performance of the pilot project. The bill draft request will include a sunset provision to ensure that the Legislature has an opportunity to fully evaluate the progress and performance of the pilot project prior to providing permanent funding and/or adding new sites. **(BDR S-302)**

C. ASSISTED LIVING OPTION IN THE MEDICAID PROGRAM

3. **Provide funding for the resources to explore the feasibility of developing an assisted living option in the Medicaid program.**

The Subcommittee recommended an appropriation in the amount of $100,000 for the Division for Aging Services for administrative support needed to explore the feasibility of developing an assisted living option within the Medicaid program. An assisted living option would allow for Medicaid services to be provided to eligible individuals who reside in an assisted living facility constructed with financing available from various federal housing programs. In order for this option to work, the assisted living facility would need to be affordable for low-income seniors, and the Medicaid services would be tailored to meet each eligible individual's needs. The Medicaid services provided would include a 24-hour response capability to meet eligible individuals' scheduled or unpredictable needs. The eligibility criteria for this option and the Medicaid service component would require either a new Medicaid waiver or possibly an amendment to an existing waiver such as the Community Home-Based Initiatives Program (CHIP). The intent of this recommendation is to maintain the independence of a low-income senior within an affordable community setting by offering an enhanced level of medical services. The assisted living option would potentially reduce a current gap in the care continuum for a low-income senior who may be forced into a nursing facility when, in reality, that senior may function independently within an assisted living environment if enhanced Medicaid services were available.

The assisted living option will require an extensive amount of planning, data collection and coordination of regulatory, budgetary and site location issues prior to implementation. The Department of Human Resources estimates this effort would be accomplished over a three-year period. The administrative support provided by the general fund appropriation will be used for this effort. The Subcommittee recommended sending a letter informing the Governor, the Budget Director and the Director, Department of Human Resources, of the Subcommittee's recommendation to pursue the assisted living option. The letter will request that the Governor consider recommending the administrative support needed by the Division for Aging Services to work on the assisted living option in The Executive Budget for the 2001-2003 biennium. **(BDR S-303)**

D. MEDICAID – HOME AND COMMUNITY BASED WAIVERS

4. **Amend the Home and Community Based Waiver for the Elderly in Group Care and increase the SSI eligibility up to 300 percent of the SSI income level.**

The Subcommittee recommended the Department of Human Resources amend the Home and Community Based Waiver for Elderly in Group Care (commonly referred to as the Adult Group Care Waiver) and increase the SSI eligibility up to 300 percent ($1,536) of the SSI income level. The Adult Group Care Waiver is designed to offer individuals an alternative to nursing home care by providing supplemental services in a group care home. The services provided include case management and personal care. Raising the income level for the Adult Group Care Waiver would establish income eligibility criteria, which is consistent among all Medicaid waivers. More importantly, this would provide a number of clients in the Community Home-Based Initiatives Program (CHIP) an opportunity to choose a less restrictive option to nursing facility care that is currently not available and potentially defray long-term care costs in the Medicaid program. The Subcommittee also recommended that any necessary modifications to the Medicaid budget be included in the Department of Human Resources budget request submitted to the Governor for the 2001-2003 biennium.

5. **Amend the Home and Community Based Waiver for the Community Home-Based Initiatives Program (CHIP) and eliminate the patient liability requirement.**

The Subcommittee recommended the Department of Human Resources amend the Home and Community Based Waiver for the Community Home-Based Initiatives Program (CHIP) and eliminate the patient liability requirement. The CHIP program is the only Medicaid waiver that includes a patient liability requirement. The requirement, when applied, has created a consistency problem for clients who may transfer to the CHIP program from another Medicaid waiver which has no patient liability requirement. The amount of patient liability collected on an annual basis is insignificant and when not collected, state funds must be used to make-up for the shortfall, which ultimately reduces the amount of services available to state-only clients in the CHIP program. Additionally, if the patient liability requirement were eliminated, the Medicaid Estate Recovery process would ultimately recover the full cost of services provided once the client is deceased. The Subcommittee recommended the Division for Aging Services include the necessary modifications associated with eliminating the patient liability requirement in the CHIP budget submitted to the Governor for the 2001-2003 biennium.

6. **Provide sufficient funding for the projected caseload growth in the Community Home-Based Initiatives Program (CHIP) in order to maintain a reasonable wait time for services.**

   The Subcommittee recommended that the Division for Aging Services request sufficient funding in the budget for the Community Home-Based Initiatives Program (CHIP) for the 2001-2003 biennium for the projected growth in population for the age groups served by CHIP in order to maintain a reasonable wait time for services. The Subcommittee recommended sending a letter to the Governor, the Budget Director and the Director, Department of Human Resources, to request that sufficient funding be included in The Executive Budget to meet the intent of this recommendation, and that tobacco settlement monies be used to fund the additional costs for reducing the wait time for state-only cases.

E. FUTURE INTERIM STUDY ON LONG-TERM CARE ISSUES

7. **Create an interim legislative committee to continue the study of long-term care issues.**

   The Subcommittee recommended a bill draft request to create an interim study committee to continue the study of long-term issues upon the adjournment of the 2001 Legislative Session. The Subcommittee also recommended the bill draft request include a general fund appropriation in the amount of $26,900 for consultant support. The consultant support would be used to provide research, analysis and guidance to the interim study committee on the complex and technical areas that may be part of the mission for an ongoing study.
   (BDR S-300)

REPORT TO THE 71ST SESSION OF THE NEVADA LEGISLATURE FROM THE LEGISLATIVE COMMISSION'S INTERIM SUBCOMMITTEE TO STUDY LONG-TERM CARE IN NEVADA

REPORT TO THE 71ST SESSION OF THE NEVADA LEGISLATURE FROM THE LEGISLATIVE COMMISSION'S SUBCOMMITTEE TO STUDY LONG-TERM CARE IN NEVADA

(S.C.R. 4)

I. INTRODUCTION

The 70th Session of the Nevada Legislature adopted Senate Concurrent Resolution No. 4 (1999) (File No. 143, *Statutes of Nevada*, page 4055), Appendix A, page 71, which directed the Legislative Commission to conduct an interim study concerning long-term care in Nevada.

The Legislative Commission appointed a Subcommittee consisting of the following six legislators (three members of the Senate and three members of the Assembly) to carry out the provisions of the resolution:

Senator Mike McGinness, Chairman	Assemblywoman Merle Berman
Senator Raymond D. Rawson	Assemblywoman Sheila Leslie
Senator Terry Care	Assemblywoman Kathy McClain

Legislative Counsel Bureau staff services for the Subcommittee were provided by Steve Abba, Principal Deputy Fiscal Analyst, Fiscal Analysis Division; Thomas Linden, Principal Deputy Legislative Counsel, Legal Division; Ann M. Iverson, Deputy Legislative Counsel, Legal Division; and Sherie Silva, Committee Secretary, Fiscal Analysis Division.

The Subcommittee held five meetings, including a work session. Four of the meetings were held in Carson City and one meeting was held in Las Vegas. All five meetings were public hearings and were video-conferenced between Carson City and Las Vegas.

During the course of the interim study, the Subcommittee reviewed subject matter on a multitude of issues designed to provide a solid foundation on long-term care services and systems in Nevada and to provide a broad understanding of national trends with long-term care policy. Specifically, the Subcommittee reviewed:

- Alternatives to institutionalization currently available in Nevada;
- Innovative approaches states are implementing to avoid institutionalization;
- Community-based options such as the feasibility of maximizing home and community-based services in the Medicaid program and exploring residential alternatives to institutionalization;
- Models that simplify and promote a single point of entry into a state's long-term care system to avoid the fragmentation of services; and

- The important role of caregivers and their need for better support systems and the role private long-term care insurance can provide for financing long-term care in the future.

Subject matter testimony was received from nationally recognized experts on long-term issues and policy and state and local officials who represent numerous agencies that work with long-term care issues. Presentations were made to the Subcommittee by officials representing a variety of advocacy groups, experts on long-term care insurance, and representatives from the long-term care industry, state agencies responsible for regulating insurance carriers, and the state agency that administers the health insurance program for state and retired state employees.

The Subcommittee adopted seven recommendations, which included four bill draft requests (BDRs) for consideration by the 2001 Legislature. The recommendations address the following issues:

- Establishing a long-term care insurance program for state and retired state employees;
- Establishing a pilot project that provides support services for caregivers;
- Establishing an assisted living option as part of the Medicaid program;
- Establishing consistent eligibility criteria for all Home and Community Based Waivers in the Medicaid program;
- Establishing a consistent policy for patient liability reimbursement for all Home and Community-Based Waivers in the Medicaid program;
- Managing the waiting list for the Community Home-Based Initiatives Program (CHIP); and
- Continuing the study of long-term care issues under legislative oversight beyond the current interim.

The information in this report summarizes the issues considered by the Subcommittee in adopting its final recommendations. All supporting documents considered by the Subcommittee and minutes from the meetings are on file and available from the Fiscal Analysis Division of the Legislative Counsel Bureau.

Respectfully submitted,

Senator Mike McGinness, Chairman
Subcommittee to Study Long-Term
Care in Nevada

II. BACKGROUND

The origins of S.C.R. 4 that authorized the interim study of long-term care can be traced to two pieces of legislation introduced during the 1999 Legislative Session and the concerns with the ever-increasing cost for nursing home care in the Medicaid program. S.B. 446 proposed providing long-term care insurance coverage for current and retired state employees. The legislation was originally proposed as a recommendation stemming from work completed by the Legislative Committee on Health Care during the interim. The Legislative Committee on Health Care received testimony that indicated that private long-term care insurance can be an important source of funding for long-term care in the future and can reduce nursing home expenditures for individuals as well as the Medicaid program. S.B. 370 (1999), prior to being amended, included the Governor's proposal to use Tobacco Settlement monies as a source of funds to establish a long-term care insurance program for Nevada residents meeting certain income requirements. The legislation also included a nest egg protection feature that allows Nevada residents who purchase long-term care insurance the opportunity to safeguard a certain portion of their income and avoid Medicaid spend-down rules if the resident ultimately needs to apply for Medicaid to help finance the cost for long-term care services.

S.B. 446 ultimately was not approved by the 1999 Legislature primarily due to the projected costs for establishing a long-term care coverage program during an austere economic period. Also, the Governor's proposal to fund a long-term care insurance program was not included in the final Tobacco Settlement legislation approved by the 1999 Legislature although the nest egg protection feature was retained and approved with passage of S.B. 370. Although not approved or significantly modified, these two pieces of legislation did bring into public focus a policy issue that is one of the biggest challenges facing not only Nevada but the nation as well: the aging of baby boomers. As a result, S.C.R. 4 was passed by the 1999 Legislature to evaluate alternatives and innovative approaches for funding long-term care as the demand and costs for these services continue to increase with the aging of the baby boomer population.

Meetings of the Subcommittee

The Subcommittee's first meeting was held on November 9, 1999 and was designed to provide the members with a solid foundation on long-term care services in Nevada. The Director of the Department of Human Resources and subject matter experts within the Department provided the Subcommittee a comprehensive presentation on Medicaid eligibility requirements for institutional care; institutional care expenditures, demographics and how institutional care is paid for; the current home and community-based waiver programs funded by Medicaid; and the evolution of the county match program which helps fund long-term care expenditures in the Medicaid program.

The Subcommittee also received testimony from the Nevada Association of Counties (NACO), the Nevada Health Care Association, the Retired Public Employees Association (RPEN) and the American Association of Retired Persons (AARP) on their views and proposals for long-term care policy for consideration by the Subcommittee during the course of the study.

The Subcommittee's second meeting was held on January 13, 2000. The second meeting focused on two primary areas. First, the Subcommittee received presentations from a number of notable speakers, including Robert Mollica with the National Academy for State Health Policy on innovative approaches states are implementing to avoid institutionalization. The information presented broadly addressed community-based options, the expansion of home and community based waiver services in the Medicaid program, and strategies states are using to reshape their systems for delivering long-term care services. Additionally, the Subcommittee received testimony from several interest groups proposing to allow Medicaid services for eligible individuals residing in assisted living facilities. The testimony on the proposal known as the "assisted living option" indicated a critical gap in the continuum of care for low-income seniors could potentially be filled if the proposal were adopted.

Secondly, the Subcommittee received testimony from several speakers, including Steffani Crawley representing the American Council of Life Insurance, on the role private long-term care insurance could play in financing long-term care in the future. The information presented provided the Subcommittee a broad perspective on today's long-term care insurance products, coverage options, benefit structure and costs, what states are doing to promote the purchase of long-term care insurance, the role of education, and the potential impact long-term care insurance may have in saving Medicaid dollars.

The Committee's third meeting was held on March 9, 2000. The third meeting explored in greater depth the feasibility of introducing an assisted living option in the Medicaid program and the Department of Human Resources' attempt to acquire grant funding to support the effort. Additionally, the Department of Human Resources presented information on potential gaps in Medicaid waiver services and provided recommendations on how to close the gaps. The Department of Human Resources also presented an overview of Nevada's existing delivery system for long-term care services compared to creating a comprehensive single point of entry system.

Since long-term care insurance can play an integral role in financing long-term care in the future, the Subcommittee continued to explore avenues to maximize this option. The Subcommittee received testimony from the Executive Officer, Public Employees' Benefits Program, on critical issues to be considered when determining the feasibility of establishing a comprehensive long-term care insurance program for state employees. Additionally, a representative from the Insurance Division provided an update on the survey requested by the Subcommittee of long-term care insurers in Nevada. The survey was designed to obtain information on the cost of providing long-term care insurance coverage for state employees and retirees based on a standardized benefit package.

Lastly, representatives from the Alzheimer's Association presented their recommendations for improving and expanding respite care for lay persons who care for individuals afflicted with the Alzheimer's disease.

The Subcommittee's fourth meeting was held on April 27, 2000, and the Subcommittee invited two notable speakers to testify. Lynn Friss Feinberg with the Family Caregiver Alliance provided an overview on California's Caregiver Resource Center (CRC) system. The CRC provides a wide range of support services to caregivers designed to defer institutionalization and to enable caregivers to maintain a normal routine and provide quality care. Cindy Hannum with the Senior and Disabled Services Division in Oregon provided an overview of the evolution of Oregon's model for delivering long-term care services. The state of Oregon has been at the forefront in re-designing its long-term care delivery system to one that emphasizes the value of community based care, a strong case management component, the availability of varied services designed to provide cost effective alternatives to institutionalization, and localized control.

Additionally, representatives from the American Association of Retired Persons (AARP) provided testimony on recommendations proposed for the Subcommittee's consideration. The recommendations submitted by AARP proposed to continue the study of long-term care in Nevada beyond this interim, to establish working advisory groups of subject matter experts to assist the interim subcommittee, and to charge the interim subcommittee with specific tasks designed to improve Nevada's long-term care system.

Additional topics addressed during the meeting included an update from the Insurance Division on the survey of long-term care insurers in Nevada to determine the estimated cost for providing long-term care insurance for state employees and retirees. Also the Public Employees' Benefits Program provided information on various less costly options to promote the purchase of long-term care insurance in lieu of establishing a comprehensive long-term care insurance program for state employees and retirees.

The final meeting of the Subcommittee, the work session, was held on June 29, 2000. The Subcommittee took public testimony, and reviewed the recommendations presented and discussed during the course of the interim, and then voted on its final recommendations.

III. DISCUSSION OF RECOMMENDATIONS

The following is an overview of the recommendations approved by the Subcommittee. The overview includes a brief explanation of the background information and testimony considered by the Subcommittee in formulating its recommendations. Where appropriate, additional background information in support of the recommendations approved by the Subcommittee is located in the appendices of this report.

A. LONG-TERM CARE INSURANCE

1. IMPLEMENT A LONG-TERM CARE INSURANCE PROGRAM FOR STATE EMPLOYEES AND RETIREES

Background: The Subcommittee was concerned that the aging of the baby boomer population and the corresponding increase in nursing home residents will increasingly burden the Medicaid program. According to national studies, 43 percent of the persons who reach the age of 65 will spend some time in a nursing facility. Of those entering a nursing facility, 55 percent will receive care for at least one year, and one out of five will need care for five years or more. Not only will the total number of nursing home residents increase, but also so will the costs. It is estimated that the annual cost of a nursing home stay will increase from $47,000 annually to $97,000 by 2030, assuming inflation rates continue at the current trend. Currently, Medicaid pays over 40 percent of total nursing home expenditures for the elderly.

The Subcommittee was also concerned with the limited efforts to educate baby boomers about the limitations of federal and state programs that pay for long-term care, as well as the need to increase the awareness about the risk of needing long-term care and the impact unplanned long-term care expenditures have on an individual's financial security. The Subcommittee determined if government is serious about encouraging people to purchase long-term care insurance, it will need to play a more active role. Using S.B. 446 introduced during the 1999 Legislative Session as a starting point, the Subcommittee, after its first meeting, decided to explore the feasibility of establishing a long-term care insurance program for state employees and retirees.

During the review of this issue, the Subcommittee received considerable testimony on the role private long-term care insurance could play in potentially reducing the anticipated growth in government financing for long-term care in the future due to the aging of the baby boomer population. The Subcommittee has also received testimony that less than six percent of the elderly population and a very small number of baby boomers have purchased long-term care insurance. Overall, approximately 1.1 percent of the total population in the United States owns long-term care insurance. In Nevada the incidence of individuals owning long-term care insurance is lower than the national average. As of 1997, approximately 4,300 individuals were covered by long-term care insurance in Nevada, which was approximately .25 percent of the state's population at that time.

Currently the number of employer-sponsored long-term care insurance plans is less than one percent, and the average employee participation rate in such plans is less than 10 percent. According to a recent report from the Employee Benefit Research Institute (EBRI), the average employee participation in voluntary employment-based long-term care insurance plans is about five percent. In order for private long-term care insurance to potentially soften the projected impact to Medicaid and Medicare programs, there would need to be a dramatic increase in the prevalence of employer sponsorship and an equally dramatic increase in the participation levels of eligible workers.

Benefit Packages and Costs: In order to obtain a more complete understanding of the costs for long-term care insurance, the Subcommittee asked the Insurance Division to conduct an extensive survey of the major insurers offering long-term care insurance in Nevada (10 insurers), requesting their estimates on the annual premium rate for a large group policy for state employees and retirees. This information was presented to the Subcommittee at the April 27, 2000 meeting (see Appendix B) and is summarized below. The assumptions for the benefit package provided to the insurers surveyed were as follows:

- The large group is composed of current employees and retirees. The group size is in excess of 25,000 individuals with the average age being 49.
- Coverage of $100 per day for nursing facility care and at least 50% for home care.
- 20 day elimination period.
- 3 years of coverage.
- 5% compounded interest inflation protection.
- The policy would cover all eligible employees and retirees with no underwriting.

The Insurance Division received responses to the survey from four insurers. The information below lists the quotes and pricing comments provided by the four insurers.

Company	Annual Premium	Annual Cost For Employees and Retirees
CNA Continental Casualty	$393	$393 x 25,153 = $9,885,129
Unum	$630	$630 x 25,153 = $15,846,390
John Hancock	$853	$853 x 25,153 = $21,455,509
New York Life	$1,102	$1,102 x 25,153 = $27,718,606
Range	$393 - $1,102	$9,885,129 - $27,718,606
Average	$745	$745 x 25,153 = $18,738,985

Notes:

* CNA Continental Casualty – 60-day elimination. Premium estimate not provided for over 90.
* Unum – Will not issue for over the age of 80. Indemnity not expense.
* John Hancock- 60-day elimination. Inflation benefit significantly increased premium.
* New York Life – 60% home care. Retirees underwritten.

The Subcommittee also requested the Public Employees' Benefits Program to project the estimated annual cost for establishing a long-term care insurance program for state employees and retirees based on the two benefit packages authorized for the voluntary program by the Board for the Public Employees' Benefits Program. The two benefit packages for the voluntary program were authorized by the Board at the June 6, 2000 meeting and are summarized below (also see Appendix C).

	Option 1	Option 2
• **Facility benefit**	$2,000 per month	$4,000 per month
• **Home care**	Total home care 50% of facility	Total home care 50% of facility
• **Elimination period**	90 days	90 days
• **Duration**	3 years (facility) 6 years (home)	6 years (facility) 12 years (home)
• **Inflation Protection**	None	5% simple

Notes:
* Buy-up options could be offered in conjunction with Option 1.
* All premiums are age rated; retirees are underwritten; and the options will not issue over the age of 80.

The carrier that is participating in the voluntary long-term care insurance program offered by the Public Employees' Benefits Program estimated the cost to cover active state employees for the benefit package included in Option 1 at $5 million annually and for the benefit package included in Option 2 at $20 million annually. The estimated annual premium cost per state employee was not provided. The Executive Director, Public Employees' Benefits Program, estimated the cost to cover retirees with the benefit package included in Option 1 at $2.2 million annually, or a total of $7.2 million for active state employees and retirees. An estimate of the cost to cover retirees with the benefit package included in Option 2 was not available.

Alternative proposals: In light of the significant costs to establish a fully funded long-term care insurance program for state employees and retirees, the Subcommittee also considered several less costly alternatives. The alternatives considered by the Subcommittee were each designed to promote the purchase of long-term care insurance.

One alternative considered by the Subcommittee is the feasibility of providing an annual appropriation that would be used to provide a subsidy for individuals who voluntarily purchase long-term care insurance. The primary benefits of this alternative are:

- It is less costly;
- Individuals may be more inclined to participate in a voluntary program if a portion of the annual premium cost is subsidized by the state;
- A portion of the annual appropriation could be banked and invested, which at some point would theoretically reduce the amount of the annual appropriation needed or could be used to increase the annual subsidy depending upon investment return;
- An educational program could be easily designed to promote interest in a subsidized program.

The Subcommittee also received information that indicates there are disadvantages to providing a subsidy for individuals who voluntarily purchase long-term care insurance. For example, determining what portion of the annual appropriation is to be used as a subsidy is difficult, primarily because the number of individuals who choose to participate is unknown and the age of those who choose to participate will drive the costs. Additionally, there are several administrative hurdles to contend with, and the Public Employees' Benefits Program does not have a data system that is capable of administering a subsidy program. This concern could be alleviated by contracting with the carrier to administer the subsidy program; however, the cost may be expensive.

Another alternative considered by the Subcommittee is to increase the awareness level of state employees on how to finance the cost of long-term care through more aggressive educational and marketing efforts. The Subcommittee received considerable testimony on the essential role education plays in encouraging individuals to plan for their long-term care needs. In reviewing this alternative, the Subcommittee considered the feasibility of expanding the educational efforts as a first step to make state employees more aware of the need to incorporate long-term care insurance as an essential part of retirement planning and to stress the importance of purchasing insurance at younger ages when it is more affordable.

According to information provided by the Public Employees' Benefits Program, the carrier for the voluntary long-term care insurance program plans to spend approximately $200,000 on educational efforts to promote the program. This amount will enable the carrier to develop and disseminate two mail communications to all state employees per year and to hold two statewide workshops per year. The Subcommittee was informed that doubling the education and marketing budget to $400,000 (by designating an additional $200,000 in state funds) would allow for two additional mail communications and two additional statewide workshops, or the ability to develop more targeted and/or individualized educational efforts and programs for the various age groups of state employees. The Public Employees' Benefits Program would need to work closely with the carrier to design the enhanced education effort and to determine what portions of the campaign would be implemented by the carrier and by the Program. Additionally, a monitoring component should be included to determine if the enhanced education effort is effective and to what degree.

After carefully considering the information presented on the costs to establish a fully funded long-term care insurance program as well as the less costly alternatives, the Subcommittee recommended the following:

> **The Subcommittee recommended a bill draft request to implement a long-term care insurance program for all state employees and retired state employees. The Subcommittee recommended designating the Public Employees' Benefits Program, under the direction of its Board, as the lead agency responsible for implementing and administering the long-term care insurance program. The Public Employees' Benefits Program has experience with administering the existing voluntary long-term care insurance program available to state**

employees as well as administering the health insurance program for state employees and retirees. The effective date for implementing the long-term care insurance program is January 1, 2003, which allows an adequate amount of time for planning the program and coincides with the annual enrollment process for the state health insurance program. The estimated annual cost to establish the long-term care insurance program is $7.2 million and is based on the following minimum benefit package:

- Facility benefit - $2,000 per month
- Home care – Total home care 50% of facility
- Elimination period – 90 days
- Duration – three years facility and six years home

The bill draft request will include a general fund appropriation and highway fund appropriation to cover the annual per employee premium cost for long-term care insurance coverage. The Subcommittee recommended that, to the extent possible, the annual premium cost for long-term care insurance coverage be allocated against the various revenue sources currently used to fund state employee salary and fringe benefit costs. Allocating the costs in this manner will ensure that the non-general fund and non-highway fund revenue sources pay a proportionate share of the costs for the long-term care insurance program.

The Subcommittee recommended sending a letter informing the Governor of the role that long-term care insurance could play for potentially reducing the anticipated growth in government financing for long-term care in the future. (BDR 23-299)

B. SUPPORT SERVICES TO CAREGIVERS

2. ESTABLISH A PILOT PROJECT THAT REPLICATES THE CAREGIVER RESOURCE CENTER (CRC) MODEL IN CALIFORNIA

Background: According to a national survey completed in 1997 by the National Alliance for Caregiving and the American Association of Retired Persons (AARP), nearly one in four U.S. households was involved in family caregiving. Informal caregiving plays a major role in providing long-term care services in the United States. The availability of family support makes it possible for many individuals with disabilities to remain in their homes, rather than being forced to enter an institution for their care. According to published literature, the presence of a family or other unpaid caregiver may obviate the need for publicly paid services or complement publicly paid services.

Testimony received from the Alzheimer's Association cited the lack of resources available to help relieve some of the emotional and financial pressures on family caregivers. The testimony and literature submitted for the Subcommittee's review also suggested that providing services and support for family caregivers such as respite, information and referral services and training could help to alleviate stress and depression which typically afflicts family caregivers. The Subcommittee recognized there is the potential for saving public dollars when family caregivers help their incapacitated family member stay at home. To better evaluate innovative programs that have been developed to support family caregivers, the Subcommittee invited Lynn Friss Feinberg with the Family Caregiver Alliance to testify on California's Caregiver Resource Center (CRC) system. A copy of Ms. Feinberg's position paper on policies and options for supporting informal and family caregiving is included in Appendix D. The key components of the CRC model are as follows:

- The CRC system provides support services to caregivers who are defined as any unpaid family member or individual who assumes responsibility for the care of a brain-impaired adult, and "family member" as any relative or court-appointed guardian or conservator who is responsible for the care of a brain-impaired adult. A brain-impaired adult means a person whose brain impairment has occurred after the age of 18.

- The CRC model targets middle-income families, and the CRC legislation does not allow caregivers who are Medicaid eligible to receive respite services.

- The CRC model provides a range of support services to defer institutionalization, to allow caregivers to maintain a normal routine, and to provide quality care. The services the CRC model typically provides include the following: specialized information, advice and referrals to caregiving families; comprehensive in-home assessments to determine the caregiver's needs and skills, to determine the care recipient's functional and behavioral problem and the impact on the caregiver; family consultation, which includes short-term counseling, support groups, psycho-educational groups and one-time legal consultation; and respite care (capped at $425 per month although respite costs average between $250-$350 per family per month). The CRC model maximizes consumer choice by allowing families to select the respite option which best fits their needs.

- Caregivers who are eligible to receive respite services participate in the payment for those services. A uniform co-payment schedule has been adopted that takes into account the family's income and size. According to Ms. Feinberg's testimony, the typical family caregiver contributes an average of 10 percent of the cost of respite care.

- The CRC system is funded through the California Department of Mental Health, which contracts with non-profit community agencies to operate the model. The California legislation also established a Statewide Resources Consultant role to operate a statewide clearinghouse on caregiving issues, manage the statewide CRC database, and provide coordination, consultation, training, research, technical and program assistance to the each of the individual CRC sites.

The Subcommittee was impressed with the support systems available to family caregivers through the CRC model and was interested in the plausibility of replicating the model for Nevada's demographics. According to Ms. Feinberg's testimony, the CRC model could be replicated, and she suggested if resources were limited that a pilot project could be implemented first, subject to an evaluation. Ms. Feinberg indicated this was the direction initially chosen by California. Accordingly, the Subcommittee requested a budget be developed to establish two CRC pilot sites in Nevada, one in an urban setting and one in a rural setting.

According to information provided by Ms. Feinberg, a pilot project in an urban setting should be staffed with a minimum component of five positions. The staffing component includes one program manager, two family consultants (social workers), one intake worker (eligibility worker) and one clerical support position. The cost projections for a rural site assume a staffing component of three positions to include a family consultant, one intake worker and one clerical support position. The salary costs for each of the positions were based on comparisons made to similar positions in the state classified service, and the costs for travel and operating were based on the average per position cost incurred by the Division for Aging Services for administering the CHIP program. The costs to outfit the positions were based on information included in the Governor's budget instructions for the 2001-03 biennium.

The cost for the purchase of services includes a one-time legal consultation to help families sort through legal and financial issues, estate planning, etc. The amount budgeted for respite services was based on the amount spent for respite services in California as a percent of the average CRC budget. According to information presented in Ms. Feinberg's testimony, the California Department of Mental Health requires each CRC site to spend a minimum of 20 percent of its budget on respite services. According to Ms. Feinberg, on average, each CRC site spends approximately 25 to 28 percent of its budget on respite services. The assumption used for calculating respite services was based on 30 percent of the projected budget for an urban and rural site. Based on these assumptions, the estimated cost to establish one CRC site at both an urban and rural site is as follows:

Urban Site

Staffing component (five positions)	$265,665
Travel	$ 8,784
Operating	$ 37,330
Equipment	$ 22,774
Purchase of Services*	$158,866
Total Cost Urban Site	**$493,419**

* Note: Purchase of Services based on the following assumptions:

Legal consultation - 300 hours at $150 per hour = $ 45,000
Respite services - $379,553 admin. costs + legal consultation x 30% = $113,866
Total: Legal consultation + respite services - $45,000 + $113,866 = $158,866

Rural Site

Staffing component (three positions)	$137,893
Travel	$ 6,360
Operating	$ 22,658
Equipment	$ 12,691
Purchase of Services*	$ 82,540
Total Cost Rural Site	**$262,142**

* Note: Purchase of Services based on the following assumptions:

Legal consultation - 150 hours at $150 per hour = $ 22,500
Respite services - $200,134 admin. costs + legal consultation x 30% = $ 60,040
Total: Legal consultation + respite services - $22,500 + $60,040 = $ 82,540

Total Urban & Rural Site **$755,561**

The Subcommittee felt it would be beneficial if the Statewide Resources Consultant in California could provide consultation services to assist with implementing a CRC model in Nevada. According to information provided by Ms. Feinberg, the Statewide Resources Consultant is available to provide consultation services at a cost of $150 per hour. Assuming that 160 hours of consultation time is needed, the total cost for consultation services and travel is estimated to be $27,179 ($150 per hour x 160 hours = $24,000 + $3,179 travel = $27,179). Adding consultant services to the implementation costs for an urban and rural site increases the total cost to $782,740.

