

LITTLE HOOVER COMMISSION



LONG TERM CARE: PROVIDING COMPASSION WITHOUT CONFUSION

December 1996

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State of California

LITTLE HOOVER COMMISSION

December 17, 1996

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President Pro Tempore of the Senate
and Members of the Senate

The Honorable Cruz M. Bustamante
Speaker of the Assembly
and Members of the Assembly

The Honorable Rob Hurtt
Senate Republican Leader

The Honorable Curt Pringle
Assembly Republican Leader

Dear Governor and Members of the Legislature:

In the next few decades, California's elderly and disabled population will soar as the Baby Boom generation ages and medical advances stave off death from disabling injuries and diseases. Many of these people will need long-term care services to cope with functional limitations -- and much of the financial burden will fall on government. California can expect to see the \$5 billion it spends today on long-term care double in the next 25 years just to provide the current level of service.

But most long-term care advocates believe that the current level of service is inadequate and that the State's efforts are not well directed. Many people go without adequate care and deteriorate to the point of requiring institutionalization because in-home assistance is difficult to obtain. Others are pushed into costly skilled nursing facilities prematurely because of the perverse financial incentives of government assistance.

Since the 1980s, the Little Hoover Commission has studied the State's long-term care programs, over the years making multiple recommendations to reform state policies regarding skilled nursing facilities, residential care facilities and in-home care. This year, the Commission decided to review the entire range of long-term care in one study and provide policy makers with a fresh perspective on improving services through integration and coordination. The