Total Urban & Rural Site & Consultation Services **$782,740**

The Subcommittee, after carefully considering the benefits a proto-typical CRC model would provide family caregivers in Nevada and the costs for replicating the model, recommended the following:

> **The Subcommittee recommended a bill draft request with a general fund appropriation in the amount of $782,740 to establish a pilot project that replicates the Caregiver Resource Center (CRC) model in California. The CRC model provides support services to caregivers who are responsible for the care of a brain-impaired adult whose brain impairment has occurred after the age of 18. The CRC model targets middle-income families. The CRC model provides a range of support services designed to defer institutionalization, to allow caregivers to maintain a normal routine and to provide quality care. The services the CRC model typically provides include the following: specialized information, advice and referrals to caregiving families; comprehensive in-home assessments to determine the caregiver's needs and skills, to determine the care recipient's functional and behavioral problem and the impact on the caregiver; family consultation which includes short-term counseling, support groups, psycho-educational groups and legal consultation; and respite care.**
>
> **The Subcommittee recommended the pilot project include two CRC sites, one site located in an urban area of the state and one site located in a rural area of the state. The Subcommittee recommended designating the Division for Aging Services as the lead agency responsible for implementing the pilot project. The appropriation recommended as part of the bill draft request includes funding to retain a consultant. The consultant support is intended to assist the Division for Aging Services with implementing the pilot project and for issues such as establishing eligibility criteria for program services, training, developing a request for proposal process if non-profit organizations are contracted with to provide CRC services, and for developing reporting criteria to measure the performance of the pilot project. The bill draft request will include a sunset provision to ensure that the Legislature has an opportunity to fully evaluate the progress and performance of the pilot project prior to providing permanent funding and/or adding new sites. (BDR S-302)**

C. ASSISTED LIVING OPTION IN THE MEDICAID PROGRAM

3. PROVIDE FUNDING FOR THE RESOURCES TO EXPLORE THE FEASIBILITY OF DEVELOPING AN ASSISTED LIVING OPTION IN THE MEDICAID PROGRAM

Background: An assisted living option allows for Medicaid services to be provided to eligible individuals who reside in an assisted living facility constructed with financing available from the various federal housing programs. In order for this option to work, the assisted living facility needs to be affordable for low-income seniors and the Medicaid services would be tailored to meet each eligible individual's needs. The Medicaid services provided include a 24-hour response capability to meet eligible individuals' scheduled or unpredictable needs. The eligibility criteria for this option and the Medicaid service component could potentially be provided in conjunction with the Community Home-Based Initiatives Program (CHIP); however, an amendment to the waiver would be required. Another option would be to develop a model waiver; however, developing a new waiver would be time consuming and labor intensive. It should be noted that the Medicaid program only pays for medical services, not individuals' room and board costs. The intent of an assisted living option is to maintain the independence of a low-income senior within an affordable community setting by offering an enhanced level of medical services. The assisted living option appears to have the potential of reducing a current gap in the care continuum for a low-income senior who may be forced into a nursing facility when, in reality, that senior may still function independently within an assisted living environment if enhanced Medicaid services were available.

The opportunities presented by an affordable assisted living option within the Medicaid program were first discussed by Robert Mollica with the National Academy of State Health Policy during his presentation before the Subcommittee on profiling what other states are currently doing to maintain an individual's independence and keeping that individual out of a nursing facility. Several organizations testified in support of establishing an assisted living option, including the American Association of Retired Persons (AARP) and the Health Care Association. Additionally, representatives from Washoe Legal Services, Washoe County Senior Law Project, Washoe County Senior Services and the Affordable Housing Resource Council provided a comprehensive presentation at the Subcommittee's January 13, 2000 meeting that outlined the benefits that melding medical services with an affordable assisted living program would have in remedying current gaps in Medicaid coverage (see Appendix E).

The testimony which supported the concept of the assisted living option was appealing; however, the Subcommittee needed more definitive information which would better quantify the costs and services to be provided and the overall benefits to be redeemed if the option were implemented. The Subcommittee requested the Department of Human Resources more closely examine the assisted living option, as well as evaluate whether or not it would be worthwhile for the Department to apply for grant funding from the Robert Wood Johnson (RWJ) Foundation for the Coming Home Initiative. The Coming Home Initiative was a sequel to a previously funded program by the RWJ Foundation and provided $300,000 over a three-year period for up to eight states to facilitate the implementation of demonstration projects for affordable assisted living. A copy of the publication from the RWJ Foundation is included as Appendix F.

In response to the Subcommittee's request, the Department of Human Resources formed a work group to begin to evaluate the feasibility of implementing an assisted living option, as well as to prepare the application for the Coming Home Initiative. The Division for Aging Services submitted an application for the Coming Home Initiative on June 13, 2000. A copy of the project summary is attached as Appendix G. It should be noted that the Division was notified that Nevada was not one of the eight states chosen to receive funding for the Coming Home Initiative. The notification was received after the Subcommittee's last meeting, at which time the Subcommittee's recommendations were finalized.

Information the Subcommittee requested from the Department of Human Resources included providing a timeline to implement the assisted living option, realizing that there has not been adequate time to fully analyze and flush out the issues associated with adopting the option. The Department provided a response (see Appendix H) that indicated the option would be implemented over a three-year period. The timeline provided correlates with the timeline the Department included in the application for the Coming Home Initiative (see Appendix G). Based on the timeline provided by the Department, Medicaid services for the assisted living option would not commence until sometime in FY 2004, and the budget issues to support the implementation of the option would not be addressed until the 2003 Legislative Session.

The information provided to the Subcommittee in support of the projected timeline indicates the Department of Human Resources, in conjunction with the work group, will develop the assisted living option over two phases. Phase I involves an extensive planning and data collection process over fiscal years 2001 and 2002 and includes amending the CHIP waiver to allow for 24-hour services to eligible seniors residing in an affordable assisted living facility. Phase II involves coordinating the regulatory, budgetary, and site location issues over fiscal years 2003 and 2004 to implement the project once approval of the amended waiver has been received from the federal Health Care Financing Administration (HCFA).

To meet the projected timeline, the Department indicated it was essential that sufficient resources be provided to support the planning and data collection efforts necessary to implement the assisted living option. The Department indicated the agencies that would be responsible for developing the assisted living option do not have the existing staff or resources to perform these tasks. The Department indicated the administrative resources needed were comparable to those requested in the grant application for the Coming Home Initiative and include a program coordinator to provide staff support to the project and travel and operating costs to support the work group at a cost of approximately $100,000 per year.

The Department of Human Resources' analysis on eligibility, client make-up, the Medicaid service component and the costs for implementing the assisted living option can be found in Appendix H and is summarized below. Please note, the information summarized below is based on a preliminary analysis completed by the Department of Human Resources and is subject to significant changes as the feasibility of implementing an assisted living option is further evaluated.

- Eligibility requirements - The Department believes the CHIP waiver would be the most efficient mechanism to use to implement the assisted living option, although this issue needs to be researched further. The eligibility criteria for income, property and resources would be the same as the CHIP waiver, which is 300 percent of the SSI income level ($1,536 per month); individuals 65 and older; persons who meet a nursing facility level of care; and persons who are at risk of institutionalization.

- Pilot project size and client make-up - The Department believes a pilot project of 150 slots is reasonable based on the experience of other states. The client make-up would include 25 to 50 clients who reside in an intermediate care facility (ICL) (5 to 10 percent of the Medicaid population at ICL 1 and ICL 2 levels) and approximately 100 clients who would be drawn from an existing home environment.

- Medicaid services - The Department's preliminary observations indicate the Medicaid service component for assisted living should include the following services: case management, personal care, homemaker care, chore, attendant care companion, medication oversight, therapeutic social and recreational programming provided in a home-like environment in a licensed community care facility, in conjunction with residing in the facility. The services would include a 24-hour on-site response staff. Services would be bundled.

- Costs – Due to the conceptual nature of the assisted living option's design, the Department was only able to provide very preliminary and unrefined information on the potential costs and/or savings to implement the option. The Department's preliminary analysis indicates the additional cost to implement the assisted living option at approximately $338,000 per year. The analysis was based on a pilot project of 150 slots, numerous assumptions that take into consideration the costs for enhanced services made available through the waiver, and filling a certain number of slots with clients who are de-institutionalized, which may result in savings. The additional costs do not factor in the staff and operating costs the Department feels are needed once the assisted living option is ready for implementation in FY 2004. The Department indicates six new positions would be needed, to include three case managers, two eligibility workers and one waiver coordinator. **It should be noted, these are very preliminary estimates and should not be considered reliable until a more comprehensive cost benefit analysis is completed.**

The Subcommittee felt the assisted living option has significant merit; however, a great deal more definitive information is needed to fully evaluate the feasibility of implementing the option. After careful consideration, the Subcommittee recommended the following:

The Subcommittee recommended an appropriation in the amount of $100,000 for the Division for Aging Services for administrative support needed to explore the feasibility of developing an assisted living option within the Medicaid program. An assisted living option would allow for Medicaid services to be provided to eligible individuals who reside in an assisted living facility constructed with financing available from various federal housing programs. In order for this option to work, the assisted living facility would need to be affordable for low-income seniors, and the Medicaid services would be tailored to meet each eligible individual's needs. The Medicaid services provided would include a 24-hour response capability to meet eligible individuals' scheduled or unpredictable needs. The eligibility criteria for this option and the Medicaid service component would require either a new Medicaid waiver or possibly an amendment to an existing waiver such as the Community Home-Based Initiatives Program (CHIP). The intent of this recommendation is to maintain the independence of a low-income senior within an affordable community setting by offering an enhanced level of medical services. The assisted living option would potentially reduce a current gap in the care continuum for a low-income senior who may be forced into a nursing facility when, in reality, that senior may function independently within an assisted living environment if enhanced Medicaid services were available.

The assisted living option will require an extensive amount of planning, data collection and coordination of regulatory, budgetary and site location issues prior to implementation. The Department of Human Resources estimates this effort would be accomplished over a three-year period. The administrative support provided by the general fund appropriation will be used for this effort. The Subcommittee recommended sending a letter informing the Governor, the Budget Director and the Director of the Department of Human Resources of the Subcommittee's recommendation to pursue the assisted living option. The letter will request that the Governor consider recommending the administrative support needed by the Division for Aging Services to work on the assisted living option in The Executive Budget for the 2001-2003 biennium. (BDR S-303)

D. MEDICAID – HOME AND COMMUNITY BASED WAIVERS

4. AMEND THE HOME AND COMMUNITY BASED WAIVER FOR THE ELDERLY IN GROUP CARE (COMMONLY REFERRED TO AS THE ADULT GROUP CARE WAIVER) AND INCREASE THE SSI ELIGIBILITY UP TO 300 PERCENT OF THE SSI INCOME LEVEL

Background: The Adult Group Care Waiver is a program designed to offer individuals an alternative to nursing home care by providing supplemental services in a group care home. The services provided include case management and personal care. The Division for Aging Services is responsible for administering the program under the stipulations of an inter-local agreement with the Division of Health Care Financing and Policy. This program enables individuals to remain in a less restrictive and less expensive residential setting. There are approximately 80 clients currently participating in the Adult Group Care Waiver. The Welfare Division is responsible for determining eligibility, and the eligibility criteria to qualify for the program is as follows:

- The individual must be 65 years of age or older;
- The individual must be currently residing in a nursing home, hospital, or receiving services from the Community Home-Based Initiatives (CHIP) program;
- The income criteria is set at the federal SSI income level ($512);
- The individual's assets can be no more than $2,000 or less;
- The individual must be functioning at an intermediate level of care; and
- The client must be ambulatory.

The Adult Group Care Waiver provides a nursing facility alternative only for those individuals who have income at the SSI level or below ($512). Clients, for example, in the CHIP program who have income above the SSI level and who need more personal care and/or supervision have only the option of selecting a nursing facility to receive these services, a more costly alternative versus a group care setting. Raising the income level for the Adult Group Care Waiver to 300 percent of SSI ($1,536) would establish income eligibility criteria which is consistent among all Medicaid waivers. More importantly, this would provide a number of clients in the CHIP program an opportunity to choose a less restrictive option to nursing facility care that is currently not available.

The proposal to increase the income eligibility criteria for the Adult Group Care Waiver was made by the American Association of Retired Persons (AARP) and Robert Mollica with the National Academy for State Health Policy, and was noted as a significant gap in service by the Department of Human Resources.

The Division for Aging Services provided the Subcommittee information (see Appendix I) which indicates that during the period of July 1, 1999 through April 30, 2000, there were 30 CHIP clients who went into a nursing facility because their income was above the SSI level and therefore they could not qualify for the Adult Group Care Waiver. Although it is difficult to estimate the number of additional clients who may qualify for the Adult Group Care Waiver by raising the income eligibility to 300 percent of SSI, it was assumed that 40 additional clients would access the program. The additional cost for these 40 clients is as follows:

> 40 clients x $4,102 (annual cost of case management and personal care services in a group home setting) = $164,080.

Assuming these 40 clients went into a nursing facility without the availability of the group care option, and assuming one-half of the clients would have been designated at an Intermediate Care Level (ICL) I and one-half of the clients would have been designated at an ICL II, the institutional costs are as follows:

20 clients x $22,620 (ICL I cost) per year =	$ 452,400
20 clients x $27,840 (ICL II cost) per year =	$ 556,800
Total nursing facility cost per year =	$1,009,200

The estimated savings is the difference between the nursing facility costs and the additional costs for providing case management and personal care services to the 40 clients who theoretically would choose the option of residing in a group care setting.

$1,009,200 - $164,080 = $ 845,120

It is important to note the potential costs and savings for this proposal are entirely dependent on the number of clients who access this option if the SSI income eligibility is increased. Additionally, the counties participating in the county match program would realize a majority of the potential savings from less costly placements if the income eligibility criteria for the Adult Group Care Waiver were increased.

The Subcommittee felt it was critical to have eligibility criteria which is consistent between the various Medicaid waivers currently administered. Additionally, raising the SSI eligibility level for the Adult Group Care Waiver would offer more individuals the opportunity to choose a less restrictive living environment compared to nursing home care. The Subcommittee, in consideration of these benefits and the potential savings to the Medicaid program by avoiding nursing facility costs, recommended the following:

> **The Subcommittee recommended the Department of Human Resources amend the Home and Community Based Waiver for Elderly in Group Care (commonly referred to as the Adult Group Care Waiver) and increase the SSI eligibility up to 300 percent ($1,536) of the SSI income level. The Adult Group Care Waiver is designed to offer individuals an alternative to nursing home care by providing supplemental services in a group care home. The services provided include case management and personal care. Raising the income level for the Adult Group Care Waiver would establish income eligibility criteria, which is consistent among all Medicaid waivers. More importantly, this would provide a number of clients in the Community Home-Based Initiatives Program (CHIP) an opportunity to choose a less restrictive option to nursing facility care that is currently not available and potentially defray long-term care costs in the**

Medicaid program. The Subcommittee also recommended that any necessary modifications to the Medicaid budget be included in the Department of Human Resources budget request submitted to the Governor for the 2001-2003 biennium.

5. AMEND THE HOME AND COMMUNITY BASED WAIVER FOR THE COMMUNITY HOME-BASED INITIATIVES PROGRAM (CHIP) AND ELIMINATE THE PATIENT LIABILITY REQUIREMENT

Background: Of the four waiver programs administered by Nevada Medicaid, the Community Home-Based Initiatives (CHIP) program is the only waiver that includes a patient liability requirement. The amount of the patient liability is determined by the Welfare Division as part of the eligibility determination process and is collected on eligible clients whose income is over 200 percent of the SSI income ($1,024) level. To qualify for the CHIP program, an individual may earn up to 300 percent of the SSI income level ($1,536 per month). Currently, 101 clients on the CHIP waiver have a patient liability. The annual revenue generated by patient liability is approximately $89,000 per year and offsets the need for state general funds and federal funds used to fund the CHIP program in the same amount. The Division for Aging Services bills each client who has a patient liability responsibility on a monthly basis. The amount of patient liability collected by the Division for Aging Services is deducted from the monthly billing submitted to Medicaid for waiver services provided under the CHIP program.

Testimony and supporting documentation provided by the Department of Human Resources (see Appendix J) indicated there are several reasons that support eliminating the patient liability requirement for the CHIP program which were not apparent when the waiver was originally implemented. The reasons are as follows:

- First, this is an eligibility requirement that is unique to the CHIP program, and when applied, creates a consistency problem for clients who may transfer to the CHIP program from another Medicaid waiver program. For example, a client who transfers from the Medicaid waiver for the Physically Disabled, which has no patient liability requirement, to the CHIP program when that client reaches 65 years of age may now be responsible for paying a patient liability (depending upon the client's income level).

- Second, the Division for Aging Services is not able in all cases to collect the amount of patient liability assessed an eligible client. In those cases, state general funds, which are used to fund the state-only cases in the CHIP program, are used to make up for the shortfall. The use of state funds to make up for the shortfall reduces the amount of services and/or client slots that can be ultimately funded for state-only cases in the CHIP program.

- Third, the amount of patient liability collected on an annual basis is insignificant, and its elimination would alleviate an administrative burden associated with the accounts receivable process.

- Fourth, the amount of patient liability collected is currently deducted from the amount recovered from the Medicaid Estate Recovery process. If patient liability were eliminated under the CHIP program, the Medicaid Estate Recovery process would ultimately recover the full cost of services provided once the client is deceased.

If the patient liability requirement were eliminated, there would be an initial cost impact to the CHIP budget of approximately $89,000 annually (50/50 state/federal) in lost revenue. To make up for the lost revenue in the CHIP budget, a combination of state and federal funds would have to be recommended ($44,500 state and $44,500 federal Medicaid funds). However, assuming the Medicaid Estate Recovery process ultimately recovers the full cost of services provided, the elimination of the patient liability requirement would be cost neutral.

Considering the overwhelming justification to eliminate the patient liability requirement, the Subcommittee recommended the following:

> **The Subcommittee recommended the Department of Human Resources amend the Home and Community Based Waiver for the Community Home-Based Initiatives Program (CHIP) and eliminate the patient liability requirement. The CHIP program is the only Medicaid waiver that includes a patient liability requirement. The requirement, when applied, has created a consistency problem for clients who may transfer to the CHIP program from another Medicaid waiver which has no patient liability requirement. The amount of patient liability collected on an annual basis is insignificant and when not collected, state funds must be used to make-up for the shortfall, which ultimately reduces the amount of services available to state-only clients in the CHIP program. Additionally, if the patient liability requirement were eliminated, the Medicaid Estate Recovery process would ultimately recover the full cost of services provided once the client is deceased. The Subcommittee recommended the Division for Aging Services include the necessary modifications associated with eliminating the patient liability requirement in the CHIP budget submitted to the Governor for the 2001-2003 biennium.**

6. PROVIDE SUFFICIENT FUNDING FOR THE PROJECTED CASELOAD GROWTH IN THE COMMUNITY-HOME BASED INITIATIVES PROGRAM (CHIP) IN ORDER TO MAINTAIN A REASONABLE WAIT TIME FOR SERVICES

Background: At several meetings, the Committee received testimony regarding concerns with the waiting list for the Community Home-Based Initiatives Program (CHIP). According to information provided by the Division for Aging Services, the number of Medicaid eligible clients on the CHIP waiting list is currently 622 and the number of state-only clients on the waiting list is 51 (see Appendix I). The CHIP services provided to Medicaid-eligible clients are funded 50% with federal Title XIX funds and 50% with state general funds. The state-only eligible clients are funded entirely with state general funds. The waiting list for CHIP services is driven by many factors; however, the primary factors include the amount budgeted for caseload growth, the number of case managers authorized for the Division for Aging Services to administer the case management component of CHIP, and the vacancy rate for case managers. In light of these factors, the number of clients on the waiting list fluctuates throughout the year.

Although the number of clients on the waiting list is significant, arguably more important is the length of time a client who is eligible for CHIP must wait before services can be accessed. Currently the wait time for CHIP services for clients who are Medicaid-eligible is approximately 2 to 3 months in the north and 4 to 6 months in the south. The wait time in the southern part of the state has dropped this past fiscal year from 9 to 12 months and should continue to drop in FY 2001. Additionally, the Division for Aging Services, as part of the assessment process, identifies individuals who are at risk and need CHIP services. All efforts are made to provide needed CHIP services to these individuals without a wait period. The Legislature over the past several years has consistently provided funding for the projected caseload growth of the elderly population who are Medicaid-eligible and access CHIP services. The funding authorized for caseload growth has not only reduced the waiting list but also the wait time for services. For example, the projected Medicaid caseload to receive CHIP services will increase by approximately 17.7% in FY 2000 compared to the FY 1999 caseload and by an additional 13.6% in FY 2001 over the projected caseload in FY 2000.

Additionally, the 1999 Legislature appropriated approximately $970,000 over the 1999-01 biennium for CHIP in an attempt to eliminate or at least significantly reduce the state-only waiting list. The appropriation funded 82 additional state-only slots for CHIP. The appropriation to increase the number of state-only slots for the current biennium was the first increase in funding for this eligible group in several years.

The testimony received indicated that individuals, unless they are determined to be at risk, would always experience a waiting period before CHIP services for both Medicaid-eligible and state-only clients are accessible. However, if the wait period for CHIP services is maintained within a reasonable length of time, i.e. 2 to 4 months, the number of clients on the waiting list becomes less significant. In order to maintain the current wait time, funding for CHIP for the upcoming biennium will need to at least keep pace with the projected growth in population for age groups served by CHIP.

The Subcommittee, based on the testimony received and their concern that services from CHIP are made available to eligible individuals within a reasonable time period, recommended the following:

> **The Subcommittee recommended that the Division for Aging Services request sufficient funding in the budget for the Community Home-Based Initiatives Program (CHIP) for the 2001-2003 biennium for the projected growth in population for the age groups served by CHIP in order to maintain a reasonable**

wait time for services. The Subcommittee recommended sending a letter to the Governor, the Budget Director and the Director, Department of Human Resources, to request that sufficient funding be included in The Executive Budget to meet the intent of this recommendation, and that tobacco settlement monies be used to fund the additional costs for reducing the wait time for state-only cases.

E. FUTURE INTERIM STUDY OF LONG-TERM CARE ISSUES

7. CREATE AN INTERIM LEGISLATIVE COMMITTEE TO CONTINUE THE STUDY OF LONG-TERM CARE ISSUES

Background: The Subcommittee received a significant amount of testimony requesting that the study of long-term care in Nevada be continued beyond this interim. The organizations that specifically supported this proposal include the American Association of Retired Persons (AARP), the Health Care Association, the Alzheimer's Association and the Nevada Women's Lobby. The testimony from the organizations that recommended continuing the study indicated the complexity and enormity of the subject matter warrants the study's continuation since it was not possible in the span of five meetings to address all pertinent issues. Additionally, although a number of significant issues were addressed during the course of the hearings, the organizations felt that several issues required more in-depth study in order to evaluate the effectiveness of Nevada's long-term care system and make recommendations to improve the system based on a more comprehensive analysis. The organizations that testified also requested that any legislation to continue the study provide a mechanism to allow for establishing advisory committees made up of subject matter experts to assist the Subcommittee in carrying out its assigned mandates. The proposal to continue the study of long-term care is not precedent setting. The 1999 Legislature, with passage of A.C.R. 13, approved continuing the study of the juvenile justice system in Nevada that was originally initiated by the 1997 Legislature with passage of A.C.R. 57.

AARP's testimony suggested the following areas could be considered as part of the mission for an ongoing study's scope of work (see Appendix K).

- Develop acceptable definitions, through statutory and/or regulatory language, for various residential and home care long-term care services, i.e. assisted living;
- Develop standards for various residential and home long-term care services in non-medical residential care, to include training requirements and quality assurance; and
- Evaluate the feasibility of developing a single point of entry system.

The Subcommittee determined the mission of an ongoing study could also include monitoring the implementation of programs the Subcommittee recommended and/or issues outlined in SCR 4 that could not be fully addressed due to time constraints during the interim. The following examples were discussed:

- Monitor the implementation of a pilot project that replicates the Caregiver Resource Center model in California if ultimately approved by the 2001 Legislature;

- Monitor the implementation of an assisted living option in the Medicaid program if ultimately approved by the 2001 Legislature;

- Evaluate the potential to integrate acute care services provided by Medicare and long-term care services provided by Medicaid.

One of the considerations in continuing the study of long-term care discussed by the Subcommittee was cost. The cost for an interim study typically includes the salary, travel and operating support costs for the legislators assigned to the Subcommittee and staff costs that are already included in the Legislative Counsel Bureau's budget. The budget approved by the Legislative Commission for the study of long-term care was $7,400. The Subcommittee also felt the cost to continue the study should include consultant support to provide research, analysis and guidance to the Subcommittee on the complex and technical areas that may be part of the mission for an ongoing study. A consultant working on the Committee's behalf would be independent, a subject matter expert, and knowledgeable of the national trends on the issues to be considered. The Subcommittee felt this would be an invaluable resource, not only to the legislators assigned the study, but also to members of the advisory committee if one were appointed. The estimated cost for consultant support is $26,900. This cost estimate was based on information received from Robert Mollica with the National Academy for State Health Policy, and breaks down as follows:

Consultant Time	$20,500 ($82 per hour x 250 hours)
Consultant Travel	$ 6,400 (8 trips x $800 per trip)
Consultant Total	**$26,900**

TOTAL COMMITTEE COST + CONSULTANT COST = $34,300

The Subcommittee, in consideration of the testimony received and their understanding that the subject matter of long-term care needs to be further examined, recommended the following:

The Subcommittee recommended a bill draft request to create an interim study committee to continue the study of long-term issues upon the adjournment of the 2001 Legislative Session. The Subcommittee also recommended the bill draft request include a general fund appropriation in the amount of $26,900 for consultant support. The consultant support would be used to provide research, analysis and guidance to the interim study committee on the complex and technical areas that may be part of the mission for an ongoing study.
(BDR S-300)

IV. ACKNOWLEDGEMENTS

The staff of the Legislative Commission's Subcommittee to Study Long-Term Care in Nevada wishes to thank the following individuals for taking the time and traveling long distances to present expert testimony to the Subcommittee: Robert Mollica, National Academy for State Health Policy; Steffani Crawley, AEGON Insurance Group; Craig Hartung, Larson and Hartung Insurance Associates; Lynn Friss Feinberg, Family Caregiver Alliance; and Cindy Hannum, Oregon Department of Human Resources, Senior and Disabled Services Division. The expert testimony provided a wealth of information and a unique perspective on long-term care issues that was extremely valuable in developing the recommendations ultimately approved by the Subcommittee.

In addition, staff from the Department of Human Resources, the Public Employees' Benefits Program and the Division of Insurance provided valuable information, suggestions and analysis for the Subcommittee's review. The Subcommittee's staff would like to thank Charlotte Crawford, Director, Department of Human Resources; Mary Liveratti, Administrator, Aging Services Division; Myla Florence, former Administrator, Welfare Division; Janice Wright, former Administrator, Division of Health Care Financing and Policy; Jan Marie Reed, Executive Officer, Public Employees' Benefits Program; and Guy Perkins, Chief Insurance Examiner, Division of Insurance.

The Subcommittee's staff would also like to thank Dr. William Hausman, Hilke Faber and Carla Sloan with the American Association of Retired Persons (AARP) for their assistance in arranging for Cindy Hannum's presentation on the Evolution of the Oregon Model for Long-Term Care.

V. SUGGESTED LEGISLATION
(BILL DRAFT REQUESTS)

BDR S-300	Directs Legislative Commission to appoint subcommittee to continue study of long-term care in this state.
BDR S-302	Establishes pilot program to provide support services for persons who provide care for certain persons with brain damage.
BDR 23-299	Requires board of public employees' benefits program to provide long-term care coverage for state employees and retirees.

The bill draft request for the assisted living option (see Item III-C) will be available after commencement of the 2001 Legislative Session.

SUMMARY—Directs Legislative Commission to appoint subcommittee to continue study of long-term care in this state. (BDR S-300)

FISCAL NOTE: Effect on Local Government: No.

Effect on the State: Contains Appropriation not included in Executive Budget.

AN ACT relating to long-term care; directing the Legislative Commission to appoint a subcommittee to continue the study of long-term care in this state; authorizing the subcommittee to appoint an advisory committee; requiring the subcommittee to employ a consultant; making an appropriation; and providing other matters properly relating thereto.

WHEREAS, The Legislative Commission was directed by Senate Concurrent Resolution No. 4 of the 70th session of the Nevada Legislature to appoint a subcommittee to conduct an interim study concerning long-term care in this state; and

WHEREAS, The study was conducted during the 1999-2000 legislative interim and it facilitated discussions among the members of the subcommittee and national, state and local experts concerning a multitude of issues relating to long-term care in this state; and

WHEREAS, Because of the number and complexity of issues addressed by the subcommittee, the subcommittee concluded that a second phase of discussion, oversight and consideration of those issues was necessary to ensure significant improvements in long-term care in this state; now, therefore,

THE PEOPLE OF THE STATE OF NEVADA, REPRESENTED IN
SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

Section 1. 1. The Legislative Commission shall appoint a subcommittee, consisting of three members of the Senate and three members of the Assembly, to continue the study of long-term care in this state.

2. The members of the subcommittee:

(a) Shall employ a consultant who has special expertise in the areas of the study to assist the subcommittee in carrying out its duties; and

(b) May appoint an advisory committee, consisting of persons who are knowledgeable in the areas of the study, to consult with and to assist the subcommittee in carrying out its duties.

3. If the subcommittee appoints an advisory committee pursuant to subsection 2:

(a) The chairman of the subcommittee shall designate one member of the advisory committee to serve as chairman of the advisory committee; and

(b) The members of the advisory committee serve without compensation and are not entitled to receive a per diem allowance or travel expenses.

4. The study must include, without limitation:

(a) A review and evaluation of the statutes and regulations in this state relating to long-term care and a determination of whether and, if necessary, the manner in which those statutes and regulations should be amended to incorporate and define the types of services related to long-term care that are available in this state, including, without limitation, a facility for assisted living;

(b) The development of standards governing the provision of nonmedical services related to long-term care and whether those services are provided in a facility for long-term care or as part of home health care, including, without limitation, standards governing:

(1) The procedures used to evaluate and monitor the quality of those services; and

(2) The amount of training that a person who provides those services is required to complete;

(c) An evaluation of a system of long-term care that integrates the services related to long-term care that are provided in other states to allow a person to access those services from a single point in the system and a determination of the feasibility of using such a system in this state;

(d) The monitoring of the recommendations made by the subcommittee appointed pursuant to Senate Concurrent Resolution No. 4 of the 70th session of the Nevada Legislature, and any legislation recommended by that subcommittee and enacted by the 71st session of the Nevada Legislature; and

(e) An evaluation of the feasibility of obtaining a waiver from the Federal Government to integrate and coordinate services related to acute care that are covered by Medicare and services related to long-term care that are covered by Medicaid in this state.

5. Any recommended legislation proposed by the subcommittee must be approved by a majority of the members of the Senate and a majority of the members of the Assembly appointed to the subcommittee.

6. The Legislative Commission shall submit a report of the results of the study and any recommendations for legislation to the 72nd session of the Nevada Legislature.

Sec. 2. 1. There is hereby appropriated from the state general fund to the subcommittee appointed pursuant to section 1 of this act the sum of $26,900 for the services and cost of travel of the consultant employed by the subcommittee pursuant to section 1 of this act.

2. Any remaining balance of the appropriation made pursuant to subsection 1 must not be committed for expenditure after June 30, 2002, and reverts to the state general fund as soon as all payments of money committed have been made.

Sec. 3. This act becomes effective upon passage and approval.

SUMMARY—Establishes pilot program to provide support services for persons who provide care for certain persons with brain damage. (BDR S-302)

FISCAL NOTE: Effect on Local Government: No.

Effect on the State: Contains Appropriation not included in Executive Budget.

AN ACT relating to health care; requiring the aging services division of the department of human resources to establish a pilot program to provide support services for persons who provide care for certain persons with brain damage; authorizing the division to contract for the provision of services required to carry out the pilot program; making an appropriation; and providing other matters properly relating thereto.

THE PEOPLE OF THE STATE OF NEVADA, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

Section 1. As used in this act, unless the context otherwise requires, the words and terms defined in sections 2 to 9, inclusive, of this act have the meanings ascribed to them in those sections.

Sec. 2. "Brain damage" means a significant destruction of brain tissue that results in the loss of the functioning of the brain and includes, without limitation:

1. Progressive, degenerative, and dementing illnesses, including, without limitation, presenile and senile dementias, Alzheimer's disease, multi-infarct disease, Pick's disease and Kreutzfeldt-Jakob's disease.

2. Degenerative diseases of the central nervous system that may result in dementia or severe impairment of the brain, including, without limitation, epilepsy, multiple sclerosis, Parkinson's disease, amyotrophic lateral sclerosis and Huntington's disease and other hereditary diseases.

3. Permanent damage caused by strokes, including, without limitation, cerebral hemorrhage, aneurysm and embolism.

4. Posttraumatic, postanoxic and postinfectious damage caused by incidents, including, without limitation, coma, accidental injuries to the skull, closed head injuries, loss of oxygen and encephalitis, herpes simplex, tuberculosis and other infections.

5. Permanent brain damage or temporary or progressive dementia caused by tumors, hydrocephalus, abscesses, seizures and substance toxicity.

Sec. 3. "Brain-impaired adult" means a person whose brain damage occurred after the age of 18.

Sec. 4. "Caregiver" means any family member or other person who:

1. Provides care for a brain-impaired adult; and

2. Is not compensated for providing that care.

Sec. 5. "Division" means the aging services division of the department of human resources.

Sec. 6. "Family member" means any person who provides care for a brain-impaired adult and is:

1. Related to the brain-impaired adult; or

2. Appointed guardian or conservator of the brain-impaired adult by a court of competent jurisdiction.

Sec. 7. "Request for proposals" has the meaning ascribed to it in NRS 333.020.

Sec. 8. "Respite care" means the supervision of or care provided for a brain-impaired adult by a person other than the caregiver to:

1. Relieve the caregiver from the responsibility of providing care for the brain-impaired adult on a continuous basis; and

2. Enable the caregiver to fulfill obligations and engage in activities other than providing care for the brain-impaired adult.

Sec. 9. "Support services" means the services provided to a caregiver pursuant to the pilot program established by section 10 of this act. The term includes the services set forth in paragraphs (a), (b) and (c) of subsection 1 of section 13 of this act.

Sec. 10. 1. The division shall:

(a) Establish a pilot program to provide support services to caregivers of brain-impaired adults;

(b) Designate an urban area and a rural area in this state where the support services will be provided;

(c) Determine the number of employees required for each area where the support services will be provided; and

(d) Consult with other organizations that provide services to brain-impaired adults, family members and caregivers to coordinate the support services provided pursuant to the pilot program with the services provided by other organizations, including, without limitation, the division of mental health and developmental services of the department of human resources.

2. The division may enter into a contract for the provision of services required to carry out the pilot program established pursuant to subsection 1.

Sec. 11. The division may, within the limitations of legislative appropriation, contract with a consultant to assist the division in carrying out its duties pursuant to sections 2 to 14, inclusive, of this act, including, without limitation:

1. If the division determines that it will enter into a contract pursuant to section 10 of this act:

(a) Developing a request for proposals; and

(b) Evaluating the responses received by the division to the request for proposals;

2. Developing a sliding scale for determining the amount that a person is required to pay for the support services he receives; and

3. Developing criteria for the report that is required to be submitted to the director of the legislative counsel bureau pursuant to section 12 of this act.

Sec. 12. 1. The division shall:

(a) Determine the support services that the pilot program will provide in each area.

(b) If the division determines that it will enter into a contract pursuant to section 10 of this act:

(1) Prepare requests for proposals based on the services required to carry out the pilot program as determined pursuant to this subsection;

(2) Accept those proposals; and

(3) Review the proposals submitted and award a contract for support services.

(c) On or before February 1 of each year following a fiscal year in which the pilot program provided support services, submit a report concerning the pilot program to the director of the legislative counsel bureau for transmittal to the senate standing committee on finance and the assembly standing committee on ways and means if the legislature is in session, or to the interim finance committee if the legislature is not in session.

2. As used in this section, "fiscal year" means a period beginning on July 1 and ending on the following June 30.

Sec. 13. 1. Each area where support services are provided must:

(a) Provide information, advice and referrals to a caregiver relating to:

(1) Diagnostic procedures;

(2) Long-term care;

(3) Legal and financial matters;

(4) Mental health; and

(5) Caregiving techniques;

(b) Provide respite care;

(c) Provide training and educational programs for brain-impaired adults, family members, caregivers and providers of support services;

(d) Identify the services required by the caregivers residing in that area, determine whether those services are provided by the pilot program and provide that information to the division; and

(e) Assist the division in such activities as the division determines are necessary to carry out the provisions of sections 2 to 14, inclusive, of this act.

2. The respite care provided pursuant to this section:

(a) Must, to the extent practicable, be provided in a local facility or by a local agency, including, without limitation:

  (1) An agency to provide nursing in the home; and

  (2) A facility for the care of adults during the day;

(b) Must, to the extent practicable, be provided in a manner that allows the caregiver to chose whether the respite care will be provided for a period of consecutive days or for a number of cumulative days within a specific period; and

(c) May be provided by a provider of respite care chosen by the caregiver, including, without limitation:

  (1) A provider of home health care other than an agency to provide nursing in the home; and

  (2) A facility outside the home other than a facility for the care of adults during the day.

3. As used in this section:

(a) "Agency to provide nursing in the home" has the meaning ascribed to it in NRS 449.0015.

(b) "Facility for the care of adults during the day" has the meaning ascribed to it in NRS 449.004.

Sec. 14. 1. A person who receives support services may be required to pay a portion of the cost of those support services based upon his ability to pay, except that he must not be required to pay more than the actual cost of the support services.

2. A person may not be denied support services solely because of his inability to pay for the support services.

3. A person who is eligible to receive Medicaid is not entitled to receive respite care provided by the pilot program.

Sec. 15. 1. There is hereby appropriated from the state general fund to the aging services division of the department of human resources the sum of $782,740 to carry out the pilot project established pursuant to section 10 of this act.

2. Any remaining balance of the appropriation made pursuant to subsection 1 must not be committed for expenditure after June 30, 2003, and reverts to the state general fund as soon as all payments of money committed have been made.

Sec. 16. This act becomes effective on July 1, 2001, and expires by limitation on June 30, 2005.

SUMMARY—Requires board of public employees' benefits program to provide long-term care coverage for state employees and retirees. (BDR 23-299)

FISCAL NOTE: Effect on Local Government: No.

Effect on the State: Contains Appropriation not included in Executive Budget.

AN ACT relating to public employees; requiring the board of the public employees' benefits program to provide long-term care coverage for state employees and retirees; making appropriations; requiring an assessment of certain state agencies for transfer to the board of the public employees' benefits program to contribute towards that coverage; and providing other matters properly relating thereto.

THE PEOPLE OF THE STATE OF NEVADA, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

Section 1. NRS 287.010 is hereby amended to read as follows:

FIRST PARALLEL SECTION

287.010 1. The governing body of any county, school district, municipal corporation, political subdivision, public corporation or other public agency of the State of Nevada may:

(a) Adopt and carry into effect a system of group life, accident*,* ~~[or]~~ health *or long-term care* insurance, or any combination thereof, for the benefit of its officers and employees, and the dependents of officers and employees who elect to accept the insurance and who, where necessary, have authorized the governing body to make deductions from their compensation for the payment of premiums on the insurance.

(b) Purchase group policies of life, accident*,* ~~[or]~~ health ***or long-term care*** insurance, or any combination thereof, for the benefit of ~~[such]~~ ***those*** officers and employees, and the dependents of ~~[such]~~ ***those*** officers and employees, as have authorized the purchase, from insurance companies authorized to transact the business of such insurance in the State of Nevada, and, where necessary, deduct from the compensation of officers and employees the premiums upon insurance and pay the deductions upon the premiums.

(c) Provide group life, accident *,* ~~[or]~~ health ***or long-term care*** coverage through a self-insurance reserve fund and, where necessary, deduct contributions to the maintenance of the fund from the compensation of officers and employees and pay the deductions into the fund. The money accumulated for this purpose through deductions from the compensation of officers and employees and contributions of the governing body must be maintained as an internal service fund as defined by NRS 354.543. The money must be deposited in a state or national bank or credit union authorized to transact business in the State of Nevada. Any independent administrator of a fund created under this section is subject to the licensing requirements of chapter 683A of NRS, and must be a resident of this state. Any contract with an independent administrator must be approved by the commissioner of insurance as to the reasonableness of administrative charges in relation to contributions collected and benefits provided. The provisions of NRS 689B.030 to 689B.050, inclusive, apply to coverage provided pursuant to this paragraph, except that the provisions of NRS 689B.0359 do not apply to ~~[such]~~ ***that*** coverage.

(d) Defray part or all of the cost of maintenance of a self-insurance fund or of the premiums upon insurance. The money for contributions must be budgeted for in accordance with the laws governing the county, school district, municipal corporation, political subdivision, public corporation or other public agency of the State of Nevada.

2. If a school district offers group insurance to its officers and employees pursuant to this section, members of the board of trustees of the school district must not be excluded from participating in the group insurance. If the amount of the deductions from compensation required to pay for the group insurance exceeds the compensation to which a trustee is entitled, the difference must be paid by the trustee.

Sec. 2. NRS 287.043 is hereby amended to read as follows:

287.043 1. The board shall:

(a) Establish and carry out a program to be known as the public employees' benefits program which:

(1) Must include a program relating to ***long-term care insurance and*** group life, accident or health insurance, or any combination of these; and

(2) May include a program to reduce taxable compensation or other forms of compensation other than deferred compensation,

FLUSH for the benefit of all state officers and employees and other persons who participate in the program.

(b) Ensure that the program is funded on an actuarially sound basis and operated in accordance with sound insurance and business practices.

2. In establishing and carrying out the program, the board shall:

(a) Except as otherwise provided in this paragraph, negotiate and contract with the governing body of any public agency enumerated in NRS 287.010 ~~[which is desirous of obtaining]~~ ***that wishes to obtain*** group insurance for its officers, employees and retired employees by participation in the program. The board shall establish separate rates and coverage for those officers, employees and retired employees based on actuarial reports.

(b) Give public notice in writing of proposed changes in rates or coverage to each participating public employer who may be affected by the changes. Notice must be provided at least 30 days before the effective date of the changes.

(c) Purchase policies of ***long-term care insurance and group*** life, accident or health insurance, or any combination of these, or, if applicable, a program to reduce the amount of taxable compensation pursuant to 26 U.S.C. § 125, from any company qualified to do business in this state or provide similar coverage through a plan of self-insurance established pursuant to NRS 287.0433 for the benefit of all eligible public officers, employees and retired employees who participate in the program.

(d) Except as otherwise provided in this Title, develop and establish other employee benefits as necessary.

(e) Investigate and approve or disapprove any contract proposed pursuant to NRS 287.0479.

(f) Adopt such regulations and perform such other duties as are necessary to carry out the provisions of NRS 287.0402 to 287.049, inclusive, including, without limitation, the establishment of:

(1) Fees for applications for participation in the program and for the late payment of premiums or contributions;

(2) Conditions for entry and reentry into the program by public agencies enumerated in NRS 287.010;

(3) The levels of participation in the program required for employees of participating public agencies;

(4) Procedures by which a group of participants in the program may leave the program pursuant to NRS 287.0479 and conditions and procedures for reentry into the program by ~~[such]~~ ***those*** participants; and

(5) Specific procedures for the determination of contested claims.

(g) Appoint an independent certified public accountant. The accountant shall provide:

(1) An annual audit of the program; and

(2) A biennial audit of the program to determine whether the program complies with federal and state laws relating to taxes and employee benefits.

FLUSH The accountant shall report to the board and the interim retirement and benefits committee of the legislature created pursuant to NRS 218.5373.

3. ***When purchasing a policy of long-term care insurance for the program pursuant to paragraph (c) of subsection 2, the board shall consider:***

(a) The monetary limit and the period of coverage for care provided at a facility for long-term care;

(b) The monetary limit and the period of coverage for care provided by an agency to provide nursing in the home or any other provider of home health care;

(c) The length of any delay in eligibility for benefits; and

(d) Whether the coverage includes protection against inflation.

4. The board may use any services provided to state agencies and shall use the services of the purchasing division of the department of administration to establish and carry out the program.

~~[4.]~~ *5.* The board may make recommendations to the legislature concerning legislation that it deems necessary and appropriate regarding the program.

~~[5.]~~ *6.* The state and any other public employers that participate in the program are not liable for any obligation of the program other than indemnification of the board and its employees against liability relating to the administration of the program, subject to the limitations specified in NRS 41.0349.

~~[6.]~~ *7.* As used in this section ~~[, “employee]~~ *:*

(a) “Agency to provide nursing in the home” has the meaning ascribed to it in NRS 449.0015.

(b) “Employee benefits” includes any form of compensation provided to a state employee pursuant to this Title except federal benefits, wages earned, legal holidays, deferred compensation and benefits available pursuant to chapter 286 of NRS.

(c) “Facility for long-term care” has the meaning ascribed to it in NRS 632.0155.

Sec. 3. NRS 287.0433 is hereby amended to read as follows:

287.0433 The board may establish a plan of ***long-term care insurance and group*** life, accident or health insurance and provide for the payment of contributions into the fund for the public employees' benefits program established pursuant to NRS 287.0435, a schedule of benefits and the disbursement of benefits from the fund. The board may reinsure any risk or any part of such a risk.

Sec. 4. NRS 287.044 is hereby amended to read as follows:

287.044 1. A part of the cost of the premiums or contributions for that group insurance, not to exceed the amount specified by law, applied to ~~[both]~~ group life and group accident or health ***or long-term care*** coverage, for each public officer, except a senator or assemblyman, or employee electing to participate in the program, may be paid by the department, agency, commission or public agency which employs the officer or employee in whose behalf that part is paid from money appropriated to or authorized for that department, agency, commission or public agency for that purpose. Participation by the state in the cost of premiums or contributions must not exceed the amounts specified by law. If an officer or employee chooses to cover his dependents, whenever this option is made available by the board, except as otherwise provided in NRS 287.021 and 287.0477, he must pay the difference between the amount of the premium or contribution for the coverage for himself and his dependents and the amount paid by the state.

2. A department, agency, commission or public agency shall not pay any part of those premiums or contributions if the group life insurance or group accident or health ***or long-term care*** insurance is not approved by the board.

Sec. 5. NRS 287.0479 is hereby amended to read as follows:

287.0479 1. If approved by the board pursuant to this section, a group of not less than 300 officers, employees or retired employees, or any combination thereof, that participate in the program may leave the program and secure ***long-term care insurance and group*** life, accident or health insurance, or any combination thereof, for the group from an:

(a) Insurer that is authorized by the commissioner of insurance to provide ~~[such]~~ ***that*** insurance; or

(b) Employee benefit plan, as defined in 29 U.S.C. § 1002(3), that has been approved by the board. The board may approve an employee benefit plan unless the board finds that the plan is not operated pursuant to such sound accounting and financial management practices as to ensure that the group will continue to receive adequate benefits.

2. Before entering into a contract with the insurer or approved employee benefit plan, the group shall submit the proposed contract to the board for approval. The board may approve the contract unless the departure of the group from the program would cause an increase of more than 5 percent in the costs of premiums or contributions for the remaining participants in the program. In determining whether to approve a proposed contract, the board shall follow the criteria set forth in the regulations adopted by the board pursuant to subsection 4 and may consider the cumulative ~~[impact]~~ ***effect*** of groups that have left or are proposing to leave the program. Except as otherwise provided in this section, the board has discretion in determining whether to approve a contract. If the board approves a proposed contract pursuant to this subsection, the group that submitted the proposed contract is not authorized to leave the program until 120 days after the date on which the board approves the proposed contract.

3. The board shall disburse periodically to the insurer or employee benefit plan with which a group contracts pursuant to this section the total amount set forth in the contract for premiums or contributions for the members of the group for that period but not to exceed the amount appropriated to or authorized for the department, agency, commission or public agency that employs the members of the group for premiums or contributions for the members of the group for that period, after deducting any administrative costs related to the group.

4. The board shall adopt regulations establishing the criteria pursuant to which the board will approve proposed contracts pursuant to subsection 2.

Sec. 6. NRS 331.184 is hereby amended to read as follows:

331.184 The state risk manager shall:

1. Direct and supervise all administrative and technical activities of the risk management division ~~[.]~~ ***of the department of administration.***

2. Determine the nature and extent of requirements for insurance, other than group life, accident , ~~[or]~~ health ***or long-term care*** insurance, on risks of an insurable nature of the state and any of its agencies, the premiums for which are payable in whole or in part from public money.

3. Negotiate for, procure, purchase and have placed, through a licensed insurance agent or broker residing or domiciled in Nevada, or continued in effect all insurance coverages, other than employee group life, accident , ~~[or]~~ health ***or long-term care*** insurance, which may be reasonably obtainable, whether from insurers authorized to transact business in this state or under the surplus lines provisions of chapter 685A of NRS.

4. Conduct periodic inspections of premises, property and risks to determine insurability, risk and premium rate, and submit a written report of each inspection and appraisal, together with any recommendations that appear appropriate, to the administrator of the agency most responsible for the premises, property or risk, and to the director of the department of administration.

5. Provide for self-insurance if the potential loss is relatively insignificant or if the risk is highly predictable and the probability of loss is so slight that the cost of insuring the risk is not a prudent expenditure of public ~~[funds,]~~ ***money,*** or if insurance is unavailable or unavailable at a reasonable cost.

6. Select reasonable deductibles when it appears economically advantageous to the state to do so.

7. Select comprehensive and blanket coverages insuring the property of two or more state agencies when that appears economically advisable.

8. Investigate and determine the reliability and financial condition of insurers, and the services they provide.

9. Minimize risks by adopting and promoting programs to control losses and encourage safety.

10. Perform any of the services described in subsections 2, 3 and 4 for any political subdivision of the state at the request of its managing officer or governing body.

11. Perform any other function of risk management as directed by the director of the department of administration.

Sec. 7. NRS 354.6145 is hereby amended to read as follows:

354.6145 The governing body of any local government may establish an internal service fund in which contributions of employees and the governing body are placed to provide for group life, accident***,*** ~~[and]~~ health ***and long-term care*** benefits on a self-insured basis.

Sec. 8. 1. There is hereby appropriated from the state general fund to the board of the public employees' benefits program the sum of $4,644,000 for the long-term care coverage for state employees and retirees from state employment that the board of the public employees' benefits program is required to provide pursuant to NRS 287.043, as amended by this act.

2. Any remaining balance of the appropriation made pursuant to subsection 1 must not be committed for expenditure after June 30, 2003, and reverts to the state general fund as soon as all payments of money committed have been made.

Sec. 9. 1. There is hereby appropriated from the state highway fund to the board of the public employees' benefits program the sum of $676,800 for the long-term care coverage for state employees and retirees from state employment that the board of the public employees' benefits program is required to provide pursuant to NRS 287.043, as amended by this act.

2. Any remaining balance of the appropriation made pursuant to subsection 1 must not be committed for expenditure after June 30, 2003, and reverts to the state highway fund as soon as all payments of money committed have been made.

Sec. 10. 1. When the board of the public employees' benefits program enters into a contract for long-term care coverage as required pursuant to NRS 287.043, as amended by this act, it shall report to the budget division of the department of administration the amount of the contract. The budget division shall assess state agencies whose budgets include the expenditure of money received from the Federal Government and from any other sources other than appropriation from the state general fund or the state highway fund in an equal amount per employee that is calculated to equal the amount of the contract attributable to those agencies, but not to exceed a total of $1,879,200, and transfer the money to the board of the public employees' benefits program for the long-term care coverage for state employees and retirees from state employment that the board of the public employees' benefits program is required to provide pursuant to NRS 287.043, as amended by this act.

2. Notwithstanding the provisions of NRS 353.220, each agency that receives an assessment made pursuant to subsection 1 shall revise such work programs as necessary to pay the assessment as soon as practicable.

Sec. 11. This act becomes effective upon passage and approval for the purpose of authorizing the board of the public employees' benefits program to perform such administrative tasks as it considers necessary to provide the long-term care coverage for state employees and retirees from state employment that the board is required to provide on January 1, 2003, pursuant to NRS 287.043, as amended by this act, and on January 1, 2003, for all other purposes.

APPENDICES

APPENDIX A

Senate Concurrent Resolution No. 4 – 1999 Legislative Session

Senate Concurrent Resolution No. 4–Committee on Legislative Affairs and Operations

FILE NUMBER 143

SENATE CONCURRENT RESOLUTION—Directing the Legislative Commission to appoint a subcommittee to conduct an interim study concerning long-term care.

WHEREAS, The State of Nevada has experienced unprecedented growth in population, and a large percentage of this growth is attributable to elderly persons who have retired in this state; and

WHEREAS, Persons who are 65 years of age or older and persons with disabilities generally have the highest incidence of chronic illness and the greatest need for long-term care services; and

WHEREAS, The health care needs of this growing segment of the population must be addressed to ensure that their needs are met with the best resources available within this state; and

WHEREAS, There are generally three types of long-term care services available to elderly persons who are unable to live safely alone without assistance, including, community-based care for those who can remain at home with supportive services, group care facilities or assisted living facilities, and nursing home care provided in a medical facility; and

WHEREAS, Spending for long-term care is biased toward institutional care even though several studies have concluded that community-based care offers a cost-effective alternative to institutional care; and

WHEREAS, It is important to determine the availability of alternatives for providing long-term care other than institutionalized care within the State of Nevada, the costs of each alternative type of care, and the advantages and disadvantages of each alternative type of care to ensure that persons in need of long-term care and the agencies of the state and local governments responsible for administering public programs for the elderly are able to make informed decisions concerning health care services; and

WHEREAS, Approximately 80 percent of the funding for nursing homes comes from public sources, including, without limitation, Medicare, Medicaid and county medical assistance programs; and

WHEREAS, Acute care services provided to elderly persons through Medicare are currently not integrated with long-term care services provided to elderly persons through Medicaid; and

WHEREAS, The lack of coordination between Medicare and Medicaid leads to conflicting incentives for payment, shifting of costs between programs and providers, and duplicative administrative provisions that impede good clinical care and efficient delivery of services to elderly persons who are eligible for both Medicare and Medicaid; and

WHEREAS, To be eligible for Medicaid in a nursing home, a single person must possess less than $2,000 in nonhousing assets and must contribute all of his income toward the cost of his care, except for a small allowance for personal needs, which is generally $30 per month; and

WHEREAS, The requirement that persons in this state impoverish themselves to become eligible for long-term care benefits places many persons in need of long-term care in a very difficult situation when determining how to receive the health care services that they need to survive; and

WHEREAS, The growing number of persons in need of long-term care is of grave concern to this legislative body; now, therefore, be it

RESOLVED BY THE SENATE OF THE STATE OF NEVADA, THE ASSEMBLY CONCURRING, That the Legislative Commission is hereby directed to appoint a subcommittee to conduct an interim study of long-term care in the State of Nevada; and be it further

RESOLVED, That the study must include, without limitation:

1. The identification, review and evaluation of alternatives to institutionalization for providing long-term care, including, without limitation:

    (a) Analyzing the costs of the alternatives to institutionalization and the costs of institutionalization for persons receiving long-term care in this state;

    (b) Determining the positive and negative effects of the different methods for providing long-term care services on the quality of life of persons receiving those services in this state;

(c) Determining the personnel required for each method of providing long-term care services in this state; and

(d) Determining realistic methods for funding the long-term care services provided to all persons who are receiving or who are eligible to receive such services in this state;

2. An evaluation of the possibility of obtaining a waiver from the Federal Government to integrate and coordinate acute care services provided through Medicare and long-term care services provided through Medicaid in this state; and

3. An evaluation of the possibility of obtaining a waiver from the Federal Government to eliminate the requirement that elderly persons in this state impoverish themselves as a condition of receiving assistance for long-term care; and be it further

RESOLVED, That any recommended legislation proposed by the subcommittee must be approved by a majority of the members of the Senate and a majority of the members of the Assembly appointed to the subcommittee; and be it further

RESOLVED, That the Legislative Commission shall submit a report of the results of the study and any recommendations for legislation to the 71st session of the Nevada Legislature.

~ 1999 ~

APPENDIX B

Survey of Long-Term Care Insurers by the Division of Insurance

STATE SPONSORED LONG-TERM CARE INSURANCE FOR STATE EMPLOYEES AND RETIREES

Since the March 9, 2000, meeting of this committee the Division of Insurance (Division) has contacted 10 insurers, representing approximately 75% of Nevada's Long-Term Care market share. The Division requested premium estimates from these insurers to provide coverage for 25,153 Nevada State employees and retirees.

Three of the insurers indicated they no longer wrote *group* LTC policies. One insurer reported they would not be interested in competing for a State contract. Another insurer stated they would provide an estimate; however, the Division did not receive one. Through the referral from another insurer, the Division received a quote from one of the nation's largest insurance companies. Although the company is not currently active in Nevada, it specializes in group LTC plans.

The following page lists the quotes and pricing comments provided by four insurers. Please note that the highest estimate is 2.8 times greater than the lowest. The cost of the products can be reduced by limiting the coverage, particularly the 5% compound interest inflation protection benefit.

Attachment 1 was presented at the March 8, 2000, meeting. It is included here to illustrate the structure of the plan upon which insurers based their quotes.

LONG TERM CARE INSURANCE
FOR STATE OF NEVADA EMPLOYEES AND RETIREES

COMPANY	Name	Per Person Annual Premium Estimate	Pricing comments Pricing comments
A	Unum	$630	Will not issue for over 80. Indemnity not expense.
B	CNA Continental Casualty	$393	60 day elimination, Prices not provided for over 90, estimate used.
C	John Hancock	$853	60 day elimination, inflation benefit significantly increased premium.
D	New York Life	$1,102	60% home care. Retirees underwritten.
Average		$745	

Average	Annual Premium x 25,153 (employees & retirees)	=	$18,726,409
Lowest	Annual Premium (Company B) x 25,153	=	$9,885,129
Highest	Annual Premium (Company D) x 25,153	=	$27,718,606

Attachment 1

Follow-up to Nevada Questionnaire on Long-Term Care Insurance

Insurer Name: ______________________

Address: ______________________

Contact: ______________ Telephone number: ________

FAX number: ______________ E-Mail address: ________

Based on the following assumptions, please provide an estimate of the annual premium rate for a **Large Group** (State of Nevada) policy of long-term care insurance.

Assumptions (pricing factors)

1. The Group is composed of current employees and retirees of the State of Nevada. The group size is in excess of 25,000 people with the average age being 49. More detailed demographics are displayed below.
2. Coverage for nursing facility care and home care.
3. 20 day elimination period.
4. 3 years of coverage.
5. 5% compounded interest inflation protection.
6. Coverage of $100/day for nursing facility care and at least 50% for home care.
7. The policy would cover all eligible employees and retirees with no underwriting.

If your pricing is based on factors other than the above factors, please explain below:

____

____

If you have questions regarding this questionnaire please contact Tom Canfield, Nevada Division of Insurance, Life & Health Section at (775) 687-4270 ext. 247. Please return your completed questionnaire to Tom Canfield, Division of Insurance, Life & Health Section at:

FAX (775) 687-3937
E-Mail canfield@govmail.state.nv.us
regular mail: 788 Fairview Drive, Suite 300
Carson City, Nevada 89701-5491

Annual Premium per person

$____________

Demographic Distribution for State of Nevada Employees and Retirees

	< 30	30-35	35-40	40-45	45-50	50-55	55-60	60-65	65-70	70-75	75-80	> 80	**Total**
Male	929	1,107	1,352	1,252	2,048	1,838	1,489	1,011	729	429	296	213	**12,693**
Female	1,108	1,158	1,365	1,661	1,869	1,750	1,375	849	474	366	266	219	**12,460**
Total	**2,037**	**2,265**	**2,717**	**2,913**	**3,917**	**3,588**	**2,864**	**1,860**	**1,203**	**795**	**562**	**432**	**25,153**

APPENDIX C

Benefit Package and Projected Costs for Long-Term Care Insurance Available Through the Public Employees' Benefits Program

STATE OF NEVADA
PUBLIC EMPLOYEES' BENEFITS PROGRAM
400 W. King Street, Suite 300
Carson City, Nevada 89703-4222
Telephone (775) 684-7000 · (800) 326-5496
Fax (775) 684-7028 · TDD (775) 687-3847

KENNY C. GUINN
Governor

JAN MARIE REED
Executive Officer

JAMES P. COSTA
Chairman

OUTLINE FOR LONG TERM CARE LEGISLATIVE COMMITTEE
04/27/00

- All premiums age rated
- Automatic issue for actives
- Retirees' are underwritten
- Maximum age issue is 80
- Option 1
  - Provides a nice plan that the State could buy for all actives at $5 million.
  - We need to offer buy-up options, retiree options to buy at group rate.
- Option 2
  - If you choose to subsidize there are Administrative issues
    1. To fairly do so – set a flat percent (50%)
    2. For actives easy to administer
    3. For retirees medically underwritten. Billed at home. Maximum issue age is 80
- If we subsidize, determining what portion of the $5 million would be used each year is difficult.
  - Unknown actual participation, they still are buying something that costs them money.
  - Age of those who choose to participate will drive costs

- Assume you subsidize 50%, we may assume 25% penetration and leave 75% of employees with nothing. We could assume you spend $2 million and invest 3 but.....

How soon till no appropriation?

1. Investment return
2. Next years penetration
3. Spend on more education? or invest more?

- ➢ If you want just to assist in educating the population:
  - $200,000 per year allows us to create and mail 2 communication pieces.
  - Hold 2 seminars per year throughout the State.
  - This would increase the carrier's efforts by double!
  - Would assist folks to make informed decisions and ensure you had minimally fulfilled your obligation.

LONG TERM CARE

Proposed Voluntary Long Term Care

	Option 1	*Option 2*
Facility Benefit:	$2000 /month	$4000/month
Home Care:	Total Home Care 50% of facility	Total Home Care 50% of facility
Elimination Period:	90 Days	90 Days
Duration:	3 years (facility) 6 years (home)	6 years (facility) 12 years (home)
Inflation Protection:	None	5% Simple
Guarantee Issue:	Active Employees	Active Employees
Estimated Cost:	$5 million annually	$20 million annually

APPENDIX D

California's Caregiver Resource Center (CRC) System and Options for Supporting Informal and Family Caregiving

California's Caregiver Resource Center (CRC) System

Prepared by
Lynn Friss Feinberg, M.S.W.
Project Director, Statewide Resources Consultant, Family Caregiver Alliance
for
Legislative Committee to Study Long-Term Care in Nevada
April 27, 2000

Started as a grassroots effort, California's statewide system of Caregiver Resource Centers (CRCs) is the culmination of one community's determination to respond to a major social need. Over the past 16 years the CRC system has had a profound impact in three areas:

1. Demonstrating a successful and cost-effective model for assisting middle income family caregivers of cognitively impaired adults, without regard to income, disease, specific diagnostic, or age eligibility categories;
2. Developing and providing a range of family support services and program development for a population believed to be too difficult and costly for public dollars and systems; and
3. Acknowledging the family's role and consequent needs as a result of a loved one's brain disease or disorder.

Background and History

Before the establishment in 1976 of a small volunteer task force in San Francisco, no national, state or local entity was addressing the needs of families and caregivers of *all* adults with cognitive impairments. The task force was responsible for bringing the chronic care problems of middle income Americans with adult-onset brain diseases and disorders out of obscurity and into the public light.

Soon known as the Family Survival Project, the task force sought a sponsor. Former Assemblyman Art Agnos drafted legislation (AB 1043) to establish a pilot project to develop a community-based program of family support services in the San Francisco Bay Area. The legislation (Chapter 1058) was enacted in 1979 and program operations began in 1980. In 1982, the California Department of Mental Health awarded additional funding to the Family Survival Project (now the Family Caregiver Alliance) to establish an information and technical assistance clearinghouse statewide.

At the end of 1983, the pilot project was deemed a success. In early 1984, former Assemblyman Art Agnos introduced legislation (AB 2913) to accomplish two major goals:

1. To replicate Family Caregiver Alliance's (FCA) pilot program in California's major geographic regions through the establishment of resource centers that would provide a single-entry information network; and
2. To establish the role of Statewide Resources Consultant. FCA won the contract with the state to oversee aspects of the law that were statewide in nature.

Statewide Response to Long-Term Care Needs of Family Caregivers

On September 30, 1984 then Governor George Deukmejian signed into law the legislation, known as *The Comprehensive Act for Families and Caregivers of Brain-Impaired Adults* (Chapter 1658, Statutes of 1984, as amended by Chapter 775, Statutes of 1988 and Chapter 7, W&I code, Section 4362 et al., 1992). With the passage of this law, California became the first state in the nation to address a new significant client: the family caregiver who must take responsibility for the 24-hour needs of cognitively impaired adults suffering from Alzheimer's disease, stroke, Parkinson's disease, traumatic brain injury, Huntington's disease, and other brain diseases and disorders that strike adults.

Within four years, the California Department of Mental Health (DMH) was to contract with nonprofit community agencies to replicate the model program developed by FCA and establish statewide services. By the end of Fiscal Year 1988-89, 11 Caregiver Resource Centers (CRCs) were in place throughout California. Additionally, the law established a Statewide Resources Consultant (SRC) role at FCA to operate a statewide clearinghouse on caregiving issues and cognitive impairment, manage the statewide CRC database, and to provide coordination, consultation, training, research, technical and program assistance to the CRCs and other organizations.

The Range of Caregiver Support Services

CRCs provide a range of caregiver support services to deter institutionalization, allow caregivers to maintain a normal routine and promote quality care. Services include:

Specialized information, advice and referrals to help families understand the nature of a brain disease, prognosis and how to cope with functional and behavioral problems associated with brain disorders. Basic information is also provided on legal and financial issues, long-term care planning, community resources, and caregiving issues.

All family caregivers who require assistance beyond basic information receive a comprehensive, uniform **assessment** administered at the family caregiver's home. Through the assessment process CRC staff are able to record specific caregiver problems to assist family caregivers in determining the most appropriate type and mix of services to meet their needs. Assessment seeks to determine: the care recipient's functional and behavioral problems and the impact on the caregiver; perceived burden, that is the extent to which caregivers' personal, social and emotional well-being is affected by caregiving; and the impact of caregiving on the family caregiver's physical and mental health. The assessment tool is also used to collect demographic data for a statewide database on caregivers and adults with cognitive impairment. Caregivers are reassessed at six-month intervals as long as the need for assistance continues.

Family Consultation consists of individual sessions and telephone consultations with trained staff to explore courses of action and care options for caregivers. CRC staff, called "Family Consultants," assist families in making difficult decisions, problem-solving and coping with stress. Through family consultation, caregivers learn how to manage difficult behaviors in the person they care for, how to make their home safe for their relative, and practical skills (e.g., lifting or bathing). Caregivers also learn how to cope with their frustration, anger or isolation.

For those caregivers shown to have high levels of depressive symptoms, CRCs provide **short-term counseling** to address psychosocial issues related to the caregiving role, such as feelings of hopelessness, guilt or anxiety. Depending on the needs of the family caregiver, licensed clinicians can provide up to six sessions of individual, group or family counseling.

CRCs sponsor a range of **support groups,** such as concurrent groups for individuals with early-stage dementia and their caregivers, and an on-line caregiver support group through the FCA website. In addition, several CRCs conduct **psychoeducational groups** which are structured eight or ten-session classes to teach caregiver skills to manage anger or frustration.

One-time **legal consultations** are used to help families sort through complex legal and financial issues including surrogate decision-making and advance directives, conservatorship, estate planning and other matters. CRCs subcontract with attorneys specializing in elder care and estate planning.

Respite care for families offers financial assistance for a flexible array of respite options to give families "a break" from constant care demands. Monthly respite vouchers are provided through subcontracts with local home care agencies, adult day programs, or facilities offering overnight respite. Or, families may choose the "direct pay" option, where they receive a cash subsidy (capped at $425 per month[1]) to hire an independent provider to provide in-home respite care. The CRC program

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[1] In practice, CRCs cap this service at $250-$350 per month.

maximizes consumer choice by allowing families to select the option(s) which best fit their needs. Several CRCs across California also sponsor periodic weekend respite "camps" and retreats. To be eligible for respite assistance, the caregiver must live with the care recipient and cannot be eligible for Medicaid. A copayment schedule, uniform for all CRCs, is used for respite services and takes into account both family income and family size.

Profile of the Family Caregivers and Adults with Cognitive Impairment[2]

Family Caregiver

- The typical caregiver served by the CRCs is female, married, 60 years old, and has been caring for her husband who has had Alzheimer's disease for an average of 5.4 years.
- Caregivers range in age from 18 to 103 years. One in five (20%) are at least 75 years of age.
- Wives comprise the largest group of caregivers (34%), followed by adult daughters/in-law (32%), husbands (14%), sons/in-law (8%), parents (5%), siblings (2%) or others (5%).
- Nearly half (48%) of the families served have median household incomes under $30,000 (1998 dollars).
- Over half (55%) of the caregivers under age 65 are employed outside the home, juggling work and caregiving responsibilities. Nearly one in three (29%) caregivers under age 65 – those most likely to be in the labor force – quit their jobs to give care.
- Family caregivers report providing an average of 80 hours per week of care to their cognitively impaired relative, or more than 11 hours per day.
- Caregiving exacts an enormous emotional and physical toll on families. Among those caregivers assessed at CRCs across the state, six in ten (60%) show clinical symptoms of depression. Nearly one in three (29%) rate their own health as fair to poor, and more than four in 10 (44%) feel highly burdened by their caregiving responsibilities.
- The top five needs of family caregivers are for emotional support (90%), respite care (82%), behavior management strategies (45%), legal help (37%), and placement assistance (21%).

Adult with Cognitive Impairment

- Adults with cognitive impairment range in age from 18 to 102 years, with an average age of 74 years. Nearly two thirds (62%) are 75 years of age and older.

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[2] Source: CRC Uniform Assessment Database, 1998 (N = 2,348 California caregivers)

- Two out of three (66%) have a dementing illness, and most (82%) live at home with a spouse or other relatives.

- On average, the adults with cognitive impairment have 14 difference functional and behavior problems (e.g., trouble concentrating, wandering), suggesting heavy care needs. Nearly half (48%) require assistance with three out of five activities of daily living (e.g., bathing, dressing, eating).

Funding, Service Utilization and Cost Effectiveness

The total appropriation from the state's General Fund for the 11 CRCs and the SRC is currently $9.247 million. In FY 98-99 the CRC system received a $4 million augmentation to expand and increase services to family caregivers. Twenty five percent of state funding for the 11 CRCs was spent on purchase of service respite care in FY 98-99 ($2.142 million). CRC family clients receive a variety of services tailored to meet individual needs and circumstances. Based on data from FY 98-99:

- The top four services used were (in order of frequency): family consultation, follow-up information and referral, in-home respite assistance, and support groups.

- Over 11,000 individuals were served by California's CRCs.

- The average annual service use per client across all CRC core services was 36.3 hours.

- A total of 1,670 families received an average of seven hours of respite care per week from of the 11 CRCs.

- Without respite care, many families would be faced with placing their relative in a nursing home. The average monthly cost of nursing home care for a Medicaid patient (Medi-Cal in California) is $2,663, nearly *11 times* the $245 average monthly cost of CRC respite services (including the average $16 per month co-payment contributed by family clients).

- As of March, 2000 nearly 3,000 California families were on CRC respite waiting lists statewide. The average length of time clients must wait for CRC respite assistance is 21 months.

Today, family-related matters are systematically addressed which, nearly 25 years ago, were thought to be too private for a public response. Sixteen years after the passage of Chapter 1658, California's CRC system continues to provide an array of family-based services and to use their collective voices to champion the cause of long-term care for cognitively impaired adults, families and caregivers.

Options for Supporting Informal and Family Caregiving

A POLICY PAPER

The American Society on Aging

August 1997

Funded by The Pew Charitable Trusts

Options for Supporting Informal and Family Caregiving

A POLICY PAPER

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EXECUTIVE SUMMARY

One of the major challenges of the twenty-first century will be to provide accessible, affordable, and quality long-term care to the growing numbers of frail older people. Currently, federal cutbacks in health and human services are having a profound effect on the ability of states to develop long-term-care systems that are responsive to consumer needs. States must now assume greater responsibility for shaping the financing, eligibility, coverage, and delivery systems that provide long-term care.

At the same time, policymakers are beginning to recognize the critical role of families in the provision of long-term care and are addressing family-related matters that historically were thought to be too private for a public response. In fact, decision makers—in both the public and private sectors—are becoming personally affected by caregiving because they themselves are providing care to older parents, spouses, and other relatives and friends.

Policymakers have a strong interest in maintaining the strength and durability of family and informal caregiver networks as the primary providers of long-term care. Caregiver support is increasingly becoming a priority for many state governments because of the high costs of *not* taking any action.

The motivation to bring about change is present in every state, driven by economics, values, and, of course, politics. States have two main incentives for providing caregiver support and expanding home and community-based care options as part of a long-term-care system: The first is a matter of *values*, the strong preference of older people to remain at home, in their communities, with their families, for as long as possible. The second is driven by *economics*, the desire to control the rising costs of long-term care, particularly for nursing homes.

While strengthening the role of families in long-term care can produce cost savings for states and is generally the preferred option expressed by individuals, emphasizing this role also can place severe strain on family caregivers. Therefore, it is crucial in any long-term-care strategy to provide support services for caregiving families.

This paper provides a common starting point for both policymakers and consumer advocates to shape a state policy agenda that recognizes and supports the central role of families in the provision of long-term care to frail and disabled older people. The paper highlights key issues and facts about family and informal caregivers and makes the case that states should want to invest in programs that support and strengthen family care. Key strategies for action by both state policymakers and advocates are summarized to assist in the development of family caregiver support policies.

Families, Not Institutions, Are The Major Providers Of Long-Term Care

- Families provide 80 percent of all care at home and are commonly referred to as "family caregivers."
- The term *caregiver* refers to anyone who provides assistance to someone else who needs it to maintain an optimal level of independence.
- The availability of family caregivers is often the deciding factor in whether a loved one can remain at home or must move to a more costly nursing home.

Nearly All Public Opinion Polls Show That Long-Term Care Is A Powerful Family Issue

- Polls show that the majority of Americans support a publicly financed long-term-care program that includes home- and community-based options as well as nursing home care.
- Families worry about the catastrophic costs they could face if a family member should need long-term care.
- While older people overwhelmingly prefer homecare to nursing home care, it is the cost of nursing home care that most affects the economic security of the family.

Demographic And Social Trends Will Affect Family Care In The Future

- Long-term-care costs may more than double in the next 25 years. At the same time, the population is rapidly aging, and the American family is changing.

- By 2030, when the baby boomers reach age 65, approximately one in five Americans will be at least 65—or about 70 million older people, more than *twice* their number in 1995.

- Five social trends may affect the supply of caregivers in the future: (1) increasing divorce and remarriage rates; (2) increasing geographic mobility; (3) decreasing family size; (4) delayed childbearing; and (5) more women in the workplace.

Research Shows That Caregiving Often Exacts A Heavy Emotional, Physical, And Financial Toll

- Many caregivers experience immense stress and feelings of burden, high rates of depression, and feelings of anger and anxiety.

- Caregiving can adversely affect one's physical health and ability to continue providing care—leaving two impaired persons, rather than one.

- The emotional and physical strain of caring for a frail older relative is often exacerbated by worries over paying for care, particularly for nursing homes.

- The financial impact of caregiving takes a particular toll on family members when it affects their ability to work. Research has shown that some caregivers must quit their jobs to give care, while others experience increased absenteeism, lower productivity at work, lost career opportunities, and loss of future earnings.

The Costs of Care Are an Economic Burden for Most Families

- Medicare does not cover long-term care, private insurance is expensive and limited in coverage, and out-of-pocket costs are high.

- Middle-class families are hit the hardest.

- An institutional bias still drives long-term-care spending.

- Despite older peoples strong preferences for home and community-based services, long-term-care dollars are overwhelmingly spent on nursing home care.

- The cost of nursing home care—averaging about $40,000 a year per person care for—is beyond the means of most people.

Policymakers Are Beginning To Recognize The Critical Role Of Families In The Provision Of Long-Term Care As A Way To Help Control Rising Costs Of Care

- Four main policy strategies currently support caregiving families: (1) direct services (e.g., respite care); (2) financial incentives and compensation, including direct payments and tax incentives; (3) the cash-and-counseling model; and (4) employer-based mechanisms.

- Research has shown that most caregivers prefer services to dollars.

State-Funded Caregiver Support Programs Are Diverse And Dependent Upon Individual State Priorities And Resources

- No comprehensive list of state-funded caregiver programs exists because of the fragmentation of services and variations in eligibility, mode of delivery, and scope of services.

- Respite care is the service most typically funded by state governments.

- Two successful programs stand out in terms of scope, service package, and funding; these can be replicated by other states: Californias Caregiver Resource Centers and Pennsylvania's Family Caregiver Support Program.

In the near future, the demands placed on family and other informal caregivers are likely to escalate, affecting nearly every American family. This paper shows that *caregiving is not just an aging issue, it is a family issue and a policy issue*. It is vitally important for consumer advocates to seize the policy agenda and urge states to develop family caregiver support policies to protect families from the financial and emotional bankruptcy that often is the cost of long-term care.

Finally, advocates should arm themselves with the facts. They should use this report and should focus attention on the two major recommendations for state action:

- The need to recognize and strengthen the central role of families in the provision of long-term care.

- The need to shift the focus and incentives in long-term care away from institutional care to home and community-based care.

Strengthening the role of families is both *cost-effective and compassionate public policy.* We can no longer afford not to act—our own future and that of our parents, grandparents, and children depends on it.

INTRODUCTION

As we rapidly approach the twenty-first century, Americans are increasingly being faced with the challenges of providing long-term care to the growing numbers of people with chronic illnesses and disabling conditions. The future looks very unlike the past. Indeed, a number of societal dynamics—demography, healthcare financing, family structure, and medical advances—have pushed long-term care to center stage at the national, state, and local policymaking levels.[1]

Who are the major providers of long-term care in the United States? Contrary to popular belief, *families, not institutions, are the major providers of long-term care, providing some 80 percent of care.* Often at great sacrifice, families strive to keep an impaired relative at home, avoiding more costly institutional care. Indeed, the availability of informal and family caregivers is often the deciding factor determining whether an impaired individual can remain at home or must move to more costly nursing home care.

Research has shown that about 90 percent of dependent community-dwelling older people receive care from family, friends, and neighbors; about one-quarter use a combination of formal* and informal† care; and only 9 percent rely exclusively on formal care.[2]

Public and private expenditures for long-term care—now estimated at more than $108 billion—are projected to more than double in the next twenty-five years.3 The greatest population growth will be for those aged 85 and over—the most rapidly growing elderly age group and those most in need of long-term care.

Long-term care often involves the most intimate aspects of peoples lives: personal hygiene, getting dressed, using the bathroom. Other needs may involve household tasks such as preparing meals or using the telephone. Most people who need long-term care live at home or in the community. Of the 12.8 million Americans estimated to need long-term-care assistance, only about 2.4 million live in institutional settings such as nursing homes.[3] Most, but not all, are older people: Approximately 57 percent are people aged 65 and older (7.3 million); 40 percent are working-age adults aged 18 to 64 (5.1 million); and 3 percent are children under age 18 (400,000).[3]

The term *family caregiver* is now part of the American vocabulary, in large part because of the aging of the population and the increased attention to health and long-term-care issues in the mass media. *Caregiving, however, is not just an aging issue; it is a family issue and a policy issue.*

Today, policymakers are addressing family-related matters that historically were thought to be too private for a public response. In fact, decision makers—in both the public and private sectors—are becoming *personally affected* by caregiving because they themselves are providing care to older parents, spouses, and other relatives and friends. By the year 2005, baby boomers will become a majority of those aged 50 to 74. The baby boom leaders in their 50s and 60s will bring with them a better understanding of todays family issues.[4]

At the same time, the American family is changing rapidly. Increasing numbers of women in the labor force, increasing geographic mobility, high incidence of divorce and remarriage, and delayed childbearing may strain families' capacity to provide care in the twenty-first century. These dramatic trends mean not only that there will be fewer family caregivers available, but that those who do care for disabled older people will have even less support from other family members than is the case now.[5]

Although it has been suggested that families might reduce their caregiving efforts if publicly funded long-term-care services were available, there is little evidence to support this claim.[6] Caregiver support is becoming a priority for many state governments because of the high costs of not taking any action. Several state programs now formally acknowledge the goal of reducing caregiving strain and complementing informal care so that families are able to continue providing long-term-care assistance.

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* *Formal care* is defined as care provided by professionals, paraprofessionals, or volunteers associated with a service system who provide care at home, in community agencies, or in institutions or residential facilities.

† *Informal care* is defined as care provided without pay by family, friends, or neighbors.

This paper provides a common starting point for consumer advocates to shape a state policy agenda that recognizes and supports the central role of families in the provision of long-term care to frail and disabled older people. The paper highlights key issues and facts about family and informal caregivers, summarizes the state-of-the-art knowledge about caregiver support programs and emerging trends, and makes the case for why states should want to invest in programs that support, rather than supplant, family care.

Talking Points

- Families, not institutions, are the major providers of long-term care, providing some 80 percent of care.
- The availability of family caregivers is often the deciding factor in whether an individual can remain at home or must move to a more costly nursing home.
- Long-term-care costs may more than double in the next twenty-five years. At the same time, the population is rapidly aging, and the American family is changing.
- Caregiving is not just an aging issue; it is a family issue and a policy issue.
- Caregiver support is becoming a priority for many state governments because of the high costs of not taking any action.
- Advocates can and must make the following case: To support and strengthen the role of families and other informal caregivers is *cost-effective* and *compassionate* public policy.

WHAT THE AMERICAN PUBLIC THINKS ABOUT LONG-TERM CARE: A POWERFUL FAMILY ISSUE

Polls show that the majority of Americans support a publicly financed long-term-care program that includes home- and community-based options as well as nursing home care. Indeed, how Americans view long-term care influences how they vote.[9] Close to half (46 percent) are more likely to vote against their member of Congress if he or she votes for health reform legislation without long-term care.[7] Nearly seven out of ten Americans (69 percent) prefer a publicly financed long-term-care program similar to Social Security or Medicare.[8]

Mrs. G, a 58-year-old manager in the State Department of Transportation, has cared for her 83-year-old father, a stroke survivor, in her home for the past three years. Last summer she took a leave of absence from her job to care for her father after he fell and broke his hip. Her immediate fear was that Dad would have to go into a nursing home—not what she or her father wanted. The prospect was both heartwrenching and a financial nightmare. However, Mrs. G was lucky enough to find an adult day program and caregiver resource center in her community to help keep her father at home. With this support, Mrs. G has been able to return to work and continue caring for her father.

Survey after survey and nearly all public opinion polls show that long-term care is a major issue of concern for American families. A 1996 national survey found that nearly 90 percent of Americans believe that providing long-term care is a *big problem*, and 59 percent have a family member or friend who has needed long-term care. Of these respondents, 53 percent provided hands-on care and 25 percent provided financial assistance to help pay for that care. This survey also found that long-term care is an intergenerational issue, touching younger as well as older people. Fifty-two percent of respondents born after 1965 have a friend or relative who needs long-term care. Of these younger people, 44 percent have provided hands on care, and one in five has provided financial help.[9]

Another recent survey found that one in five Americans over age 50 are at high risk of needing long-term-care services during the next twelve months.10 Families worry about the catastrophic costs they could face if a family member should need long-term care. In a 1997 national survey, 69 percent said they are worried about paying for long-term care.[11] In a 1993 Gallup Poll, two out of three respondents said that long-term-care costs were a major concern for the future.[12] While older people overwhelmingly prefer homecare to nursing home care, it is the cost of nursing home care that most affects the economic security of the family. When told of the yearly cost of nursing home care, 72 percent recognize that the cost is beyond their means.[13] Four out of ten (42 percent) would not be able to pay for one year of nursing home care at a cost of $40,000 a year, and another one-third (34 percent) would run out of money in two years.[9]

These public opinion polls and surveys point to two overriding concerns. First, Americans who need long-term-care services are likely to face serious financial difficulty in paying for that care. Second, limited public funds pay for home and community-based services, which most older people prefer. Clearly, long-term care is a powerful family issue. Action must be taken to do the following:

- Recognize and strengthen the central role of families in the provision of long-term care.

- Shift the focus and incentives in long-term care away from institutional care in nursing homes to home and community-based care.

PROFILE OF INFORMAL AND FAMILY CAREGIVERS

Here is a profile of informal and family caregivers:

Definition

The term *caregiver* refers to anyone who provides assistance to someone else who needs it to maintain an optimal level of independence.[14] Families provide the vast majority of care and are commonly referred to as "family caregivers." Caregivers may or may not live with the care recipient. The way the term *family caregiver* is defined by policymakers affects significantly the type of services provided and the cost of providing them.[15] For example, some state-funded respite programs limit eligibility to family members living with the person needing care (e.g., a spouse). In this case, family members who assume major care responsibilities but do not live with the impaired person (e.g., adult children) are excluded from respite assistance.

Prevalence

Estimates vary on the number of caregivers in the United States, depending on the definition used:

- Nearly one out of every four U.S. households (23 percent, or 22.4 million) provides care to a relative or friend aged 50 or older.[16]

- About 15 percent of U.S. adults care for a seriously ill or disabled family member.[17]

- About 13.3 million people—7 percent of U.S. adults—are spouses or adult children of disabled older people and have the potential responsibility for their care. Of these, about 85 percent (or 11.4 million) are adult children.[18]

- About 7.3 million people are informal caregivers, defined as spouses, adult children, other relatives, and friends who provide unpaid help to disabled older people living in the community. Of these, about three-fifths (or 4.2 million) are spouses and adult children, and the remaining two-fifths (3.1 million) are other relatives, friends and neighbors.[18]

Who Are The Caregivers?

Gender. Caregiving is largely a women's issue. Nearly three out of four (72 percent) caregivers are female.[19]

Age. The average caregiver is 57 years old. However, more than one in three caregivers are older adults themselves: one quarter are between 65 and 75 years old, and another 10 percent are at least 75 years of age.19 One recent national survey found that 46 was the average age of caregivers of people 50 years of age and older.[16]

The median age of employed caregivers of the elderly is 45 years old; 28 percent are under 35 years of age and 15 percent are at least 65 years old.[20]

Women in their 50s are more likely than older women to experience two or more caregiving episodes. These women are more likely than women in their 60s and 70s to live with the care recipient.[21]

Relationship to care recipient. An estimated 85 percent of caregivers are relatives of the care recipient.[20]

In general, if the care recipient is married, the primary caregiver will be the spouse; otherwise adult children, typically adult daughters, will assume the caregiving role.[22]

Nearly 23 percent of caregivers are wives, 13 percent are husbands, 29 percent are adult daughters, and 9 percent are sons. The remaining 26 percent are siblings, grandchildren, other relatives, and friends or neighbors.[19]

Older generations also care for younger generations. Increasing numbers of mid-life and older women have primary responsibility for their grandchildren and great-grandchildren. Differences are evident by cultural group, with 12 percent of African American children living with grandparents, compared to 5.8 percent of Hispanic children and 3.6 percent of white children.[17]

Living arrangements. Nearly three-fourths of caregivers live with the care recipient.[19]

Between 20 percent and 40 percent of caregivers are in the "sandwich generation," with children under age 18 to care for in addition to their disabled older relative.[23]

One-third of primary caregivers assume major care responsibilities because they live closer to the care recipient than other family members.[23]

Nearly 7 million Americans, or 3.5 percent of the U.S. adult population are long-distance caregivers (those who live a distance of one hour or more from the older adult needing assistance). The average travel time for these caregivers to reach their relative is four hours.[24]

Ethnicity. In the coming decades, the older population and their families in the United States will be more ethnically diverse.

Within the United States, recent research focusing on ethnic diversity among caregivers indicates both similarities and differences in the caregiving experience. It is clear, however, that across all ethnic groups family care is the most preferred and relied upon source of assistance.[17]

Growing evidence indicates that differences among African American, Asian, Hispanic, and white caregivers are less pronounced than differences within the groups. Similarly, research suggests that group differences may be more related to the length of time since immigration than to specific ethnic background.

Employed caregivers. Between one-third and nearly two-thirds of caregivers are also employed outside the home.[17,16] This trend is likely to continue as women continue to enter the labor force.

Between 7.4 percent and 11.8 percent of the workforce is involved in providing care for an older person.[25]

An estimated 9 percent of caregivers quit their jobs to provide care. For adult daughters, this number rises to 12 percent.[19]

Caregiving tasks. Unlike most formal service providers, families provide care at night, over weekends, and on demand. Studies have found that from 53 percent to 69 percent of people with dementia are out of bed most nights—waking the caregiver and requiring supervision.[26,27]

Two-thirds (66 percent) of caregivers assist older people with activities of daily living (ADLs)[*] Of these, 19 percent assist with one daily living task, 15 percent assist with two, and one-third (33 percent) assist with three or more.[20]

Three out of four caregivers help with grocery shopping, transportation, and housework, and about 66 percent prepare meals or manage finances. Half help administer medications.[20] These tasks are known as instrumental activities of daily living (IADLs).[†]

Time spent caregiving. The duration of caregiving can last from less than a year to over 40 years. The majority of caregivers provide unpaid assistance for one to four years; 20 percent however provide care for five years or longer.[19]

Eighty percent of caregivers provide unpaid assistance seven days a week.19 On average, caregivers provide personal care assistance and household maintenance chores for 18 hours a week. Some 48 percent give care for eight hours or less, while 21 percent provide help for nine to 20 hours per week, and 14 percent give care for 21 hours per week or more. Eleven percent provide round-the-clock care.[16]

Time spent caregiving varies by type of impairment. One statewide study of caregivers of cognitively impaired adults found caregivers spending an average

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[*] Activities of daily living (ADLs) include bathing, eating, walking, and other personal care activities.

[†] Instrumental activities of daily living (IADLs) include preparing meals, grocery shopping, using the telephone, managing money, taking medications, doing housework, and other activities of independent living.

of 13 hours per day providing care—more than a full-time job outside the home.[27]

Who Is Being Cared For?

Almost 100 million people in the United States have one or more chronic conditions.[28]

Nearly 40 percent of older people living in the community—12 million people aged 65 and over—are limited by chronic conditions. Of these, three million (or 10 percent of older people) are unable to perform ADLs. Additionally, an estimated 1.5 million older people needing long-term care live in nursing homes.[28]

> "While you love them more than anything in the world, it's a seven-day, twenty-four-hour-per-day job. You give up almost everything—seeing friends, part-time job, just being able to jump in the car and do household errands. Your life is never your own again."
>
> *(67-year-old wife caring for her husband, who has Parkinson's disease)*

Long-term-care needs increase dramatically with age. The need for assistance with at least one ADL is under 3 percent for those less than 65 years of age but increases dramatically with age from 9.3 percent for ages 65 to 69 years, to 10.9 percent for ages 70 through 74 years, 18.9 percent for ages 75 through 79 years, 23.6 percent for ages 80 through 84 years, and 45.4 percent for those 85 years of age and older.[29]

An estimated 10 percent of people 65 years of age and older, and nearly half of those 85 and older, suffer from Alzheimer's disease. People with Alzheimer's disease or another dementing illness can never safely be left alone and often require round-the-clock care.[5]

Demographic And Social Trends Affecting Family Care In The Future

Various demographic and social trends will affect family care in the future.

Demographic trends. The magnitude of the aging of America is enormous and will challenge every sector of our society by the middle of the twenty-first century. At the turn of the century in 1900, 75 percent of the U.S. population died before the age of 65. Today, over 70 percent of the population live beyond age 65.29 *At every age, people are likely to have more older people in their families today than in the past.*[30]

The older population, that is, those people 65 years of age or older, numbered 33.9 million in 1996, or 12.8 percent of the U.S. population—about one in every eight Americans.31 This population will continue to grow, with the most rapid increase expected between the years 2010 and 2030 when the baby boom generation reaches age 65. By 2030, one in five Americans, or an estimated 70 million, will be at least 65 years of age—more than *twice* the number in 1995.[31]

Minority populations are projected to increase to 25 percent of the older population in 2030, up from 13 percent in 1990. Between 1990 and 2030, the white population is estimated to increase by 91 percent, compared with 328 percent for older minority groups, including Asians (643 percent), Hispanics (570 percent), African Americans (159 percent), and American Indians and other groups (294 percent).[32]

Not only is the older population increasing, but it is rapidly getting older. In 1996, people reaching age 65 had an average life expectancy of an additional 17.7 years (19.2 years for females and 15.5 years for males).[31] Those people 85 years of age and older are the most rapidly growing elderly age group. In 1996 those 85 and older numbered 3.8 million, or 10 percent of the older population.[31] *By 2040 there will be almost four times as many people over 85 as there are today.*[32]

As the population ages, the number of people with chronic conditions requiring long-term care will increase dramatically. Over the next 25 years, the number of people with chronic impairments is estimated to increase by 35 million people to 134 million Americans.[28]

One of the cruelest chronic conditions of old age is Alzheimer's disease, a progressive neuro-degenerative disease. The prevalence of Alzheimer's disease and related dementias rises dramatically with age, particularly for those aged 85 and older. Today, about 4 million Americans are afflicted with Alzheimers disease. It is estimated that by the year 2050, *more than three times* as many people—or 14 million Americans—could have this devastating disease.[33]

Social trends. A number of changing patterns of family life may affect the continued ability of families to provide care for impaired older family members. Among the trends are the following: (1) increasing divorce and remarriage rates; (2) increasing geographic mobility and more long-distance caregivers; (3) decreasing family size; (4) delayed childbearing, which may increase the size of the "sandwich generation," that is, those caring simultaneously for children and their parents or other older relatives; and (5) increasing female labor force participation. Despite these trends, which could affect the potential pool of family members available to provide care, *caregiving is likely to remain an intrinsic part of the experience of American families well into the twenty-first century.* Research has shown that even when the primary caregiver is no longer able to provide care, another relative, usually someone from the same or the next generation, steps in to take over caregiving responsibilities.[34]

Ultimately, social trends affect the *supply* of caregivers, while demographic trends increase the *demand* for caregiving as the population ages and becomes more likely to need long-term care. In the twenty-first century, the demands placed on family and other informal caregivers are likely to intensify dramatically, affecting nearly *every* American family.[28]

Talking Points

- Almost 100 million people in the United States have one or more chronic conditions. Over the next twenty-five years, this number is expected to increase to 134 million Americans.

- Nearly one in four U.S. households is involved in caring for a relative or friend aged 50 or older.

- Caregiving is largely a women's issue. Some 72 percent of caregivers are female, mostly wives and adult daughters.

- The average age of a caregiver is 57. More than one in three, however, are older themselves (65 years of age and older).

- Caregiving can last from less than a year to over forty years. Some 80 percent of caregivers provide unpaid assistance seven days a week.

- People are likely to have more older people in their families today than in the past.

- By 2030, when the baby boomers reach age 65, one in five Americans will be at least 65, for a total of about 70 million older people, more than twice the number in 1996.

- Five social trends may affect the supply of caregivers in the future: (1) increasing divorce and remarriage rates; (2) increasing geographic mobility; (3) decreasing family size; (4) delayed childbearing; and (5) more women in the workplace.

- In the twenty-first century the demands placed on family and other informal caregivers are likely to escalate, affecting nearly *every* American family.

Mr. and Mrs. J live in upstate New York. Mr. J is a 74-year-old retired painter who quit his job five years ago to care for Mrs. J, age 66, who has Parkinson's disease. They had to sell the house that they had lived in for twenty-five years and move to an apartment because Mrs. J could no longer climb the stairs. They get little outside help; only someone who comes to clean once a week. Their two adult children live in California. While the children call frequently and each visits about three times a year, they are busy with their own careers and young children. Mr. J suffers from high blood pressure. His greatest worry is that something will happen to him and he will no longer be able to care for his wife.

EFFECTS OF CAREGIVING: WHAT DOES RESEARCH TELL US?

Caregiving affects people in different ways. No two caregivers are alike. However, there are common themes in the way caregiving affects the family and other informal caregivers. Research has shown that providing care to older people often exacts a heavy emotional, physical, and financial toll. Caring for an older relative is not the same as childrearing, since children usually continue to gain independence and self-sufficiency. In contrast, family caregivers of older people face the painful, inevitable deterioration of their loved ones, leading ultimately to greater debilitation or death. Prolonged caregiving has negative effects on the emotional and physical health of caregivers, even though it is willingly undertaken and often a source of great personal satisfaction.[17,35]

Emotional Toll

A body of research has shown that many caregivers are emotionally strained by the responsibilities of providing long-term care to a disabled older relative or friend. Caregivers experience a sense of burden[36] and very high rates of depression (up to 68 percent).[27,37] Family caregivers are more depressed than age-matched controls in the general population[38] and are more apt to feel anger and anxiety.[37,39] A number of studies have shown that caregiver emotional distress increases as the care recipient's level of functional impairment becomes more severe.[17,40,41] Disruptive behaviors associated with dementia are particularly distressing for families.[5,27]

Not surprisingly, the stresses of caregiving are more severe for those, like the spouse, who live with the care recipient. While men and women are affected similarly, women appear to experience higher levels of distress.[42,43]

Physical Toll

Caregiving often leads to increased susceptibility to health problems.[40,44] For example, heavy lifting and turning, frequent bedding changes, dressing, bathing and helping the person use a toilet or dealing with incontience can put physical strain on caregivers.45 One-third of caregivers report themselves to be in fair-to-poor health, a much higher percentage than the general population.[5] The majority of family caregivers are over the age of 50 and at risk for experiencing physical health problems of their own.[19,46] Studies show lowered immune function[48] and nearly double the normal use of psychotropic drugs.[47] Recent research suggests that caregivers physical health problems are the result of ongoing stresses from their caregiving role.[49]

Financial Toll

The emotional and physical strain of caring for a frail older relative is often exacerbated by worries over paying for care. Some caregiving spouses forego paying out-of-pocket for any help at home because they are anxious and concerned about how they will pay for extended care in the event their husband or wife requires costly nursing home care. Other older spouse caregivers who live on fixed incomes cannot afford to pay for help, even though that help could make the essential difference in their ability to continue care.[5] Studies show that about one-third of caregivers report family incomes in the poor to near-poor range, and a sizable number of families have adjusted family incomes below poverty level—more than families of the same age group with no caregiving responsibilities.[5,50,51]

The financial impact of caregiving is most apparent for family caregivers when it affects their ability to engage in and perform effectively at work. Between one-third to nearly two-thirds of caregivers now work outside the home.[19,16] This trend is expected to increase as a result of more women in the labor force and longer life expectancies.[52] In California, 43 percent of family caregivers under the age of 65—those most likely to be in the labor force—juggle work, family, and caregiving responsibilities. Among those caregivers not working, 28 percent had quit their jobs to provide care for a family member.[53]

Studies have shown that employees caring for older relatives experienced more conflict between the competing demands of work and family than did co-workers who did not have caregiving responsibilities.[54,55] Negative effects have included time lost from work (absenteeism, taking time off without pay, reducing work hours), lower productivity while at work, quitting a job to provide care, lost career opportunities, and lower future earnings.[56]

Talking Points

- Caregiving exacts an enormous emotional toll. Research has shown that many caregivers experience immense stress and feelings of burden, high rates of depression, and feelings of anger and anxiety.

- Caregiving can adversely affect one's physical health and ability to continue providing care—leaving two people impaired, rather than one.

- The emotional and physical strain of caring for a frail older person is often exacerbated by worries over paying for care, particularly nursing home care.

- The financial impact of caregiving takes a particular toll on family members when it affects their ability to work. In one study, 28 percent of non-working caregivers had quit their jobs to provide care. Others experience increased absenteeism, lower productivity at work, lost career opportunities, and lower future earnings.

COSTS OF CARING: THE ECONOMIC BURDEN

Long-term care is a major expense for many older people and their families. Three main issues underscore the importance of examining the costs of care:

- *Medicare does not cover long-term care.* Contrary to popular belief, Medicare pays for short-term, subacute nursing care; it does not cover the costs of long-term care, either in nursing homes or at home.1 Medicare only helps with time-limited care in a nursing home or with the transition home after someone has been hospitalized. Moreover, Medicare specifically prohibits the type of custodial care needed by people with chronic illnesses and disabilities.[57]

- *Private long-term-care insurance is expensive and limited in coverage.* Most older people cannot afford private long-term-care insurance. Only about 4 percent of people 65 and older have any kind of private long-term-care insurance.[58] Benefits are generally limited in scope and duration. The best policies, which provide comprehensive benefits over the long term, in 1993 charged premiums that averaged $2,137 for persons aged 65 and $6,811 for those over the age of 79.[59] Most studies have found that only about 20 percent of older people can afford private long-term-care insurance.[60,61]

Under the recently enacted federal health insurance legislation, known as the Kennedy-Kassebaum bill, long-term-care insurance premiums incurred after December 31, 1996, are now deductible as medical expenses, up to a limit that varies by age.[62] However, with so few older people able to purchase such private insurance, this tax break will benefit very few.

- *Out-of-pocket costs are high.* Older people and their families pay out-of-pocket for about 44 percent of the total costs of long-term care.[61] Out-of-pocket payments account for 51 percent of nursing home costs and 26 percent of homecare expenditures.[61] Nearly 40 percent of persons with chronic illness report they cannot afford the services they need.[28]

How Is Long-Term Care Paid For?

Long-term care is paid for in a number of ways:

- Family and friends—mostly women—provide the overwhelming majority of long-term care for frail and disabled older people on an unpaid basis.[2,3]

- On a paid basis, an estimated $108 billion was spent on long-term care in the United States in 1993.[3]

- Nearly two-thirds (64 percent) of these costs ($69.1 billion) were paid for with public dollars, $43.1 billion from the federal government and $26 billion from state governments.[3]

- The remaining one-third (36 percent) of these costs ($38.5 billion) were paid for by private sources, mostly as out-of-pocket spending by individuals and their families.[3]

- Private long-term-care insurance paid less than one percent of the total cost, estimated at about $200 million.[1]

> "At first I couldn't understand why he did the things he did, such as cut up water hoses and hide and destroy so many things. Now I believe I feel more frustration. As his illness progresses, it's getting harder for me to constantly care for him and cope with all other responsibilities."
>
> *(84-year-old wife caring for her husband, who has Alzheimer's disease)*

A bias toward institutionalization still drives long-term-care spending. Long-term care expenditures are largely used for institutional care. Of the estimated $108 billion spent on long-term care in 1993, 72 percent of the dollars went for nursing home care and only 28 percent went for homecare.[61]

While nursing homes are clearly important in the continuum of care, most people want to remain in their own homes as long as possible. The following case brings the bias in favor of institutionalization issue into focus:

Contrary to popular belief, Medicaid, not Medicare, is the largest source of public funding for long-term care. Medicaid is a federal/state health program for low income people of all ages and is the payer of last resort. Many families spend down to poverty paying for care for an older relative.[64] About three-fifths of Medicaid long-term-care funds are for older people.[58]

In 1994, total Medicaid expenditures exceeded $137 billion. Of these funds, about one-third, or $45.8 billion, was spent on long-term care. Only $8.5 billion of these funds was spent for home and community-based care, amounting to 18.6 percent of all Medicaid long-term-care expenditures and 6.2 percent of total Medicaid expenditures nationwide. In sharp contrast, Medicaid expenditures for nursing homes were over $28 billion, or triple the funds for home and community-based care.[65]

The cost of nursing home care is beyond the means of most people. The cost of a year's care in a nursing home averages $40,00058 and can be higher than $100,000.1 In contrast, the median income for households headed by persons 65 and older in 1996 was $28,983.[31] Only 40 percent of older persons have annual household incomes of more than $35,000. This is less than the cost of one year of nursing home care.[31,64]

Middle-class families are hit the hardest. Impaired older people and their families who do not qualify for Medicaid, yet cannot afford to pay for home and community-based care or nursing home care, are most at risk of financial bankruptcy. These families desperately need help.

The average per capita cost of caring for a noninstitutionalized older person with one chronic condition is $2,970. This cost climbs to $6,018 for an older person with two or more chronic conditions. In contrast, the per capita cost for older people with acute health problems only is $1,652.66

Out-of-pocket expenses for homecare were estimated to average $242 a month in 1993. People age 65 and older spent an average of $348 a month, while expenditures for those under 65 years of age averaged $134 a month for homecare.[50]

Studies document the economic burden on families. The total annual cost of home and community-based care for a disabled older person is estimated to be $9,600 (in 1993 dollars) for both informal care and formal services. Up to 80 percent of these costs are borne by families.[68]

Two-fifths of all caregivers report that they have incurred additional expenses as a result of caregiving. Twenty-six percent of caregivers spend up to 10 percent of their monthly income on caregiving. Nearly one-third (31 percent) of caregivers have incurred bills for travel, 24 percent for medical diets for the person in need, and 25 percent for telephone and utility charges.[57]

Nearly 80 percent of older people and their families who buy home-accessibility equipment (e.g., grab bars, wheelchair ramps) pay with their own money.[67]

The financial burden on families of people with dementing illnesses is particularly severe. These families, who may provide care for 10 years or longer, bear the burden of informal care. They also pay a large share of the formal care cost:

- In one study, average care costs for a person with dementia over a three-month period amounted to $4,564, or over $18,000 a year. Cash expenditures by caregivers for formal services or equipment averaged only 29 percent of the total care costs, with *unpaid labor* accounting for 71 percent of the family care costs.[69]

- In another study, the annual cost of care for people with Alzheimer's disease living in the community (in 1990 dollars) was valued at $47,083. Almost three-fourths of that cost—or $34,517—is borne by informal and family caregivers. The impaired people received an average of 286 hours of unpaid care per month—or about 10 hours a day of care from family and informal caregivers.[70,71]

- About 75 percent of caregivers for people with dementia reported that they did not use paid formal services because they could not afford them.[72]

Employers—in both the public and private sectors—also pay for the cost of care. Availability of home and community-based services is critical to employers because these services relieve workers of their caregiving duties. Studies of the prevalence of personal caregiving among employees caring for older relatives range from 2 percent to 12 percent.[73] Depending on the prevalence estimate used, employer costs—such as costs of absenteeism, replacing a worker who quits, or workday interruptions—can run from $5.5 million to as high as $33 million per year.[73,74]

Talking Points

- Long-term care is an economic burden for most families. Middle-class families are hit the hardest.

- Medicare does not cover long-term care, private insurance is expensive and limited in coverage, and out-of-pocket costs are high.

- Long-term care is largely provided by family and friends on an *unpaid* basis.

- Total spending on long-term care in the United States was about $108 billion in 1993. About 64 percent of the costs were paid with public dollars (mostly Medicaid), and about 36 percent were paid for by private sources, mostly out-of-pocket spending. Less than one percent of the cost was paid by private long-term-care insurance.

- A bias in favor of institutionalization still drives long-term-care spending. Of the estimated $108 billion spent on long-term care (1993 dollars), 72 percent went for nursing home care and only 28 percent went for homecare.

- The cost of nursing home care—averaging about $40,000 a year—is beyond the means of most people.

- The costs to employers—in both the public and private sectors—is also high: One study estimates that employer costs can run from $5.5 million to as high as $33 million per year.

- Older people and their families who do not qualify for Medicaid yet cannot afford to pay for long-term care are most at risk of financial bankruptcy.

- Despite older peoples *strong* preferences for home and community-based services, there are few service options: Long-term-care dollars are overwhelmingly spent on nursing home care.

- To reduce the costs of caring, states and the federal government must establish public policy to support and strengthen families in their caregiving role and shift the focus and incentives in long-term care from institutional care to home and community-based services.

FAMILY CAREGIVER SUPPORT PROGRAMS: THE STATE OF THE ART

Policymakers are beginning to recognize the critical role of families in the provision of long-term care as a way to help control rising costs of care. Four main public policy approaches are promoted to support caregiving families: (1) direct services; (2) financial incentives and compensation, including direct payments and tax incentives; (3) the cash-and-counseling model; and (4) employer-based mech-anisms.

Direct Services To Support Family Caregivers

Home and community-based services can help care for the caregiver by directly assisting families in their day-to-day caregiving responsibilities. Caregiver-specific services have the potential for reducing caregiver distress and improving coping skills so that families can continue to provide care. Direct services complement and assist families without supplanting their caregiving roles.

> "When I compare past with present it makes me very sad and depressed. I try to think positive most of the time. [I feel fearful] only when his condition worsens. Many nights I am up with him at least two or three times per night."
>
> *(54-year-old wife caring for her husband, who suffers from Alzheimer's disease)*

Support services needed by family caregivers may include a range of information and emotional and financial supports. Most caregiver support programs are provided through voluntary agencies (e.g., the Alzheimer's Association or the American Cancer Society) or through limited state programs funded under Title III of the Older Americans Act, Medicaid waivers, or state general funds. Eligibility for these programs is often restricted by age, diagnostic group, or income. (See page 15 for examples of state programs.) Moreover, many states have gaps in available services or have no caregiver support programs at all.[14]

Recent research on caregiver support services has shown very promising results. In a study investigating patterns of service use for one type of respite service (adult daycare) for caregivers of persons with dementia, researchers found that the sustained use of adult day services by caregivers of persons with dementia can substantially reduce their levels of caregiving-related stress and improve their mental health.[75] In a longitudinal study of family caregivers of people with Alzheimer's disease, researchers found that caregivers who used ongoing education, attended six sessions of counseling, *and* participated in a support group were 35 percent less likely to place their spouse in a nursing home than those in the control group. Spouse caregivers who received this combination of caregiver support services deferred institutionalization of their spouse by an average of 329 days.[76]

Information and assistance are the number-one need of family caregivers.[77] More often than not, the average family is unaware of services available in the community and the means of gaining access to them. Information is needed on how and where to get help, implications of a diagnosis, costs of care, and how to plan for future care needs. Increasingly, families are using the Internet to access information on caregiving and available services.

Long-term-care planning and care management help assess the needs of families and the impaired person, explore courses of action and care options, and arrange any necessary support services in the community. Helping the family respond to crises and adjust to new daily routines is essential to help families cope over the long-term.

Support groups emphasize coping strategies and peer support to help caregivers.78 Support groups are offered by organizations representing nearly every form of chronic illness (e.g., Alzheimer's disease, stroke, cancer) and are very popular.[79]

Counseling assists families in solving problems and in resolution of psychosocial issues related to caring for the impaired person.[80] Psychoeducational (group) models are also effective and are intended both to provide information and to help caregivers develop a specific set of coping skills.[79]

Respite care addresses one of the most pressing needs identified by families, namely, temporary relief to reduce the strain that caregivers experience on a day-to-day basis.[5,81] Respite care can allow time to go to the doctor or the grocery store, participate in a support group, or attend a class to learn caregiving skills.[5] A unique feature of respite care is the help it offers to both the caregiver and the care recipient. Respite care can be provided at home (in-home care), or in a group or institutional setting (out-of-home services). Out-of-home services include adult day centers, foster homes, nursing homes, hospitals, respite camps, and other facilities. Researchers have suggested that respite care can relieve the burden of the caregiving situation and allow families to continue to care for loved ones who would otherwise have been placed in a nursing home.[78,82] Families who have used respite programs overwhelmingly value the service and report high levels of consumer satisfaction.[5,81,83]

Home modification programs help caregivers adapt their homes to make it possible to provide care. Very limited resources are available for home repairs. There is generally no reimbursement for consumable supplies (e.g., incontinence products) purchased by family caregivers at home.

Legal and financial planning are key services to help families plan for the costs of future long-term care and to make arrangements for medical decisions and advance directives. Cognitive impairment, in particular, creates complex legal and financial problems for impaired persons and their families, who may need advice on property rights, contracts, estate planning methods, durable powers of attorney, conservatorships, and other matters.

Education and training programs can effectively help families with practical advice regarding day-to-day concerns. Research has shown that these programs can produce positive outcomes for the caregiver[84,85] and delay nursing home placement.[85]

> "My health has suffered and my blood pressure went up. I cry often; it's not a bowl of cherries. I hope I'll have enough money to live on."
>
> *(83-year-old husband caring for his wife, who had a stroke nine years ago)*

Financial Incentives And Compensation

Financial incentives and compensation can take several forms:

Direct payments to families take many forms and embody the emerging trend in consumer-directed care. Generally, programs provide family caregivers with cash grants or vouchers to purchase services for the care of their older relative. The justifications for family payments arise out of commitments to support family care, the lack of other resources, and the desire to minimize long-term-care costs.[86] At present, thirty-five states have programs that pay family caregivers for the provision of homemaker, chore, or personal care services.[86] Of these, thirteen states use Medicaid waivers to pay family members to provide care to a functionally impaired relative; the rest use state funds as the source of funding for family compensation.[86,87]

"My most stressful moments have occurred when I had a job in the shop which was on a tight schedule and it seemed that mother was calling me into the house every five minutes. I now wear a stop watch while working so that I can keep track of exactly how much time I do spend on a job. I punch it off when she calls me into the house and punch it back on when I'm working again."

(40-year-old daughter caring for her mother, who has a brain tumor)

There are several disadvantages to direct payments to families as they now exist. Nine out of the thirty-five states (about 25 percent) require caregivers to give up outside employment if they are receiving caregiver compensation. This strategy provides little relief to caregivers to replace lost income. Other program restrictions include kinship criteria (e.g., excluding adult children, or grandparents caring for grandchildren), living arrangements (e.g., excluding caregivers who do not share a household with the care recipient), and type of services covered.[86,87]

Tax incentives have gained more political appeal among some policymakers recently because they are relatively easy to administer and have a cost-sharing component. Tax incentives generally include deductions or credits.

The two main types of tax deductions are adjustments to gross income or itemized deductions from taxable income. Tax deductions tend to favor higher-income people, giving them more subsidy per dollar deducted than taxpayers in lower-income brackets.[15,88] Beginning in 1997, out-of-pocket expenses for long-term care, including custodial care and long-term-care insurance premiums, are deductible as medical expenses. The expenses must be for care for a "chronically ill individual" who needs help with at least two ADLs or requires "substantial supervision to protect against threats to health and safety due to severe cognitive impairment."[62]

The other major tax strategy is the use of tax credits. Unlike tax deductions, tax credits generally benefit low-income taxpayers. Tax credits usually require the caregiver to live with the care recipient and be employed outside the home. These requirements tend to limit the use of this tax strategy, particularly when one family member—usually the female spouse—has the full-time job of caregiving.[87]

Cash-and-Counseling Model

A promising consumer-directed strategy is the cash-and-counseling model. This model combines elements of financial support with direct services, such as information and counseling, to help consumers make informed choices about long-term care. At least ninety-four countries have governmental programs that provide cash allowances to disabled individuals who require supervision or assistance with activities of daily living or household tasks. Not only is this option appealing to people with disabilities and to their families, but it could prove successful to the federal government and to states as a cost-effective use of limited long-term care resources.[89]

The national cash-and-counseling demonstration project for Medicaid recipients of long-term care is now underway in four states (Arkansas, Florida, New York, and New Jersey), funded by The Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Under this demonstration project, older and younger people with disabilities will choose between traditional case-managed personal assistance services and cash grants along with information services. The cash component provides monthly cash allowances, and the counseling component provides people with consumer information, advice, and assistance to help them direct their own care. Possible uses of the cash include purchasing services from a homecare agency, paying a relative or friend to provide personal care, or purchasing respite care. Proponents of this model cite several potential benefits including the following: (1) empowerment of consumers, (2) support for families and other informal caregivers, (3) a unified model for serving persons of all ages with disabilities, (4) lower unit costs of care and lower total costs to governments, and (5) encouragement of consumer-directed chronic care systems.89 Use of the cash-and-counseling approach, however, raises quality assurance concerns that must be addressed at both the national and state levels.

California's statewide system of Caregiver Resource Centers (CRCs) for families and caregivers of cognitively impaired adults offers a similar option to caregivers through the use of respite vouchers along with ongoing support services. Research has shown that this consumer-directed "direct pay" program (wherein caregivers are given vouchers to hire and manage their own respite workers) is both preferred by caregivers and more cost-effective than the agency-based program (wherein caregivers are given vouchers to purchase service hours from homecare agencies under subcontract with the CRC).[90]

Employer-Based Mechanisms

Increasingly, both public and private employers are using either unpaid leave for caregiving or dependent care assistance plans to provide indirect financial assistance to caregivers. Enactment of the Family and Medical Leave Act (FMLA) of 1993 was an important first step by the federal government in helping protect the jobs and work benefits of employees who also have family care responsibilities. The law permits full-time employees to take up to 12 weeks of unpaid leave per year for a birth or adoption or to care for an ill child, spouse, or parent. While providing an important measure of basic job security for workers who have caregiving responsibility, the law contains a number of restrictions that dilute its usefulness. Principally, the law provides *unpaid* leave, thus, for family caregivers who cannot afford lost income, the time off may not meet their real needs. Additionally, the law covers only about 11 percent of American worksites and 60 percent of American workers;[91] those who work in small businesses are not covered by the federal law. Workers caring for an aunt or uncle, a sibling, a grandparent, or an unmarried partner also are not covered.

As of July 1992, some thirty-one states had passed some type of family and medical leave legislation.[92] There is a great deal of variation in the provisions in each of these laws, with some states offering more generous benefits than others. State experience with leave legislation has shown that most of the beneficiaries use leaves for the birth or adoption of a child rather than for care of an ill child, spouse, or parent. Whether more caregivers will use this benefit as it becomes more known remains to be seen.[92]

A dependent care assistance plan (DCAP) is another mechanism used by some employers. Under the federal tax code, the federal government allows employers to provide employees with up to $5,000 in dependent care assistance annually. A number of restrictions regarding eligibility, allowable expenses, and definition of "dependent" limit the DCAPs utility for care of older people.[87,92] Typically, DCAPs have been for childcare rather than eldercare expenses.[92]

Direct Services Vs. Financial Support Strategies: Is One Preferable To The Other?

A number of studies have examined caregiver preferences for dollars versus services. Caregivers generally prefer services which provide relief from daily caregiving and increase coping skills over financial supports.[17,22,92] In one study, over 80 percent of families chose a support service rather than financial support.[88]

It is crucial to advocate for policies that enable families to continue to provide care. Public policies are needed to provide both direct services and financial support strategies. Moreover, policymakers need to recognize and address the real need of older people and their families: To ensure access to quality, affordable long-term care, in the least restrictive setting for the person needing care, that best meets family needs.[14] What public policy can and must do is guarantee a national program that protects families from the emotional and financial bankruptcy that are often the result of providing long-term care.

Talking Points

- Four main policy strategies currently support caregiving families: (1) direct services (e.g., respite care); (2) financial incentives and compensation, including direct payments and tax incentives; (3) the cash-and-counseling model; and (4) employer-based mechanisms. All are limited in scope.

- Cash and counseling is a promising consumer-directed model that combines the elements of financial support with direct services to help consumers make informed choices about long-term care.

- Research has shown that most caregivers prefer services to dollars.

- Public policy must guarantee a national program that protects families from the emotional and financial bankruptcy that can be the result of long-term care.

EMERGING TRENDS

The emerging trends, highlighted below, are expected to continue into the twenty-first century. Advocates can help shape these trends to strengthen caregiving families.

Shift In Long-Term Care From Federal To State Level

Federal cutbacks in Medicaid and limited national health reform have shifted the focus in long-term care from the federal to the state level. Recently, states have been exploring strategies to expand home and community-based services systems. This expansion has slowed, and in some cases reversed, the growth of nursing homes in some states (i.e., Oregon and Washington).[93] States have found that home and community-based services cost less per person, on average, than caring for a person in a nursing home.[93] Nationally, the number of nursing home residents was up only 4 percent between 1985 and 1995, despite an 18 percent increase in the population 65 and older.[94] Additionally, with the focus on providing a continuum of care, states are increasingly looking at infrastructure issues, particularly consolidating long-term-care programs within one state agency, and seeking Medicaid waivers to provide an array of home and community-based services, including family support.

Consumer-Directed Care

A trend in the delivery of quality and cost-effective home and community-based long-term care is the movement toward consumer-directed services. The concept of consumer direction implies that consumers prefer to make decisions about their service needs and are able to take a more active role in managing their own services. This growing interest in consumer-directed care is an outgrowth of the independent living movement, which was started in the 1970s primarily by younger adults with disabilities[95] and has now led to a number of new initiatives bridging the aging and disability communities.[96] The issue of allowing people to manage their own care is controversial at the state level because many states view their traditional care management process as a means for maintaining both quality of services and control over expenditures.[93]

One such consumer-directed initiative known as cash and counseling was described previously. Another new initiative is Independent Choices: Enhancing Consumer Direction for People with Disabilities. This $3-million grants program is supported by The Robert Wood Johnson Foundation. In June 1997, some thirteen demonstration and research projects were awarded grants to explore various aspects of consumer direction and choice in home and community-based services.[97] Some disability advocates anticipate consumer choice to be the next civil rights issue.[98]

Managed Care And Consumer Protections

For the foreseeable future, managed care is here to stay. Future emphasis on cost control and coordination will give rise to managed long-term-care plans in Medicare as well as Medicaid.[1] In the present debate, interest at the state level has largely focused on how managed care can contain costs. However, from the consumers perspective, how well managed care coordinates and delivers services and responds to individual and family needs is as important as its ability to contain costs.[99] Policy issues to be addressed include the following: (1) consumer protections in marketing and enrollment and disenrollment policies; (2) assuring ready access to affordable, appropriate, and quality care; (3) consumer choice of qualified providers in the least restrictive, most appropriate setting that recognizes family needs; and (4) a full range of health and long-term-care services, including access to specialists for individuals whose chronic conditions require such care.

Use Of Technology In Delivering Information And Services

Today, with a computer and modem, global choices for obtaining caregiving tips and long-term-care advice are available with a few keystrokes. The recent explosion of technology is transforming the way we gain access to and deliver services. According to Find/SVP Emerging Technologies Research, an estimated 40 to 45 million people in the United States were using the Internet in 1997; that number is projected to more than triple to 150 million Americans by the year 2000. Discussion groups, support groups, counseling, online health information, and caregiving resources are now readily available using computer technology. The proliferation of Web sites in health and long-term care reflects a need for information to help people make more informed choices about their own care and the care of their families. Issues of quality and timely information, as well as concerns about confidentiality, will probably be debated in the coming years.

MODEL STATE PROGRAMS TO SUPPORT FAMILY CAREGIVERS

There is no comprehensive listing of state-funded caregiver support programs because there is no uniform definition of family or informal caregivers. Caregiver support programs are extremely diverse and dependent upon individual state priorities and resources. Existing programs are administered by a range of state agencies, including departments of aging, mental health, health services, human services, and social services. Some programs are caregiver-specific; others are part of larger home and community-based long-term-care programs. Respite care is the service most typically funded by state governments.

Ideas of the defined client, eligibility, mode of delivery, and funding are varied and inconsistent.

In some caregiver support programs, the impaired person is the defined client; in others, the family caregiver is considered the client and the legitimate recipient of services.

Eligibility criteria vary along a number of dimensions, generally based on such factors as age, type of impairment, or income. Some programs target caregivers of older persons, while others serve caregivers regardless of the age of the care recipient. Most state-funded programs serve three general caregiver populations: those caring for the functionally impaired, the cognitively impaired (particularly with Alzheimer's disease or related dementias), and the developmentally disabled. Some programs target low-income families through Medicaid waivers. Other programs target low-middle-income families—those just above the eligibility limit for other public benefits but with limited resources to purchase needed services.

The mode of delivery varies among states. Some programs provide direct services in the form of information and referral, care management, and the like, while others provide financial support through either cash allowances or vouchers to purchase needed services. Still others offer a combination of direct services and financial compensation.

In New York, one adult daughter, Ms. H, pleaded her case all the way up to the governor's office. Two 84-year-old twin sisters with Alzheimer's disease were being cared for by an increasingly frail 86-year-old sister, with some help from Ms. H. Medicaid paid for daytime care at home. However, no such care is allowed at night since nighttime care does not meet the Medicaid reimbursement criterion for active hands-on care. Yet, the two women with Alzheimer's disease wandered at night, tripped and fell, and need active supervision. Ms. H. estimated that hiring a nighttime attendant for all three sisters would cost about $25,000 a year. The state refused to pay. Instead, the state was willing to spend $45,000 a year for each of the three sisters to move into a nursing home.[63]

Funding for programs come largely from state sources, with Federal or local matching funds in only a limited number of cases. Nonetheless, it is clear that a number of states have made efforts to address the needs of family caregivers. This section highlights the model programs in California and Pennsylvania, the two most comprehensive state-funded caregiver programs, and briefly describes efforts in several other states.

California's Caregiver Resource Centers

Begun in 1985, California's Caregiver Resource Centers (CRCs) constitute the first statewide, state-funded program to address the needs of family caregivers, and are administered by the California Department of Mental Health (under Chapter 1658, Statutes of 1984, as amended). The service model replicates the pilot project developed by the San Francisco–based Family Caregiver Alliance (FCA), formerly Family Survival Project, in the early 1980s. The law established both statewide and regional services. At the state level, Family Caregiver Alliance serves as the statewide resources consultant to the Department of Mental Health and carries out policy and program development, develops education programs, provides training and technical assistance to the CRC sites, conducts applied research, and maintains a statewide information clearinghouse on caregiving and adult-onset (age 18-plus) brain impairments. At the regional level, eleven nonprofit crcs serve as a point of entry to a broad range of services for caregiving families.

The CRCs serve low-middle-income families and caregivers of persons with adult-onset chronic, disabling brain diseases and disorders (e.g., Alzheimer's and Parkinson's diseases, stroke, traumatic brain injury). Caregivers receiving subsidized respite assistance must live with the care recipient and be ineligible for California's In-Home Supportive Services (IHSS) program or other public benefits. High priority is given to families caring for cognitively impaired adults who exhibit severe behavioral problems and for whom few respite resources exist.

In fiscal year 1997–98, the state appropriation for the eleven CRCs and the statewide resources consultant is $5.047 million. All CRCs provide a core package of caregiver support services including: specialized information and referral; caregiver assessment in the home; family consultation and care planning; individual, group and family counseling; support groups; education and training, including psychoeducational classes; vouchered legal consultations with attorneys; and vouchered respite assistance (including homecare, adult day services, overnight stays in a facility, weekend camps, and other respite options).

CRCs serve over 9,000 family caregivers a year. Six in ten caregivers completing an initial intake phone call go on to receive additional services. Nearly 800 families receive an average of seven hours of respite per week. The average monthly respite cost per family caregiver is $222, including an average copayment of $18. More than 3,000 California families are on a respite wait list.

"This help has been a lifeline. You have given me the support I needed to continue caring for my wife in our home. This is where she wants to be."

(69-year-old husband caring for his wife, who has multiple sclerosis)

Pennsylvania's Family Caregiver Support Program

The Pennsylvania Family Caregiving Support Program (FCSP), begun in 1987, is administered by the Division of Managed Care, Pennsylvania Department of Aging, under Title 6, Chapter 20, Pennsylvania Code, as amended. The FCSP provides a combination of services, financial assistance, and care management to about 7,000 caregivers a year. The statewide program is managed locally through the state's fifty-two Area Agencies on Aging. Clients are families and other caregivers who care for an older, functionally dependent relative at home. Eligible caregivers must live with the care recipient and cannot have incomes which exceed 380 percent of the poverty level.

The state appropriation for the FCSP is $9.862 million in fiscal year 1997–98. The funds cover a range of support services including the following: assessment of needs of the caregiver, care recipient, and caregiving environment; counseling in coping skills; benefits counseling and assistance in completing insurance and benefits forms; training and education; financial assistance with ongoing caregiving expenses and assistive devices; respite care and home chore services; and one-time grants for home modifications.

Financial assistance is in the form of reimbursement, on a cost-sharing basis, for the out-of-pocket purchase of supplies and services of up to $200 per month. To receive the maximum benefit, eligible families incomes may not exceed 380 percent of the poverty level. A percentage of reimbursement is covered for higher-income families. There is a $2,000 lifetime cap on financial assistance for home modifications and assistive devices.

"Respite saved my life mentally, physically, andeconomically."

(65-year-old wife caring for her husband, who has Alzheimer's disease)

New Jersey's Respite Program

The New Jersey program, offered statewide since 1988, is administered by the New Jersey Department of Health and Senior Services. The state appropriation is $4 million, and nearly 2,000 persons are served per year. The program provides respite services for elderly and functionally impaired people age 18 and over to relieve their unpaid caregivers from the stress of providing daily care. Eligible people must have an income of less than $1,450 per month and less than $40,000 in liquid resources. Respite services include companions, homemaker/home health aides, medical or social adult daycare, temporary care in a facility, overnight care in a camp setting, and private nurses.

Washington's State Respite Care Program

The Washington program started as a pilot project in 1988 and went statewide in 1989. The program is administered by the state Department of Social and Health Services, Aging and Adult Services Administration, and is operated through the state's thirteen local Area Agencies on Aging. In 1997, the respite program is funded through a state appropriation of $2.47 million; however, federal funding from the Older Americans Act may be used to provide additional respite to eligible older adults. About 2,000 caregivers receive services annually. Eligible people are unpaid caregivers who have the primary responsibility for care or supervision of a functionally impaired adult who is at risk of being institutionalized. Services include the following: assessment and care planning, supervision, respite, personal care, and nursing care. No direct payments are given to families. Caregivers pay for available respite in the community based on a sliding fee scale.

Wisconsin's Alzheimer's Family Caregiver Support Program

The Wisconsin program, begun in 1986, is administered by the Wisconsin Department of Health and Family Services, Bureau on Aging and Long-Term Care Resources. The $1.87 million state appropriation provides respite to nearly 1,000 families annually; another 4,600 receive other assistance (e.g., support groups, educational materials). To be eligible, one must be either the person with dementia or the family caregiver. Respite is delivered in a variety of ways. Counties have autonomy to use respite funds to do the following: (1) give funds to families to purchase services, (2) make payments directly to providers, or (3) use specific contract providers to deliver respite care.

New York's Caregivers Resource Centers

New York's resource centers, begun in 1989, are administered at the state level by the New York State Office for the Aging, and are located at the state's seventeen Area Agencies on Aging. In fiscal year 1997–98, the state is appropriating a total of about $360,000 for these seventeen centers to provide outreach, information, training, support groups, resource libraries, and advocacy.

Minnesota's Caregiver Support And Respite Care Projects

The Minnesota projects were begun in 1992 and are administered by the state Department of Human Services, Aging and Adult Services Division. The twenty-four project sites, located in various community agencies, receive state funding up to $20,000 each. The total state appropriation in fiscal year 1997–98 is $480,000. The primary support services include respite care using trained volunteers, caregiver support groups, and community education. Some sites provide limited paid respite assistance.

Talking Points

- No comprehensive list of state-funded caregiver programs exists due to the fragmentation of services and variations in eligibility, mode of delivery, and scope of services.

- Funding is very limited, with most states using state general revenue funds to support family and informal caregivers.

- Respite care is the service most typically funded by state governments.

- Two successful programs stand out in terms of scope, service package, and funding; these can be replicated by other states: California's Caregiver Resource Centers and Pennsylvania's Family Caregiver Support Program.

FAMILY CAREGIVER SUPPORT POLICY: A CALL TO ACTION

States and consumer advocates have a role to play.

The Role Of States In Developing Family Caregiver Support Policies

The concept of caregiver support for an aging population is a growing issue in states across the country. Federal cutbacks in health and human services are having a profound effect on the ability of states to develop long-term-care systems that are responsive to consumer needs. States are now faced with assuming greater responsibility for shaping the financing, eligibility, coverage, and delivery systems that provide long-term care to people with disabilities.

The motivation required to bring about change is present in every state, driven by economics, values, and, of course, politics. Policymakers have a strong interest in maintaining the strength and durability of family and informal caregiver networks as the primary providers of long-term care. Therefore, it is essential that home and community-based services include support services for caregiving families. States have two main incentives for expanding home and community-based care options and providing caregiver support as part of a system of long-term care:

The first is a matter of humane public policy, a desire to help frail and disabled older persons remain at home with their families and in their communities as long as possible.

The second is driven by the bottom line to control rising costs, particularly for institutional care.[15,93]

Strategies for State Action

- Utilize findings from other states. Speak with state leaders about their programs and obtain copies of existing state statutes as model language for a legislative proposal. Invite program administrators to present information on program development, implementation, and evaluation.

- Hold policy hearings on family caregiving. Give specific attention to the health and economic impacts of caregiving and appropriate programs and services to respond to identified caregiver needs.

- Use findings gleaned from a hearing or state--sponsored report to establish long-term objectives (for example, through a resolution or governor's proclamation) to develop a family caregiver support policy that integrates assistance to family caregivers as part of long-term care.

- Ensure that any state-level task force, advisory committee, or planning group that is established to develop long-term-care systems includes participation by family caregivers.

- Pursue and build public-private partnerships. For example, the Washington Aging and Adult Services Administration works with an alliance of community groups to conduct an annual caregiver conference. In Maryland, the Office on Aging works with large employers to promote an employee assistance program for working caregivers.

- Develop consumer-oriented fact sheets on specific caregiving issues. Develop a consistent dissemination strategy in coordination with all stakeholders in the state.

- Support the development of community-based projects. Provide seed money to municipalities to create local resources (e.g., a volunteer respite program).

- Implement caregiver-friendly policies for state employees who have caregiving duties.

- Keep federal policymakers informed. Caregiving clearly is a matter of national policy.

What Consumer Advocates Can Do To Make The Case For Supporting Caregiving Families

Advocates play an important role in educating policymakers about issues in family caregiving. Family caregivers can be effective advocates for themselves and others by providing personal stories about what it is like to care for a chronically ill older relative. Personal experiences of around-the-clock caregiving duties, inadequate resources, emotional strain, and financial hardships are compelling testimonies of need. By personalizing the issues, you may find that some legislators, or their staff, will have experienced caregiving firsthand.

Be prepared to address two underlying assumptions influencing both public perceptions and policy:

(1) The myth of abandonment. The pervasive myth that families abandon their older relatives when they need long-term care is untrue. In reality, families provide at least 80 percent of the care to older people, even those most severely impaired with dementing illnesses. Research clearly shows that more paid help does not lead families to abandon their involvement in the care of older relatives.[6,78,92]

(2) The myth of "woodworking effect." This myth suggests that because of increased demand, there is a potential for increased expense, particularly if caregivers quit providing care or substitute formal care for unpaid care. Research has shown that few families "come out of the woodwork" to receive services.[100,101,102,103] Rather, most caregivers are quite re-

luctant to use services, generally provide care with very little support, and use formal services only as a last resort when a crisis occurs.[5,22,40,77,85]

Strategies for Advocates

- Do your homework. Stay informed and keep up-to-date.

- Arm yourself with the facts: Use this report. A key point is that supporting caregiving families is cost-effective, as well as compassionate. If caregiver support services help families deter institutionalization of a family member, states realize enormous savings. Moreover, support for family caregivers is a critical and growing policy direction, even if cost savings from formal home and community-based services are not immediately evident.

- Form (or join) a coalition, with other advocates of government help on family-related issues to campaign for caregivers. Partner with women's rights groups, disease-specific voluntary organizations (e.g., regional chapters of the National Multiple Sclerosis Society), businesses, and aging and disability groups. Broadening your base often helps to influence policymakers. Organize and participate in briefings for legislative staff and targeted telephone and letter writing campaigns.

- Write a letter to the editor or an op-ed piece in your local newspaper. This is an excellent sounding board for educating the public (and local elected officials) about a cause. You can write about a current legislative proposal, or simply express the need to help family caregivers with practical assistance, and emotional and financial support.

- Visit your state legislator (or legislative aide) in the district office. Be sure to bring a family caregiver with you on the legislative visit to share his or her experiences as a caregiver and what types of help are needed. Plan your briefing carefully and keep it short. Use facts from this report to strengthen your case. Ask for specific support. Follow-up with a thank-you letter.

- Write a letter to your state legislator. Legislators depend on input from their constituents to learn about issues. Keep your letter brief and to the point. If you are writing about a specific bill, include the bill number. Explain why you support or oppose the bill and urge the legislator to vote accordingly. Be sure to ask the legislator to let you know what action he or she will take.

- Pay attention to which legislators serve on key aging and long-term-care committees and mobilize family caregivers in their districts.

- Testify at a public hearing. This is a way of sharing your expertise as a caregiver with key policymakers. Personal testimony can make a powerful impact.

- Keep federal policymakers apprised of your activities. Caregiving is clearly a matter of national policy.

CONCLUSION

As we approach the twenty-first century, the aging of America and changing patterns of family life are greatly increasing the demands on family and other informal caregivers who provide long-term care for older relatives and friends. At every age, people are likely to have more older people in their families today than in the past. These profound changes will affect nearly every American family in the future.

Today, almost 100 million Americans have one or more chronic conditions. Over the next twenty-five years, this number is expected to increase to 134 million Americans. The greatest growth will be for those aged 85-plus, the most rapidly growing elderly age group and the one most in need of long-term care. In 1996 those 85-plus numbered 3.8 million, or 11 percent of the older population. By 2040, there will be almost four times as many people over 85 as there are today. Over the next twenty-five years, public and private expenditures for long-term care, now estimated at more than $108 billion, are projected to more than double.

Caregiving is not just an aging issue; it is a family issue *and* a policy issue. As public policy in long-term care shifts from the federal to the state level, support for family and informal caregiving is becoming a priority issue for many state governments because of the high costs of not taking any action. States have two main incentives for providing caregiver support and expanding home and community-based care options as part of a long-term care system: The first is a matter of values, the strong consumer preference of older people to remain at home with their families and in their communities for as long as possible; the second is driven by economics, to control the rising costs of long-term-care expenditures, particularly for nursing homes.

Policymakers are beginning to recognize the critical role of families in the provision of long-term care. Contrary to popular belief, families, not institutions, are the major providers of long-term care, providing some 80 percent of care on an unpaid basis. Research has shown that the "myth of abandonment" is unfounded; more paid help does not lead families to abandon their involvement in caring for older relatives. Research has also shown that families do not "come out of the woodwork" if there is public funding for support services: most caregivers are reluctant to use formal help, provide care with very little support, experience adverse affects to their own physical and mental health, and use formal services only as a last resort when a crisis occurs.

A range of cost-effective options has been outlined in this paper to support the informal care system to help control rising costs of long-term care. While strengthening the role of families in long-term care can produce cost savings for states and is generally the preferred option expressed by individuals, it can also place severe strain on family caregivers. Therefore, it is crucial in any long-term-care strategy to provide support services to caregiving families. Several states, particularly California and Pennsylvania, have taken steps through a combination of direct services and financial supports to sustain family caregivers. Existing programs can serve as models for other states.

Caregiving will remain an intrinsic part of the experience of American families well into the twenty-first century. Therefore, it is vitally important for consumer advocates to seize the policy agenda and focus attention on the two major actions addressed in this paper:

(1) Recognizing and strengthening the central role of families in the provision of long-term care; and

(2) Shifting the focus and incentives in long-term care away from institutional care to home and community-based care.

The time to make the case is now: Strengthening the role of families and other informal caregivers is cost-effective and compassionate public policy. We can no longer afford not to act—our own future and that of our parents, grandparents, and children depend on it.

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APPENDIX E

Affordable Assisted Living for Older Nevadans

Affordable Assisted Living for Older Nevadans
For
Legislative Committee to Study Long –Term Care
January 13th, 2000
by

Ernest Nielsen
Washoe County Senior Law Project
Washoe County Department of Senior Services
775-328-2592

This discussion is about alternative housing for lower-income frail elderly persons whose only current available supportive housing are nursing homes. The goal of this discussion is to convince Nevada policy makers to consider a new Medicaid waiver program which would **leverage Medicaid funds with the State's existing affordable housing dollars** to foster the development of affordable "assisted" living for lower income frail seniors.

The target population for this new waiver would be persons 65 years old or older whose incomes are below $1,500 per month and who meet the Medicaid criteria for placement in a nursing home. This waiver seeks to waive the general requirement of statewide application and universal eligibility.

A significant percentage of elderly persons living in nursing homes are Medicaid eligible. Nursing home costs are significant. In Nevada, Medicaid reimbursement for the least expensive patients exceeds $1500 per month with average Medicaid reimbursement per patient month at $2,600 per month. Half of such costs fall upon the state. On a per capita basis, a Medicaid waiver program linked to affordable housing funding would cost the state half of what it costs to maintain the same person in a nursing home.

Over the last several decades, assisted living facilities have become an alternative to nursing home care. Such facilities provide some of the assistance that is provided by nursing homes but are more consumer friendly and are less costly on a per bed basis. Though the total cost for such facilities is less than that of nursing homes, because Medicaid, without a waiver, is not available to pay for such care, generally only the wealthy enjoy receiving such assisted living.

In Washoe County, though there are 5 large Assisted Living facilities, none are available for those whose incomes is less than $35,000 year [1] even though, nationally, such frail seniors outnumber higher income seniors 2 to 1.

Assisted Living

Assisted living services are tailored to each individual's needs, and generally include meals, housekeeping, laundry and medication reminders, activity programs and assistance

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[1] Bay Area Economics, consultants of the Washoe County HOME Consortium

with Activities of Daily Living[2] (ADL) and Instrumental Activities of Daily Living[3] (IADL) limitations. Services provided to residents are designed to respond to their unique, individual needs and improve their quality of life. Individualized assistance needs to be available 24 hours a day, to address scheduled as well as unscheduled needs. Most residents of assisted living facilities have physical and cognitive impairments that limit their ability to independently perform basic self-care and household tasks. The primary distinction between assisted living and other forms of congregate senior living facilities is that trained staff is available to provide hands-on-care to assist the resident with ADL limitations 24 hours a day. The services provided by the proposed waiver would be similar to those provided by the existing CHIPs waiver namely personal care, case management and homemaker services. Some health aide and habitation services are desirable. On an aggregated basis such services would be provided to individuals based on a needs based assessment described in a care plan. Such plan would emphasize independence, resident involvement and a supportive environment.

Medicaid pays for the total cost of care in a nursing home. Under any waiver including the one proposed here Medicaid would not pay for the housing component of the assisted living facility's costs. Medicaid funding therefore is only one piece, the service side, of creating assisted living for lower income elders.

Using Public Sector Affordable Housing Funds

Because the waiver assisted programs do not pay for housing costs, Medicaid financed assisted living is not likely to be available to Medicaid eligible persons unless the housing portion is reduced for the operator. Thus the waiver proposed and discussed here uses the existing public sector funds for affordable housing development such as federal HOME funds, federal low-income housing tax credits and Nevada's Low-Income Housing Trust Fund to finance the housing portion of the affordable assisted living. These housing programs are available only for housing costs. They may not be used for services. These programs provide the developmental capital for projects and reduce the monthly debt service costs so that lower rents can service such debt service.

Financing associated with most affordable housing being produced today, including affordable assisted living projects, is made up of three components: 1) debt financing with required periodic payments of principle and interest based on the economic viability of the project; 2) grants or "soft loans" provided through government sponsored affordable housing financing programs described above; and 3) equity dollars sometimes provided through the federal low income housing tax credit program.

The Nevada Housing Division and the three regional HOME consortiums in Nevada administer these public sector affordable housing financing programs that can support the building of affordable assisted living facilities. They generally to develop projects and not to pay for ongoing rent subsidies.

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[2] Activities of Daily Living include eating, bathing, dressing, grooming, using the bathroom, and mobility.
[3] Instrumental Activities of Daily Living include transportation, money management, shopping, preparing meals, housekeeping, laundry, and medication management.

For example, Washoe County itself is in the process of planning a comprehensive and affordable community for seniors, a portion of which will provide assisted living. However successful it will be in reducing the debt service for the housing component, the County continues to seek funds to provide the health and related assistance for those it will house. The Medicaid waiver approach discussed here would provide such funding and enable that project to provide affordable assisted living

Existing Barriers

The reason that there are no affordable assisted living projects in Washoe County, for example, is that, though we have learned well how to use public sector housing funds to develop affordable housing, there is no ready source to pay for the service component of the affordable assisted living housing. If paid by the resident, the assisted living housing would not be affordable to a great number of frail seniors.

The current Community Home-based Initiatives Program (CHIPs) Medicaid waiver pays for case management and housekeeping. It does not pay for housing costs. Though the CHIPs waiver income standard (up to 3 times the SSI income eligibility or approximately $1,500) is very acceptable, adjustments to that waiver would be needed to make an affordable assisted living project work. The CHIPs waiver is focused on the individual, wherever home is, rather than providing aggregated service in an assisted living facility where significant economies can be achieved. Further, the proposed waiver does not seek to displace the existing CHIPs waiver which serves a fundamentally important role. It simply expands the population who may enjoy non-institutional care to those who can no longer remain in their home because, for example, they need 24-hour care. The other existing waiver available to the elderly is the group home waiver which is available only to those who are SSI eligible and for which the reimbursement rate is about $9.00 per day. Such amount is not large enough to support affordable assisted living projects. The fact that the individual group home waiver recipient is SSI eligible allows payment for the housing costs from non- Medicaid sources.

From a policy perspective, there seems to be a perception held by some that a facility based assisted living waiver might cost the state more than it saves. This perception may exist because there is a possibility that individuals eligible for Medicaid funding for nursing homes, but not now in nursing homes, would be attracted to the assisted living option. If true, the sate may wish to tightly define those who would be eligible for the assisted waiver to increase the likelihood that those benefiting from the waiver would otherwise soon be in a nursing home or would be leaving a nursing home.

Other States

The states of Arizona, Oregon, Washington, Maine, Colorado, Connecticut and Illinois have implemented demonstration programs that allows funding of personal care services in assisted living facilities. For example, Maine increased payment into its community based waiver program and experienced a 7% decrease in the total expenditure of state

Medicaid dollars. The objective of these state funded demonstrated programs is to slow, if not reduce, expenditures associated with state funded long-term care

By using the Medicaid, Home and Community Based waiver program (1915 c and d—42 USC 1396n (c) and (d)), personal care services can be paid with Medicaid dollars, and when coupled with public affordable housing funds, will support low income seniors in a residential setting who would otherwise be in nursing homes.

Benefits

A Medicaid supported assisted living demonstration program in Nevada would:

- Support the development of a system of care that links health and social services with affordable housing funding.
- Promotes the concept of "aging in place" by making personal care and health- related services available, as residents' needs change.
- Provide an affordable housing option that provides lower income frail elderly persons and their families with an alternative to institutional care. The option focuses on a residential design and physical environment augmented by a support network that provides an atmosphere supporting independence, self-determination, and self-sufficiency.
- Identify key attributes and success factors in the development of these systems of housing and care to promote permanent development capacity and replication potential.
- Enhance and influence, if not change, public policy regarding housing and long-term care of frail older adults in need of assistance.
- In the long term, reduce total state Medicaid spending relative to expenditures without the waiver.

The Legislative Committee to Study Long-Term Care is an excellent forum to explore the State's participation in the development of affordable assisted living.

If we can be successful in developing these affordable models we will provide lower income frail elderly and their families with a consumer oriented solution to their long-term needs. At the same time we can provide a cost-effective alternative to institutional long-term care and lessen the burden of government funded long-term care.

APPENDIX F

Coming Home Initiative – Robert Wood Johnson Foundation

MIKE McGINNESS
SENATOR
Central Nevada District

COMMITTEES:
Chairman
Taxation

Member
Judiciary
Natural Resources

Nevada Senate

Carson City

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LEGISLATIVE BUILDING:
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February 1, 2000

Charlotte Crawford, Director
Department of Human Resources
505 East King Street
Kinkead Building
Carson City, Nevada 89710

Dear Charlotte:

Enclosed is a copy of a publication from the Robert Wood Johnson Foundation that was provided to the Legislative Committee Studying Long-Term Care in Nevada at the January 13, 2000 meeting. The publication is an informational notification to states that the Foundation has created a new "Coming Home" initiative. The new "Coming Home" initiative is designed to build on the success of the first "Coming Home" program that provided loans for rural communities to build assisted-living housing for low-income seniors linked with at-home services provided by the existing community health care systems. The new "Coming Home" initiative will make available $300,000 over a three-year period for up to eight states to facilitate the implementation of demonstration projects for affordable assisted living.

The Committee, after reviewing the publication and after having received testimony on a proposal to develop a demonstration program in Washoe County that focuses on assisted living, feels that the "Coming Home" initiative potentially has merit and possibly should be pursued. The Committee does realize the state may not be in a position or have the resources at this time to develop a demonstration proposal quickly as noted in the publication. Therefore, the Committee is requesting the Department have subject matter experts analyze the initiative to determine if there is sufficient merit for the state to develop a proposal and apply for start-up funding from the Foundation. Please note, the analysis must be completed quickly since the Foundation's timetable requires that states interested in applying for grant funding must submit a letter of intent no later than March 1, 2000. The Committee would like to have you report on whether or not the Department intends to develop a proposal and pursue funding available from the "Coming Home" initiative at our next meeting scheduled for March 9, 2000.

Lastly, the Committee is planning two more meetings and a work session before concluding its work. At this time it appears each meeting will include a discussion of issues that will have some bearing on the programs administered by the Department. I feel it is important for the Department to attend these upcoming meetings and to be available and, if needed, to provide testimony as subject matter and policy experts on issues that the Committee intends to discuss. I realize the Department's resources are limited; therefore, our staff will keep you apprised of the issues that will be discussed at each meeting so you can designate the appropriate representatives to attend and minimize any disruption to day-to-day program operations.

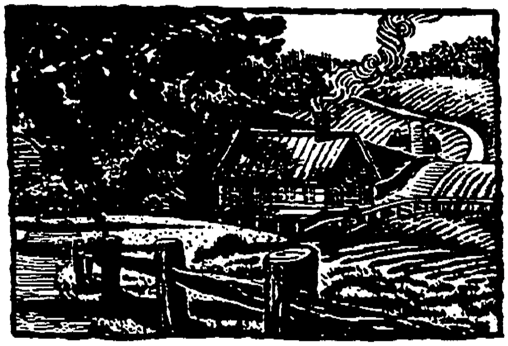
I would like to thank you for your continued cooperation and for your assistance in making this study a successful and meaningful endeavor.

Sincerely,

Senator Mike McGinness
Chairman
Committee to Study Long-Term Care

MM:ss
Enc.
cc w/enc: Scott Scherer, Chief of Staff, Governor's Office
Denice Miller, Senior Policy Advisor

CALL FOR PROPOSALS:



Coming Home: *Affordable Assisted Living*

THE
ROBERT WOOD JOHNSON
FOUNDATION

NCB
DEVELOPMENT
CORPORATION

Purpose

Coming Home, a national program of The Robert Wood Johnson Foundation in partnership with NCB Development Corporation, will provide grant support, technical assistance, and loan funds to states to create affordable models of assisted living targeted to low-income seniors and linked with existing community health care systems. The program has a specific interest in creating models that are workable in smaller and rural communities where there is a particular need for affordable assisted living.

Background

The elderly population with chronic disabilities needs health care, personal care, and social services that often goes beyond the capacity of rural communities to provide, particularly for low-income seniors. Assisted-living facilities that integrate health, personal care, and social services for the elderly have been rapidly expanding in suburban and urban areas. However, few such facilities have been developed in smaller communities or in rural America, and fewer still have been focused on low-income seniors. A major barrier has been a lack of technical assistance and pre-development capital to help states plan, design, and develop such long-term care resources.

In rural America, many elderly are forced to relocate in order to gain access to such services or are unnecessarily institutionalized in nursing homes as a consequence of their inability to find services closer to home. This lack of non-institutional, long-term care services in many rural areas may help explain why residents of nursing homes in rural areas tend to be younger and less disabled than their urban counterparts.

This program builds on the success of the first Coming Home program (1992-1998), which provided technical assistance and access to capital through a revolving loan fund for rural communities to help them develop community-based systems of chronic care that linked health and social services with housing. Results from the first five sites have shown that state agencies — both Medicaid and the housing finance authority — are willing to make the necessary reimbursement and regulatory changes to create such programs, and that nonprofit social health providers are willing to act as project sponsors. The program's revolving loan fund served as a vehicle to provide feasibility assessment and pre-development funds.

This new Coming Home initiative will seek to advance the development of affordable assisted living by helping states create a supportive policy environment, demonstrate the viability of financing the facilities, and build partnerships among state agencies, housing developers, and nonprofit providers.

The program

The Foundation is expanding the Coming Home program to support the development of models of assisted living that focus on low-income, frail seniors. This program consists of three integrated components.

First, grants of up to $300,000 each over three years will be made available to up to eight states to encourage expansion or implementation of regulatory, reimbursement, and financing environments that will facilitate demonstrations of affordable assisted living. States will be expected to provide cash or in-kind matching support in each year of the program.

Second, this program will use a revolving loan fund as a vehicle to provide both feasibility assessment and pre-development capital to the nonprofit sponsors of affordable housing in the eight grantee states. The purpose of these funds will be to encourage providers to focus their development efforts on a low-income senior population. In order to facilitate the development of these projects, NCB Development Corporation (NCBDC) and The Robert Wood Johnson Foundation have set up an $8-million revolving loan fund to provide pre-development capital. NCBDC and grantee states will identify and work with nonprofit sponsors who would be eligible for these funds.

Third, technical assistance also will be provided to the grantee states by the Coming Home program staff to assist in all phases of planning and implementation. This will include: *1)* ***policy analysis***, such as working with Medicaid to adapt a state's home and community-based services waiver for assisted living, helping to coordinate the regulations on the housing and service sides; *2)* ***financial analysis***, such as working with nonprofit social health care providers to access both public and private funds for services and housing; and *3)* ***facilitating communication*** among the various stakeholders, from community providers to state agencies to bankers. Further, the national program staff will provide information about emerging best practices in affordable assisted living.

Recognizing that states are in different stages of readiness to implement a reimbursement, regulatory, and housing environment that supports affordable assisted living, the program will focus on those states with the ability to develop demonstrations and to move the program forward quickly and efficiently.

Selection criteria

The chances for success in creating a program of this type are greatest in states that have already achieved a consensus on policy direction. In order for states to be eligible to participate in the program, they would already have a home- and community-based services waiver for assisted living in place and have, at a minimum, a mechanism for funding the services component of assisted living. Additionally, the state's housing finance authority would need to place a priority on "senior housing with services" projects. It is anticipated that these states would be within 12 months of approval for demonstration projects.

One application per state will be accepted. The applicant must be the office that administers Medicaid, the Home and Community-Based Waiver program, the housing finance authority, or an agency designated by the governor's office to be responsible for overseeing and coordinating the planning and development of the proposed program. The lead organization should either represent or be charged with convening an interagency working group that, at a minimum, must include both the Medicaid agency, and where applicable the agency that administers the Home and Community-Based Waiver program, and the housing finance authority. The working group may also include other relevant members, such as the Department of Public Health, Department of Health Services, Department on Aging, state budget office, legislative oversight committees, or others. The interagency working group may be pre-existing or formed expressly to carry out the work proposed.

The Coming Home staff anticipates that the funding will be used to assist the state agencies in a collaborative effort that will promote participation of all interested parties in the creation and operation of affordable assisted-living facilities integrated into community-based systems of long-term care.

The following criteria will be used in assessing the proposal from each state:

- The state already will have in place or be ready to implement a reimbursement mechanism that will fund the service portion of assisted living for Medicaid-eligible seniors.
- The housing finance authority will have targeted seniors as a priority in their qualified application plan (QAP), be willing to adjust the QAP to reflect seniors as a priority, or have other forms of equity or secondary debt available to create affordable housing.
- The proposed models will have the potential to lead to systemic change in statewide financing and regulatory systems allowing and encouraging nonprofit providers to create affordable assisted living beyond the demonstration stage.
- The state will be willing to create demonstrations of affordable assisted living in partnership with providers ready and willing to take on the first demonstrations. Those demonstrations will have the potential to begin within 12 months.
- The demonstrations will use an integrated approach to serving the senior population, bringing together local providers of chronic care services and incorporating other necessary community services such as adult day health care, respite care, clinic services, and nutrition.

Additional technical assistance

States that are in the early stages of developing assisted living that may not qualify for grant funds may benefit from technical assistance services and materials produced by the Coming Home program. Although the program will not make grant dollars available to these states, it will provide them with technical assistance services and published materials. Priority for technical assistance, however, will be given to grantee states.

Use of grant funds

Grant funds may be used for project staff salaries and travel, for planning activities, supplies, and other direct expenses essential to the project. Grant funds may not be used to replace funds currently being used to support similar activities or to reduce ongoing deficits from pre-existing programs.

Grantees will be expected to meet Foundation submission requirements of annual and final narrative and financial reports. Project directors and key project staff will be asked to attend annual meetings and report on their projects.

Program direction

Direction and technical assistance for the program will be provided by NCB Development Services (NCBDS), a limited liability company of the NCB Development Corporation. NCBDS was created to foster community development by providing technical assistance and pre-development financing to nonprofit community-based organizations nationwide. It is devoted to creating affordable service-enriched housing for seniors (assisted living) through the Coming Home program. The National Program Director is David Nolan. Foundation staff responsible for the initiative are Jane Isaacs Lowe, PhD, senior program officer; Robert Hughes, PhD, vice president; Diane Montagne, program assistant; Stuart Schear, senior communications officer; and Marco Navarro, financial officer.

NCBDS will oversee all aspects of the program and provide directly or through contractual relationships all technical assistance to individual states, communities, and providers. It will prepare and disseminate technical-assistance materials and establish an on-line information service that will be available to grantees as well as to states that do not receive funding under this program. NCBDS also will manage and make all funding decisions regarding the program's revolving loan funds to grantee states.

A National Advisory Committee will assist in proposal review, participate in site visits during the review process, make recommendations for grants to Foundation staff, and assist in monitoring the ongoing operation of the program. The Foundation does not provide individual critiques of proposals submitted.

Evaluation and monitoring

An independent research group selected and funded by the Foundation may conduct an evaluation of the program. As a condition of accepting Foundation funds, grantees will be expected to participate in the evaluation. Grantees also will be required to submit to the National Program Office information needed for overall program management and monitoring.

How to apply

The lead state agency wishing to apply should submit a letter of intent to:

David C. Nolan
Director, Coming Home
NCB Development Services
1333 Broadway, Suite 602
Oakland, CA 94612
Phone: 510-496-2225
Fax: 510-496-0404
e-mail: dnolan@ncbdc.org
Web site: www.ncbdc.org

The letter of intent should briefly describe the project, the partner agencies, and the contact person. Upon receipt of this letter, an application package and guidelines for preparing a proposal will be sent.

Timetable

March 1, 2000	Letters of Intent Due
June 1, 2000	Proposals Due
September 1, 2000	Grants Awarded

Note that proposals that are received before the June 1, 2000 deadline will be reviewed as soon as they are received. Site visits may be scheduled immediately after that review and awards will be announced as proposals are accepted.

About RWJF

The Robert Wood Johnson Foundation® was established as a national philanthropy in 1972 and today is the largest U.S. foundation devoted to health care. The Foundation concentrates its grantmaking toward three goal areas:

- to assure that all Americans have access to basic health care at reasonable cost;
- to improve the care and support for people with chronic health conditions; and
- to promote health and reduce the personal, social, and economic harm caused by substance abuse—tobacco, alcohol, and illicit drugs.

This document, as well as many other Foundation publications and resources, is available on the Foundation's World Wide Web site:
www.rwjf.org

THE
ROBERT WOOD
JOHNSON
FOUNDATION

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Post Office Box 2316
Princeton, New Jersey 08543-2316

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12/99

APPENDIX G

Project Summary and Implementation Timeline for the Coming Home Initiative

PROJECT SUMMARY

In order to develop affordable assisted living (AAL) we must rely on public sector programs and public sector dollars. Currently there is very fractured delivery mechanism in Nevada for these public sector dollars. Medicaid does not pay for housing, only services. The housing dollars do not cover services, only housing.

Nevada's Medicaid Office in the Division for Health Care Financing and Policy (DHCFP) has established a system with the Division for Aging Services (DAS) through an Interlocal Agreement to offer Home and Community Based Waiver (HCBW) services and allow for billing to be done through DAS to Medicaid's Fiscal Intermediary, Anthem Blue Cross and Blue Shield (ABCBS).

In Nevada, there are no statutes or regulations that define "assisted living." However, NRS 449.017 defines "residential facility for groups" as "an establishment that furnishes food, shelter, assistance and limited supervision." The Bureau of Licensure and Certification, within the Health Division, is responsible for statewide inspection surveys of medical and dependent care facilities, including nursing and group care facilities, (which includes such residential facilities for groups), for compliance with state licensure regulations contained in NRS Chapters 449 and 652.

The request for the $300,000 for the 3 year grant period will be used to staff a working group comprised of members from the Division for Aging Services, Health Care Financing and Policy Division, and the Housing Division. It will also provide the travel and other costs needed for the working group to have monthly meetings involving an advisory committee of those interested in AAL. The hiring of the coordinator will provide the staff support to allow the WG to provide the needed leadership, insight, technical expertise and focus to bring to fruition a fully functioning and well funded affordable assisted living program for the elderly, including those in rural Nevada.

The AAL project would be implemented in two phases. Phase I would involve amending the current Medicaid waiver for the elderly to allow 24-hour services to residents of AAL. During Phase I, existing affordable housing facilities would be converted to AAL by implementing the 24-hour service component.

Phase II would coordinate regulatory and budgeting actions necessary to create a minimum of 220 additional AAL units in Nevada with at least one new AAL facility to be located in rural Nevada.

TIME LINE AND WORK PLAN

Year One

- September 1, 2000: Three-year Grant period commences.
- By September 30, 2000: Grant Working Group (WG) develops project coordinator specifications/job description and submits to State Personnel for processing and posting.
- By November 15, 2000: Interviews completed and fulltime Project Coordinator selected and hired to staff Working Group.
- By March 15, 2001: Working Group forms advisory committee from local, county and state individuals and agencies involved with affordable housing (AH) and relevant service in order to ascertain existing AH resources, potential additions to same, map out areas of fragmentation, potential for coordination, and establish a network of advocates for AH.
- By April 15, 2001: Coordinator to assist Working Group to analyze data collected as well as feedback from this network and produce position papers/fact sheets to provide the Governor with information on AAL needs and policy issues related to same, as well as testifying to appropriate committees and assisting in bill drafts. The WG and coordinator will conduct a cost benefit study to assess the relative benefit of funding AAL as a cheaper alternative to other long term care facilities such as traditional nursing homes.
- By June 30, 2001: Submit HCBW amendment to Health Care Financing Administration to allow assisted living service to be added to waiver program.
- By August 31, 2001: Select three Phase I partners with appropriate housing and match with necessary service providers to increase the number of AAL units in Nevada.

Year Two

- By December 31, 2001: Amend interlocal agreement with to allow Medicaid billing for assisted living sole source support services.
- By April 15, 2002: Present comprehensive plan to Governor in support of both Phase II and the future direction that Nevada should take to maximize its AAL options.
- By July 1, 2002: Anticipated budgetary support for Phase II in place, as well as legislative requirements identified.

- By August 1, 2002: The WG to conduct a cost benefit study to assess the relative benefit of funding AAL as a more cost-effective alternative to other long term care facilities such as traditional nursing homes.

- By August 31, 2002: Develop all educational materials.

Year Three

- By October 1, 2002: Adjust protocols with Medicaid as necessary and develop monitoring and quality assurance (QA) protocols and reporting requirements applicable to Phase II projects.

- By February 15, 2003: WG to publish a comprehensive AAL plan for Nevada based on an integrated housing and support services approach. This plan will include roles for the AAL network of funders, service providers, and consumers as well as the public and private regulatory and advocacy agencies. This plan will include budgetary support and regulatory changes still needed to complete the integrated approach.

- By July 1, 2003: WG to develop and distribute guides and application kits for establishing AAL facilities or converting existing facilities.

- By August 1, 2003: Conduct workshops for prospective AAL providers and the agencies/organizations involved covering both housing and services requirements.

- By August 31, 2003: Select successful Phase II RFP applicants from Housing Division and/or DAS.

- By December 31, 2003: WG will conduct assessment of Nevada's project to identify its successes and failures and will highlight lessons learned to be shared with others in the AAL field. The results will be provided to RW Johnson Foundation in a written report detailing what AAL facilities were created, services provided, and changes made for the $300,000 invested.

- By January 31, 2004: All Phase I and II projects will be rented up.

APPENDIX H

Response from the Department of Human Resources Regarding the Feasibility of Implementing an Assisted Living Option

STATE OF NEVADA
DEPARTMENT OF HUMAN RESOURCES
DIVISION OF HEALTH CARE FINANCING AND POLICY
1100 E. William Street. Suite 116
Carson City, Nevada 89701

CHARLOTTE CRAWFORD
Director

JANICE A. WRIGHT
Administrator

KENNY C. GUINN
Governor

00 JUN 23 PM 5:13
L.C.B.
FISCAL ANALYSIS DIVISION

June 19, 2000

MEMORANDUM

TO: Steve Abba, Senior Program Analyst
Fiscal Analysis Division
Legislative Counsel Bureau

THROUGH: Charlotte Crawford, Director
Department of Human Resources

FROM: Janice A. Wright, Administrator J Wright
Division of Health Care Financing and Policy

SUBJECT: LEGISLATIVE COMMITTEE STUDYING LONG-TERM CARE

We are providing our response to your May 24, 2000 memorandum.

Question 1:
Amending and expanding the existing CHIP waiver to include an affordable assisted living option appears to provide the easiest opportunity to introduce this initiative. Please confirm.

Answer 1:
Discussions related to the benefits of amending and expanding the CHIP waiver versus the group care waiver have occurred. The Medicaid staff believe that the CHIP waiver would be the most efficient course due to service provisions already included with the waiver and eligibility criteria. Another option that was considered was to do a model waiver, however, this would be a more time consuming, labor intensive process. The consensus is that expanding the CHIP waiver is the best solution.

If the Division of Aging Services (DAS) is awarded the "Coming Home" grant, this would allow for that analysis necessary to craft this program and develop the infrastructure. If not, DAS would still need to analyze this if the Legislature approves the concept of an assisted living option.

We don't know if we could amend the CHIP waiver to add an assisted living option without first serving all existing people on the CHIP waiting list. We don't know if we would be required to establish a second waiver to allow new people to apply for the assisted living option. This is information that must be researched when the analysis is done.

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<u>Question 2:</u>
At the April 27, 2000 meeting, Ms. Wright indicated the likely population that could be served under an affordable assisted living option would be nursing home clients currently classified at an ICL 1 and at an ICL 2 level (approximately 526 clients). Additionally, Ms. Wright cited information based on experience from other states that two-thirds of the population that may qualify for this option are from an existing home environment

<u>Answer 2:</u>
Currently, there are 160 Medicaid ICL 1 and 336 ICL 2 residents in the state for a total of 496. Typically, only 5 to 10% of residents classified in these two levels would be appropriate to be placed in a Group care/Assisted living facility. This would be about 25 to 50 residents that would be appropriate to be placed from a nursing facility to a less restrictive environment, which is going from a medical model to a social model. This can be verified by the past Medical Review annual reports.

The Medical Review Team assesses level of care during all reviews and 9 out of ten residents who have been determined to be an ICL 1 or ICL 2 have refused alternate placement of group care. The reasons have been they are comfortable and do not want to go through a change; as this is a resident's right the placement is not recommended. Currently, the Group care waiver does not have a waiting list and part of this is due to residents in nursing facilities not wanting to make a change. We believe the assisted living option would be most attractive to those individuals living in their private homes now, but need some assistance with a few activities.

<u>Question 3</u>:
Please clarify what the eligibility criteria would be for an affordable assisted living option assuming the initiative is introduced as part of the existing CHIP waiver.

<u>Answer 3:</u>
The current financial eligibility criteria for the CHIP waiver is 300% of SSI, which is $1,536.

The financial eligibility criteria for the assisted living option would be the same as for the CHIP waiver which is based on Medicaid institutional eligibility criteria: 300% of SSI or $1,536. The monthly income and the property and resources would be the same criteria for the CHIP waiver and for the assisted living option. The Program eligibility would also be the same as for the CHIP waiver which is: persons 65 and older, persons who meet a Nursing Facility Level of Care, persons who are at risk of institutionalization and can be maintained in the community with the home and community based services without exceeding institutional level costs.

ICL 1 monthly costs are $1,885 and we can't exceed 75% of that or $1,014, according to the CHIP cost limits. ICL 2 monthly costs are $2,320 and we can't exceed 75% of that or $1,740, according to the CHIP cost limits.

Question 4:
Please explain the various Medicaid services that should be included as part of this initiative and the cost for those services. I realize this information may not be totally quantified at this point; however, the Department's best estimate is needed to evaluate the option. If assumptions are used, please explain the assumptions.

Answer 4:
The Medicaid services that should be included for assisted living are personal care services, homemaker, chore, attendant care companion services, medication oversight (to the extent permitted under State law), therapeutic social and recreational programming, provided in a home-like environment in a licensed (where applicable) community care facility, in conjunction with residing in the facility. This service should include 24-hour on-site response staff to meet scheduled or unpredictable needs in a way that promotes maximum dignity and independence, and to provide supervision, safety and security. Other individuals or agencies may also furnish care directly, or under arrangement with the community care facility, but the care provided by these other entities supplements that provided by the community care facility and does not supplant it. Medicaid can not reimburse for room and board per federal regulation.

Personalized care would be furnished to individuals who reside in their own living units (which may include dually occupied units when both occupants consent to the arrangement) and may or may not include kitchenette and/or living rooms and which contain bedrooms and toilet facilities.

Question 5:
The Committee has previously discussed the possibility of introducing an affordable assisted living option as a pilot project or with a specific number of funded slots similar to other Medicaid waiver programs. In the Department's opinion, if an affordable assisting living option is recommended, what would be the appropriate size of a pilot project or the appropriate number of slots to be funded to ensure that the effectiveness of the initiative can be fully evaluated to meet any federal and state requirements?

Answer 5:
A pilot project for affordable assisting option is recommended with 150 slots. Affordable assisted living is a question the housing authorities would have to address as the assisted living waiver through Medicaid would only be reimbursing the services, but not the cost of housing.

The way we arrived at the recommendation of 150 slots was based on experience from other states that typically 5 to 10% of the residents at ICL 1 and ICL 2 would be most appropriate to be placed in an assisted living facility, so that would mean 25 to 50 individuals. Other states experience indicates that about two thirds of the population that qualify for this option are from an existing home environment. If 50 individuals are from an intermediate care facility then 100 could come from an existing home environment, and we would need to add 150 slots for the CHIP waiver. Please also refer to Answer 2.

Question 6:
Additionally, please briefly explain if there are any Olmstead issues that would need to be considered if an affordable assisted living option is implemented but restricted in its size either via a pilot project or specific number of funded slots.

Answer 6:
We believe that Nevada could demonstrate compliance with Olmstead if it has a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings and a waiting list that moves at a reasonable pace, not controlled by an endeavor to keep its institutions fully populated.

The Medicaid program currently serves Medicaid clients under four waivers in a home and community based environment. These waivers have been in existence for a number of years and will continue to be Nevada's response to Olmstead.

Olmstead could be an issue especially when you have a waiting list. Nevada Medicaid at this time has a small number of **appropriate** ICL 1 and ICL 2 clients in nursing facilities that want to be placed in a less restrictive environment. The activities occurring throughout the United States related to the Olmstead Case are ongoing. The issues are not necessarily predictable and not all known at this time.

Question 7:
Please clarify the savings that might possibly be realized if an affordable assisted living option is implemented, and if nursing home clients as mentioned above are targeted as potential candidates. Additionally, please clarify in the Department's opinion if it would be appropriate to designate a specific number of cases or slots for nursing home clients only and if so, what would be an appropriate mix of nursing home clients to existing home environment clients.

Answer 7:
The Waiver services for Assisted Living, by federal definition, could include personal care, homemaker, chore, companion, medication oversight, and therapeutic social and recreational programming. Whichever services were selected would be bundled into a service titled Assisted Living. Other than case management, these would be the only waiver services the individuals would be receiving. Including the case management costs, the per capita waiver costs are projected to be $6,000 for each of the 150 new assisted living clients or an aggregate of $900,000 annually. The additional state plan costs for these individuals are estimated at $2,978 per individual or $446,700 collectively. Therefore, the 150 recipients covered under a waiver option would cost Medicaid approximately $1,346,700.

For the forty persons projected to be deinstitutionalized annually, Nevada would realize a savings of $1,009,200. This figure is based on the following information. FY 99 data demonstrates that ICL 1 costs $1,885 and an ICL 2 costs $2,320 per month. Assuming 20 come from ICL 1 and 20 from ICL 2, the savings is $1,009,200. The difference demonstrates a potential savings to the state of $396,060, only if other Medicaid clients do not fill those 40 beds which are vacated.

The number of 40 residents was selected as it between the numbers of 25 to 50 residents that would be appropriate as described on page 2. This service package is more attractive than the group care package which is projected to result in more persons selecting it. Further there would be a concerted effort on the part of case workers to inform residents of the advantages of living in assisted living rather than in a nursing facility. There has not been a strong discharge planning or case management effort to inform the residents of the choices and there has not been such a good choice previously. Some of the states who were awarded the federal grants on nursing home transition have been surprised at the number of nursing home residents who have selected community based care; however it was selected when there was a specific program to facilitate the transition and there was a positive choice to make. The task group continues to support the projected number of 40 residents coming out each year as realistic.

The additional 110 persons would be at an aggregate cost of $987,580 (including waiver and Medicaid State plan services). Since serving 150 clients on the waiver could cost $1,346,700, but a savings could occur of $1,009,200 if 40 of those clients are de-institutionalized, the additional cost could be $337,500, of which the 50% General Fund need would be $168,750. This is based on preliminary projections of services and costs that have not been refined. These dollars would reflect a potential cost avoidance by preventing people from the institutional cost, however, it would be an added expense to Medicaid, as a new population could be served. These projections assume that no individuals would lose their Medicaid eligibility by being moved out of an institution. As sometimes occurs, individuals are not eligible for Medicaid because their income is too high, but became eligible when they go into the institution. They then become eligible for full Medicaid coverage, which includes the cost of institutionalization and all other medical services. We are in the process of building our budgets now, and will develop current costs for this portion by using the next biennium proposed figures.

<u>Question 8</u>:
It is my understanding if Nevada is fortunate enough to receive one of the grant awards through the "Coming Home" initiative a portion of the award would be used for administrative needs. If Nevada does not receive one of the grant awards through the "Coming Home" initiative, please explain what, in the Department's opinion, the administrative needs (staffing and/or operating support) would be to implement an affordable assisted living option. Please identify the administrative needs by agency and the estimated cost by fiscal year (start-up and on going).

<u>Answer 8</u>:
The task force working on the Coming Home Grant is requesting grant monies to be expended for contracting an individual and their support needs to evaluate the existing infrastructures in the public and private sectors related to affordable assisted living. There are a number of services being delivered currently. There are also housing options in existence and future projects in conceptual stages. There has been nothing done to

coordinate all of the factions involved in actually developing and providing affordable assisted living. Rather than add to the confusion, the goal of the grant was to help mobilize all of the necessary resources to develop a more seamless and rational approach to provide affordable assisted living. The end product would be a great asset to the State and result in a much clearer vision for the future needs of both housing and service. If Nevada is not awarded the grant, the task force believes this need still exists and the state needs to fund this project, as these tasks have to be completed prior to moving into an affordable assisted living model.

The following costs would occur as a result of Medicaid expanding the CHIP waiver. Administrative costs for the 150 slots: two FTE's for Welfare, three case managers for the Division for Aging, one Medicaid FTE and associated administrative costs, e.g. travel, work stations, benefits, etc. These 6 FTE's would also increase the work demands of the supervisors and administrative hierarchy of each agency and related costs. Funding only the administrative aspects of the waiver option without clarifying the existing complexities stated above will compound the problems existing in the current infrastructure.

Position Salary & Fringe	Ancillary Costs	Total
1. 2 ECSII @$45,421 (Grade 34/1) $90,842	$21,224	$112,066
2. 3 – SWPSI@$43,561 (Grade 33/1) $130,683	31,836	162,522
3. 1 - MSSIII@$45,421	10,612	56,033
		$320,621

Question 9:
Finally, assuming that funding is provided during the upcoming legislative process, in the Department's opinion when, at the earliest, could an affordable assisted living option be realistically implemented?

Answer 9:
We estimate the following time line for a realistic approach to implementing affordable assisted living as a service covered by Medicaid: SFY2001 would hopefully grant us through the legislature one position to oversee the planning process; SFY2002 would be consumed with all of the data collection and analysis obtained during the planning process in order to implement an organized approach between housing and services; SFY2003 would require the time to put this option into the budget infrastructure development process and receive legislative approval; and SFY2004 would allow sufficient time to amend the waiver accommodating the time frame that HCFA is currently demonstrating for amendment approval, e.g. 90 days once the amendment is

received, return of the amendment for questions to be answered by the State, re-submission of comments to HCFA and an additional 90 day time frame for each sequential request.

We trust that the information provided meets with your needs and that you will contact us should you need further assistance. Thank you for this opportunity to share information with you.

APPENDIX I

Response from the Division for Aging Services dated June 1, 2000

STATE OF NEVADA
DEPARTMENT OF HUMAN RESOURCES
DIVISION FOR AGING SERVICES
3416 Goni Road, Building D, Suite 132
Carson City, Nevada 89706
(775) 687-4210 • Fax (775) 687-4264
dascc@govmail.state.nv.us

KENNY C. GUINN
Governor

CHARLOTTE CRAWFORD
Director

MARY LIVERATTI
Administrator

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L.C.B.
FISCAL ANALYSIS DIVISION

MEMORANDUM

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JUN - 1 2000
DIRECTOR'S OFFICE
DHR

DATE: June 1, 2000

TO: Steve Abba, Senior Program Analyst
Legislative Counsel Bureau

THROUGH: Charlotte Crawford, Director
Department of Human Resources

FROM: Mary Liveratti, Administrator
Division for Aging Services

REGARDING: Legislative Committee Studying Long-Term Care

Pursuant to your memo of May 12, 2000, the Division for Aging Services is responding to your request for information regarding the Community and Home-based Initiatives Program (CHIP) and the Adult Group Care Waiver Program for the work session meeting of the Legislative Committee to Study Long Term Care.

1. Requested information:

For the work session, please provide information on the projected cost if the eligibility level for the Group Care Waiver was increased to 300 percent of the SSI level to be consistent with the eligibility criteria for the CHIP and Physically Disabled waivers. As part of the projection, please include all medical and administrative costs as well as the potential savings that may be realized by deferring cases from nursing homes.

Reply:

During the period of July 1, 1999 through April 30, 2000, there were 30 CHIP clients who went into nursing homes because they were unable to access the Group Care Waiver because they were over the income eligibility. If we assume there will be 40 additional clients by increasing the income eligibility to 300 percent of the SSI level, the cost projection would be:

Las Vegas Regional Office
340 N. 11th Street, Suite 203
Las Vegas, Nevada 89101
(702) 486-3545
Fax: 486-3572
dasvegas@govmail.state.nv.us

Reno Regional Office
445 Apple Street, Suite 104
Reno, Nevada 89502
(775) 688-2964
Fax: 688-2969
dasreno@govmail.state.nv.us

Elko Regional Office
850 Elm Street
Elko, Nevada 89801
(775) 738-1966
Fax: 753-8543
daselko@sierra.net

40 clients x $4,102 per year = $164,080

Assuming half of the clients would be ICL I and half would be ICL II, the institutional cost would be:

20 clients x $22,620 per year = $ 452,400
20 clients x $27, 840 per year = $ 556,800
Total nursing home cost = $1,009,200

Estimated savings: $ 845,120

2. Requested information:
Please provide information on the current waiting list for the CHIP program broken out by Medicaid cases and state-only cases. Additionally, please clarify how long an individual on the waiting list/s identified above must wait to receive CHIP services once eligibility has been determined. Since it appears a waiting list for CHIP services will always exist to a certain extent, please explain from the Department's perspective what a reasonable wait period would be for a client to access CHIP services once eligibility has been determined.

Reply:
The current waiting list for CHIP is:

Medicaid program:	622
State-only program:	51

The time between eligibility determination and service placement is relatively short. Once eligibility is determined, the majority of clients receive services within a week. However, clients living in outlying areas may wait several weeks if a service provider is not available.

There is a longer wait time while eligibility is being determined. The time between the submission of an application for CHIP and determination of eligibility is currently running two to three months in the North and four to six months in the South.

In order to determine eligibility, a social worker must assess whether the individual is at risk of nursing home placement. The social worker must conduct a face-to-face visit to assess the person's level of functioning, determine the services needed, develop a plan of care and assist with the Medicaid or State application.

The Medicaid/State application determines if the person meets the income/asset eligibility requirements. Medicaid eligibility is determined by the State Welfare Division and may take up to 45 days. In some cases, the time is longer if additional information is needed or the applicant does not cooperate with requests for information.

For State-only cases, the Division for Aging Services determines the financial eligibility. Eligibility is usually determined within two weeks. It should be noted that there is no asset limit for the State-only program, so verification is less time consuming.

3. Requested information:

In the February 24, 2000 correspondence, the Department indicated that the patient liability issue has been a problem with administering the CHIP waiver and especially troublesome for individuals transferring from the Disabled waiver. It appears from the information provided that is the patient liability requirement was eliminated, little savings to the Medicaid program would actually be realized. In fact, it would appear there may be several program benefits realized. The benefits would include not having to use state funds from the state-only cases to pay for uncollected patient liability, not having to spend administrative time to account for patient liability and not having to duplicate the Medicaid Estate Recovery process which would recover the cost for services as a later date.

Please confirm if these observations are accurate, and that the revenue generated from the patient liability requirement is approximately $89,000 per year. Additionally, please explain why the patient liability requirement was originally included as part of the CHIP waiver and if eliminating the requirement would have any detrimental impact to the CHIP program or any other Medicaid/Aging Services program.

Reply:

Yes, your observations are accurate regarding the benefits. I cannot explain why the patient liability requirement was originally included as part of the CHIP waiver because I was not involved with the waiver at that time. Several people who may know why patient liability was included have retired from State service.

I do not believe there would be any detrimental impact to the CHIP program or on any other Medicaid/Aging Services program.

If you have any questions, please contact me.

cc: Scott Scherer, Chief of Staff, Governor's Office

APPENDIX J

Responses from the Division for Aging Services (dated June 1, 2000) and the Division of Health Care Financing and Policy (dated February 24, 2000)

KENNY C. GUINN
Governor

STATE OF NEVADA
DEPARTMENT OF HUMAN RESOURCES
DIVISION FOR AGING SERVICES
3416 Goni Road, Building D, Suite 132
Carson City, Nevada 89706
(775) 687-4210 • Fax (775) 687-4264
dascc@govmail.state.nv.us

CHARLOTTE CRAWFORD
Director

MARY LIVERATTI
Administrator

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L.C.B.
FISCAL ANALYSIS DIVISION

RECEIVED
JUN - 1 2000
DIRECTOR'S OFFICE
DHR

MEMORANDUM

DATE: June 1, 2000

TO: Steve Abba, Senior Program Analyst
Legislative Counsel Bureau

THROUGH: Charlotte Crawford, Director
Department of Human Resources

FROM: Mary Liveratti, Administrator
Division for Aging Services MJL

REGARDING: Legislative Committee Studying Long-Term Care

Pursuant to your memo of May 12, 2000, the Division for Aging Services is responding to your request for information regarding the Community and Home-based Initiatives Program (CHIP) and the Adult Group Care Waiver Program for the work session meeting of the Legislative Committee to Study Long Term Care.

1. **Requested information:**

For the work session, please provide information on the projected cost if the eligibility level for the Group Care Waiver was increased to 300 percent of the SSI level to be consistent with the eligibility criteria for the CHIP and Physically Disabled waivers. As part of the projection, please include all medical and administrative costs as well as the potential savings that may be realized by deferring cases from nursing homes.

Reply:

During the period of July 1, 1999 through April 30, 2000, there were 30 CHIP clients who went into nursing homes because they were unable to access the Group Care Waiver because they were over the income eligibility. If we assume there will be 40 additional clients by increasing the income eligibility to 300 percent of the SSI level, the cost projection would be:

40 clients x $4,102 per year = $164,080

Assuming half of the clients would be ICL I and half would be ICL II, the institutional cost would be:

20 clients x $22,620 per year = $ 452,400
20 clients x $27, 840 per year = $ 556,800
Total nursing home cost = $1,009,200

Estimated savings: $ 845,120

2. Requested information:
Please provide information on the current waiting list for the CHIP program broken out by Medicaid cases and state-only cases. Additionally, please clarify how long an individual on the waiting list/s identified above must wait to receive CHIP services once eligibility has been determined. Since it appears a waiting list for CHIP services will always exist to a certain extent, please explain from the Department's perspective what a reasonable wait period would be for a client to access CHIP services once eligibility has been determined.

Reply:
The current waiting list for CHIP is:

Medicaid program:	622
State-only program:	51

The time between eligibility determination and service placement is relatively short. Once eligibility is determined, the majority of clients receive services within a week. However, clients living in outlying areas may wait several weeks if a service provider is not available.

There is a longer wait time while eligibility is being determined. The time between the submission of an application for CHIP and determination of eligibility is currently running two to three months in the North and four to six months in the South.

In order to determine eligibility, a social worker must assess whether the individual is at risk of nursing home placement. The social worker must conduct a face-to-face visit to assess the person's level of functioning, determine the services needed, develop a plan of care and assist with the Medicaid or State application.

The Medicaid/State application determines if the person meets the income/asset eligibility requirements. Medicaid eligibility is determined by the State Welfare Division and may take up to 45 days. In some cases, the time is longer if additional information is needed or the applicant does not cooperate with requests for information.

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3. Requested information:
In the February 24, 2000 correspondence, the Department indicated that the patient liability issue has been a problem with administering the CHIP waiver and especially troublesome for individuals transferring from the Disabled waiver. It appears from the information provided that is the patient liability requirement was eliminated, little savings to the Medicaid program would actually be realized. In fact, it would appear there may be several program benefits realized. The benefits would include not having to use state funds from the state-only cases to pay for uncollected patient liability, not having to spend administrative time to account for patient liability and not having to duplicate the Medicaid Estate Recovery process which would recover the cost for services as a later date.

Please confirm if these observations are accurate, and that the revenue generated from the patient liability requirement is approximately $89,000 per year. Additionally, please explain why the patient liability requirement was originally included as part of the CHIP waiver and if eliminating the requirement would have any detrimental impact to the CHIP program or any other Medicaid/Aging Services program.

Reply:
Yes, your observations are accurate regarding the benefits. I cannot explain why the patient liability requirement was originally included as part of the CHIP waiver because I was not involved with the waiver at that time. Several people who may know why patient liability was included have retired from State service.

I do not believe there would be any detrimental impact to the CHIP program or on any other Medicaid/Aging Services program.

If you have any questions, please contact me.

cc: Scott Scherer, Chief of Staff, Governor's Office

STATE OF NEVADA
DEPARTMENT OF HUMAN RESOURCES
DIVISION OF HEALTH CARE FINANCING AND POLICY
1100 E. William Street, Suite 116
Carson City, Nevada 89701

CHARLOTTE CRAWFORD
Director

JANICE A. WRIGHT
Administrator

KENNY C. GUINN
Governor

February 24, 2000

MEMORANDUM

To: Steve Abba, Senior Program Analyst
Fiscal Analysis Division

Through: Charlotte Crawford, Director, CC/110
Department of Human Resources

From: Janice A. Wright, Administrator J Wright
Division of Health Care Financing and Policy
Mary Liveratti, Administrator,
Division for Aging Services

Subject: LEGISLATIVE COMMITTEE STUDYING LONG-TERM CARE IN NEVADA

You have requested information for the Legislative Committee Studying Long-Term Care in Nevada on Affordable Assisted Living. To assist your research, representatives from DETR, the Division for Aging Services and Medicaid met with staff from Accessible Space, Inc. (ASI) and Jon Sasser on February 14, 2000 to discuss feasibility options associated with affordable assisted living. The primary focus was on "the issues the Department would have to explore and consider for determining whether or not a waiver...has merit and should be pursued". We have prepared the following responses to your questions.

<u>Question No. 1:</u>

The issues the Department would have to explore and consider are whether or not a waiver of this type has merit and should be pursued. Please address the issue of how cost neutrality would be determined. As part of the presentation, please indicate if the Department can readily determine if there are people currently in a nursing home who would be more appropriately placed in a 24-hour assisted living situation. The resources available within the Department to pursue a waiver of this type, should also be a consideration.

<u>Answer:</u>

The issues that should be pursued include, but are not limited to:

1.) We would need to define the population that would be served in order to understand what types of services would be needed, how many recipients would fall into this category of need, and how those services (or-if) are currently being provided;

2.) We need to define assisted living;
3.) We need to determine the unmet needs of existing clients;
4.) A waiver is certainly an option and the discussion extended into which existing waiver (such as the CHIP waiver) would be most appropriate to amend, or would we need a new waiver; not having the information identified in numbers 1-3 above, we were unable to make a determination in this area;
5.) Other non-waiver options were discussed, e.g. replicating a model used by DETR and ASI that uses Medicaid dollars to provide services to the disabled or establishing a per diem rate based on the types of services that might be needed and are currently funded by Medicaid; we discussed options of whether this would be a sole source provider situation or require an RFP process.

The issue of cost neutrality was difficult to resolve as we were unsure on what to base the assumption of cost neutrality. HCFA requires that cost neutrality exist on each waiver program. For example, this is assured by requiring that the HCBW per capita cost of waiver services and other Medicaid services not exceed a comparable recipient's per capita cost of institutional services and other Medicaid services. This is projected annually for the 5 year life of a waiver and cannot be exceeded. State's may establish more restrictive cost caps.

The Department cannot readily determine if there are currently residents of a nursing home who would be more appropriately placed in a 24-hour assisted living situation. The experts at the meeting believed that there would be relatively few people coming out of nursing homes to move into affordable assisted living. However, the cost savings to the State would be in preventing people from having to go into nursing homes by allowing those people improved access to the group home level.

The Department does not currently have existing resources to work on this waiver, but could develop those needs based on the request of the committee.

<u>Question No. 2:</u>

Can an existing waiver such as the CHIPS waiver, be used to reach the targeted population?

Answer:

The pursuit of a Medicaid waiver was considered, however, the general consensus of the group was to evaluate the potential of amending an existing waiver, specifically the CHIP waiver managed by the Division for Aging Services.

<u>Question No. 3:</u>

What are the type of services that this waiver should provide?

Answer:

We discussed the types of services that should be provided, e.g., PCA, Homemaker and Personal Emergency response systems, however, did not have enough understanding of what other states are offering to capture sufficient Medicaid dollars. Jon Sasser is going to provide us with the name of a contractor who has worked with a number of states in developing affordable assisted living. Through this and other resources we will evaluate the types of services that are medically necessary. It is anticipated that it will require at least six to eight weeks to gather and analyze the information.

Question No. 4:

The population that could be served and the eligibility issues that would need to be addressed in order to serve the targeted population, e.g., should there be restrictions on the source of clients eligible for this waiver or should the program be available to any Medicaid eligible elderly person?

Answer:

The population and eligibility issues were tabled until we had information from other states. We discussed the need to fill in the gap for clients in DETR's program that will have to be re-evaluated when they reach 65. Again, once we have data from other states, we will be better informed to make recommendations.

Question No. 5:

Should a pilot project be considered in lieu of a full-scale program? If so, how would the pilot program conceptually be structured and how many slots would be necessary to adequately analyze the effectiveness of the pilot program?

Answer:

Without knowing more about the types of medically necessary services that could be offered and reimbursed by Medicaid, it is difficult to recommend whether a pilot project would be appropriate. Based on our initial evaluation, it appears that there would need to be considerable volume of clients in order to draw down sufficient dollars for the reimbursement of services.

Additional factors that would need to be considered were we to develop a waiver in the assisted living area are:

1.) Waiver Budgets cannot include room and board but rather the cost of services (personal care, homemaker, day care, transportation, etc.) needed by the person in order to remain outside the nursing facility;
2.) Having enough providers to offer choice to the consumers;
3.) Defining the income guidelines for those waiver recipients since the current Group Care Waiver for the Elderly is limited to those persons at the SSI income level;
4.) Identifying the costs of such a service and factoring it into cost neutrality.

A pilot project could be considered, however, the discussion surrounding a non-waiver option led to the conclusion that we would probably need a significant volume of recipients in order to make the project feasible from a funding perspective. Again, without knowing what services the population might need, it was hard to project volume. If a waiver amendment was the course pursued, then it may not fall into a pilot category.

Question No. 6:

Can the Department present information on Nevada's delivery system compared to states that have or are in the process of incrementally creating a comprehensive single entry point system?

Answer:

A comprehensive single entry point system would enable individuals and their family members to obtain information about available long term care service options, an assessment to evaluate their service needs and a care planning process to develop a service plan that is appropriate and cost effective. A case management system is usually used to perform these functions. In addition, agencies that perform these functions may also be able to authorize a range of home and community based, residential and institutional services.

Some states use Area Agencies on Aging (AAA) as their single entry point, but Nevada does not have area agencies. In Nevada, the case management system under the State Division for Aging Services acts as a single entry point for older persons to access long term care services through the home and community based waiver programs for the elderly. These case managers provide information and referral on all long term care services. However, on-going case management services are only provided to individuals who qualify for the home and community based care programs administered by Aging Services. There is no centralized case management service for all elder Nevadans who need long term care services.

Nevada does not have a comprehensive single entry point for all potential consumers of long term care services. For example, younger disabled persons access information through the Department of Employment, Training and Rehabilitation or the Division of Health Care Financing and Policy. Persons with mental retardation access information and referral through the Division for Mental Health and Developmental Services.

Pre-admission screenings for nursing home admissions may be part of a single entry point system. Nevada does utilize a nursing home pre-admission and assessment screening. This screening is used for all new admissions to nursing homes and for all applicants of home and community based care under the Medicaid Waivers. This screening was developed to ensure individuals are placed at the appropriate level of care.

Question No. 7:

Persons on the Senior CHIP waiver have to pay a patient liability, which has been problematic:

Answer:

Currently, 101 persons on the CHIP Medicaid Waiver program have a patient liability. The annual revenue generated by patient liability is about $89,000 per year. Patient liability is deducted from the billing submitted to Medicaid for waiver services provided by Aging Services.

Accounting staff for Aging Services prepared a bill each month for each client with a patient liability. Payments are tracked and reconciled monthly. Last year we were unable to collect approximately $10,000 in patient liability. Funds from the state-funded CHIP program are used to make up the shortfall. Every effort is made to try to collect the patient liability, which often involves our social workers and their supervisors, in addition to the accounting staff. Failure to pay the patient liability can result in termination from the program.

If patient liability were eliminated, Aging Services would bill Medicaid for the full cost of services provided. Out of $89,000, the share for the state general fund would be $44,500 and the federal share would be $44,500.

Currently, patient liability payments are deducted from the amount recovered under Medicaid Estate Recovery. If patient liability were eliminated under the CHIP waiver program, the Medicaid Estate Recovery unit would recover the full cost of services provided.

Question No. 8:

Individuals who transfer from the Disability Waiver to the CHIP Waiver when they turn 65 years old, move from a program in which they pay no patient liability into a program in which it is required;

Answer:

If patient liability is maintained in the CHIP program, another option for consideration would be to waive the patient liability for persons who transfer from the Disabled Waiver onto the CHIP Waiver. There is no patient liability under the Disabled Waiver. The number of Disabled Waiver clients who have transferred to CHIP has been rather low, less than 10 persons. However, with the increase in slots under the Disabled Waiver, this number could increase in the future.

Question No. 9:

The group care waiver is a nursing home alternative only for those at an SSI level. Other CHIP clients who make above SSI who need more care or supervision have only the option of a nursing facility – a more costly alternative.

Answer:

We are in the process of extracting information regarding the number of CHIP cases that closed due to nursing home placement, who were unable to access the Group Care Waiver for the Elderly because their income was above the SSI level. Although we track the number of closures due to nursing home placement, we have not been tracking this information by income level. We should be able to project a potential cost by the date of the committee meeting.

I hope this is the information the committee was seeking. Please don't hesitate to contact us if you have any questions on this issue.

APPENDIX K

Recommendations to the Legislative Subcommittee to Study Long-Term Care in Nevada from the American Association of Retired Persons (AARP)

AARP in Nevada

RECOMMENDATIONS TO THE LEGISLATIVE COMMITTEE TO STUDY LONG-TERM CARE IN NEVADA

S.C.R.4 (1999)

1. Continuation of the Legislative Committee to Study Long Term Care (CSLTC) in Nevada for at least the next five years, through the 2005 Legislature, is essential. Consideration should be given to establishing a Long Term Care Committee as a Standing Committee of the Nevada Legislature.

2. The Legislative Committee to Study Long Term Care in Nevada should formally establish work groups to include subject matter experts from state and local government, provider organizations, and consumer organizations.

   The CSLTC must have sufficient staff, or consultant, resources to facilitate and report the results of the designated work groups.

3. The immediate goal of the CSLTC should be, through statutory or regulatory changes, to define:
   - Assisted Living in Nevada
   - Standards of care in non-medical residential care to include training requirements for all staff
   - Quality assurance and care outcome mechanisms of care in non-medical residential care settings

4. The CSLTC should direct the development of a single point of entry system for Nevada that is available and affordable for all consumers without regard to income eligibility for state or local government programs. The single point of entry program design should include:
   - Consultation services
   - Assessment of functional, social and health status
   - Level of care evaluation
   - Financial planning
   - Coordination of services
   - Ongoing evaluation of outcomes

   A single point of entry system design could originate through pilot programs administered by the Division for Aging Services. Older Americans Act grant funds or the Independence for Seniors grant program approved by the 1999 Legislature as funded by tobacco settlement revenues are potential revenue sources for such a demonstration. Piloting in both an urban area and a rural region is recommended. The pilots should include a sliding fee scale to proved equal access to the entry system services.

AARP IN NEVADA
REPORT TO THE
LEGISLATIVE COMMITTEE TO STUDY LONG -TERM CARE IN NEVADA
S.C.R. 4 (1999)

INTRODUCTION

Good Morning. I am Dr William Hausman, Nevada State Volunteer Coordinator for Health Issues and Co-Chair of the Health and Long Term Care Action Team. With me this morning is Hilke Faber, AARP Regional Health Representative from Seattle, Washington. Carla Sloan is unable to be with us at this meeting.

This report to the Subcommittee is a response to the Subcommittee's March 9 request of Carla Sloan, our AARP State Director. We were requested to bring back to the Subcommittee specific suggestions regarding training of caregivers and the components of a single point of entry system.

You may recall, the report that Carla brought to your March 9 meeting came from a conference we had convened in Las Vegas of 49 individuals from AARP and other organizations, federal and state legislative staff and state agencies interested in improving Long Term Care in Nevada.

Immediately after your March 9 meeting, we called on several individuals for their expert judgment toward meeting your request. As a measure of the investment of those invited, 22 persons participated in this second planning meeting held in Carson City on March 30. The five-hour meeting permitted all of those present to contribute. The discussions focused on three aspects of the problem of strengthening Long Term Care in Nevada.

Looking back at this series of events, including your Subcommittee meetings to date, we are impressed with the complexity of the task of "fixing" the current state of the LTC system in our state. The March 30th meeting assured us that the priorities set up by the working groups in the February workshop, and reported to you in early March, were valid, and addressed very critical aspects of the LTC system.

Underlying our concerns is the fact that increasing numbers of Nevadans will need to avail themselves of a broad range of LTC services presently available in the state and likely to be expanded in the near future. These individuals need protections which will ensure quality and prevent overly complex procedures for admission to and financing of care. And, they need to be placed in the least restrictive setting **and** at a cost that they and their families can afford.

It is also evident that translating the very real needs of this segment of our population into appropriate legislation and administrative solutions is a very large order, but one that must be met. We are fully aware that realistic time expectations must be set up and incorporated into whatever recommendations are offered to the full Legislature by the Interim Subcommittee on Long Term Care.

For further information please contact:

Dr. William Hausman, Co-Chair
AARP Health & Long Term Care Action Team
3785 Ranch Crest Drive
Reno, NV 89509-6871
(775) 329-0248

Mrs. Doris Alcorn, Co-Chair
AARP Health & Long Term Care Action Team
9328 Sun Rose Avenue
Las Vegas, NV 89134-6022
(702) 228-0261

Carla Sloan, State Director
AARP Nevada State Office
2920 N. Green Valley Parkway, #321
Henderson, NV 89014
(702) 898-2426

Hilke Faber, Health Representative
AARP West Region Office
9750 Third Avenue, N.E., Suite 400
Seattle, WA 98115
(206) 526-7918

BACKGROUND

What needs to be addressed at this time:

On the basis of the thoughtful suggestions of a number of groups and individuals with whom we have consulted, there appear to be three critical areas that **initially** merit close scrutiny by this Subcommittee and by the various agencies involved with their implementation. These areas include:

(1) the **definitions** of the range of facilities and programs currently involved in LTC;
(2) the **standards** of care in these programs and facilities; and
(3) the **process of assisting** candidates and their families negotiate the various levels of LTC, locating a program or facility appropriate for their needs, and arranging admission **with minimal, complicating procedures.**

Each of these areas are complex and each merits close attention. We will attempt to address the significance of and the special issues inherent in each area and to make some suggestions that we believe will help this Subcommittee to carry out its work. Our hope is that the various individuals, facilities and organizations involved in long term care in Nevada can be assisted in their work while the needs of the increasingly large populations that they serve are effectively met.

Definition of Long Term Care Programs and Facilities:

In recent years, there has been a proliferation of the types and numbers of facilities offering long term care to individuals whose needs do not require expensive medically-oriented skilled nursing facilities. In existing regulations, these residential settings are loosely defined as "group homes", ranging from small "ma and pop"-run facilities that care for three or four individuals to large assisted living facilities, often run by large, out-of-state corporations. They provide living arrangements and basic personal care for individuals (or couples) whose need for support ranges from minimal care requirements to specialized management of Alzheimers Disease. Before standards of care and the requirements for staff training can be addressed effectively, definitions and expectations of these facilities must be clarified in the governing regulations.

Quality of Care:

When the levels and types of home-based programs and residential care facilities have been appropriately defined, then **quality of care** must be addressed. Basic to this issue, is recruitment of competent and adequately trained caregivers and assurance of continuing enhancement of the personal care giving skills of those workers. The present training requirements for employment and retention of caregivers in such facilities are not adequate. They include a requirement for *at least eight hours of training within 3 months of employment,* in facilities which offer care for **residents with Alzheimers Disease**. For employment in a residential facility for **elderly and disabled persons** the requirement is for *at least 4 hours of training in the first 60 days of employment.* We seriously question both the limited training requirements and the extensive period of time allowed before training standards are satisfied in the existing regulations.

Once the definitions of these types of facilities are established, provisions must be made to adopt more appropriate **standards** for the caregivers employed by them. Such criteria should reflect standards expected of **all** who are hired to care for the residents in these settings and those cared for at home.

The process of setting up such standards might be placed in the hands of a consultative steering committee comprised of representatives of the Division of Licensure, the Division of Aging, the State Board of Nursing, an industry representative and members of advocacy groups such as the Alzheimers Association and AARP. Our experience in the past few months with two meetings of such representative groups has been positive and instructive. We feel confident that a consultative group of this sort can reach constructive agreement on a reasonable set of standards.

Single Point of Entry:

The third important change needed is that of a **single point of entry system.**

It is impressive that, when a group of individuals, knowledgeable and experienced in long term care issues, were divided into three subgroups, each addressing a different level of care, each subgroup independently agreed on the important priority of simplifying the entrance of the client into the LTC system. Those individuals, coming from different agencies, and under different auspices (eg: state, county, city, organizational), all concluded, that a single point of entry is a highly desirable goal.

Many state aging units delegate responsibility for the administration of home and community-based care services to local agencies around the state: county agencies, private or nonprofit organizations and as such are designated as "single points of entry" through which individuals enter the state's long term care system. Responsibilities of such an agency may include providing information and referral on LTC services in the community, assessment of needs, authorization for allocating public LTC dollars and to direct people to home and community-based services.

By providing information on other LTC options and helping to steer people to those services, a single point of entry system helps people stay in their homes or in their communities.

Single point of entry systems vary from state to state. No one system can serve as a model because states vary in demographics, geography and state and local government structure. States which have successfully implemented various single point of entry systems include: Oregon, Massachusetts, Indiana, New Jersey and Colorado.

Creating a single point of entry system can spark controversy among government agencies, social service providers and advocacy organizations because the single point agencies generally become "gatekeepers" for LTC services. As such, the single point agencies have considerable control over the allocation of dollars for services.

Such an important change in referral and admission procedures might be facilitated if a few pilot projects demonstrating a single point of entry were to be funded. A pilot program in an urban region and another in a rural area might demonstrate the feasibility and effective mechanisms for such an approach.

We recommend that the single point of entry design should include consultation, assessment of functional, social and health status, level of care evaluation and financial planning, coordination of services, and ongoing evaluation of outcomes.

We further recommend that the Division for Aging Services be directed to issue a Request for Proposal

Piloting in both an urban area and a rural region is recommended. The demonstrations should also include a sliding fee scale to provide equal access to consumers without regard to income eligibility for local government programs. Revenue for piloting of a community-based single point of entry system could originate from federal Older Americans Act grant funds or the Independence for Seniors grant program approved by the 1999 Legislature as funded with tobacco settlement proceeds.

Reporting on the development and implementation of the single point of entry pilot programs should be made to the Legislative Committee to Study Long-Term Care in Nevada.

RECOMMENDATIONS FOR THE PROCESS OF CHANGE:

While there is much at stake for the citizens of Nevada in the resolution of these issues, the changes suggested are not likely to be realistically legislated in a matter of a few months. The move in the 1999 Legislative Session to establish this Interim Subcommittee on Long Term Care was an important first step. Only with the sort of specialized oversight that you represent, can the work on this complex process be carried forward.

- AARP's **first recommendation**, then, is that the life of this Subcommittee on LTC be continued through and beyond the next few legislative sessions, preferably as a Standing Legislative Committee.

- AARP's **second recommendation** is that the LTC Subcommittee formally establish small work groups to include subject matter experts to assist with the details of implementing the three areas proposed:

1. Defining the various residential and home care LTC services;
2. Developing standards for these services; and,
3. Evaluating demonstration projects piloting a single point of entry system. .

AARP believes that input from as wide and diverse a group of stakeholders, including government agencies, provider organizations and consumer organizations is needed to benefit from their experiences and wisdom in shaping a comprehensive quality, accessible, affordable long term care delivery system. Further, sufficient staff, and/or consultant, resources need to be allocated to facilitate and report the results of the working groups. This has most recently, been effectively demonstrated in Washington State and the work of the Joint Legislative & Executive Task Force on LTC.

To illustrate how this can work, I refer you to the recent report of the Washington State Joint Legislative & Executive Task Force on LTC which is the culmination of two years of many hours of volunteer involvement from stakeholders, issue experts, legislative and executive staff. This Joint Task Force consisted of seven members with two legislative alternates. Three members were appointed by the Governor to include: the Secretary of designee of the Department of Social and Health Services, the Department of Health and the State Long Term Care Ombudsman. Two members were Chairs of the Senate and House Health Care Committees, and two were the Vice-Chairs and/or ranking minority members.

Staff consisted of: two staff from the Governor's Executive Policy Advisors, an Analyst from the Senate Health and LTC Committee, a Consultant with the Office of Financial Management, a staffer office of Executive Policy. In addition, five Stakeholder Issue Teams were established to examine the broad range of issues defined in their statute. These Issue Teams were open to all interested stakeholders who

participated as able. Meetings, throughout the biennium, were scheduled and chaired by members of the Joint Task Force. All meetings, as you might well imagine, were well attended with lively discussion of the issues.

I will leave their final report here with you.

ENDORSEMENT OF OTHER PROPOSALS TO THE SUBCOMMITTEE:

1. We urge you to support changing the eligibility for the Group Care Waiver, to permit individuals at up to 300% of poverty level to be eligible for care in non-medical residential homes. This would increase the income criteria for acceptance for group care from the present 150% of poverty (currently $862 /month) to 300% (currently $1,536/month).

2. The Legal Service Project, proposed by Washoe County to fund affordable assisted living, makes use of a blend of funding mechanisms. This creative proposal might represent an excellent arena for developing the single point of entry concept in an urban area.

3. Nevada's grant application to the Robert Wood Johnson Foundation for a "Coming Home" grant.

APPENDIX L

Letter to Governor Guinn Regarding the Recommendations Adopted by the Legislative Subcommittee to Study Long-Term Care in Nevada

MIKE McGINNESS
SENATOR
Central Nevada District

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Taxation
Member
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January 4, 2001

The Honorable Kenny Guinn
Governor of Nevada
State Capitol Building
Carson City, Nevada

Dear Governor:

During this past interim, I had the pleasure of serving as the Chairman of the Legislative Commission's Subcommittee Studying Long-Term Care in Nevada. The study was authorized pursuant to Senate Concurrent Resolution (S.C.R.) 4 adopted by the 1999 Legislature. I found the subject matter was not only interesting, but the issues are very complex and there is no simple formula or recipe to follow for addressing Nevada's long-term care problems. The information presented to the Subcommittee clearly indicates that we need to quickly begin developing alternatives to institutionalization and innovative approaches for funding long-term care as the demand and costs for these services continue to increase with the aging of the baby boomer population. Although the Subcommittee's work has been completed, there is much more work yet to be done, and the recommendations formally adopted by the Subcommittee represent only the beginning of a process to rethink and shape Nevada's long-term care system for the future.

The reason I am writing to you is to follow-up on several of the recommendations adopted by the Subcommittee, many of which were formally presented to you in July when you graciously invited members of the Legislature to meet with you to discuss recommendations developed in conjunction with legislative studies conducted during the interim. Additionally, as you develop your funding priorities for the upcoming biennium, I would respectfully request you consider for possible funding the recommendations adopted by the Subcommittee as reasonable investments for improving Nevada's long-term care system. The following is a brief synopsis of the recommendations, some of which include bill draft requests to be considered by the 2001 Legislature, and the projected costs.

1. The Subcommittee recommends implementing a long-term care insurance program for all state employees and retired state employees. It is widely thought that long-term care insurance can play an important role for potentially reducing the anticipated growth in government financing for long-term care in the future. The estimated cost to the state general fund is $4.1 million annually. (BDR 23-299)

2. The Subcommittee recommends an appropriation in the amount of $100,000 to the Aging Services Division for the administrative support needed to explore the feasibility of developing an assisted living option within the Medicaid program. The assisted living option would potentially reduce a current gap in the care continuum for a low-income senior who may be forced into a nursing facility when, in reality, that senior may function independently within an assisted living environment if enhanced Medicaid services were available. (BDR S-303)

3. The Subcommittee recommends the Department of Human Resources amend the Home- and Community-Based Waiver for Elderly in Group Care and increase the eligibility level up to 300 percent of the SSI level. The proposal appears to be cost neutral and would allow clients in the Community Home-Based Initiatives Program (CHIP) an opportunity to choose a less restrictive option to nursing facility care and potentially defray long-term care costs in the Medicaid program.

4. The Subcommittee recommends the Department of Human Resources amend the Home- and Community-Based Waiver for the Community Home-Based Initiatives Program (CHIP) and eliminate the patient liability requirement. The CHIP program is the only Medicaid waiver that includes a patient liability requirement. The requirement has created a consistency problem for clients who may need to transfer to the CHIP program from another Medicaid waiver. Eliminating the patient liability requirement is cost neutral because the Medicaid Estate Recovery process would ultimately recover the full cost of services provided once the client is deceased.

5. The Subcommittee recommends that sufficient funding be provided for the CHIP program for the 2001-2003 biennium for the projected growth in population for the age groups served in order to maintain a reasonable wait time for services. The Subcommittee recommended that tobacco settlement monies could be used to fund the additional costs for reducing the wait time for services.

In closing, as we enter the 21st Century we will need to focus our attention more directly than ever before to develop an effective system of delivering long-term care services. This is a society-wide challenge. There is no single solution or no one sector that by itself can improve the system. Multiple sectors must work toward an integrated solution to balance available resources and to create the right mix of appropriate services. If nothing more, the Subcommittee's work began the process of focusing attention on what needs to be done. Thank you for your consideration.

Sincerely,

Senator Mike McGinness

MM/ss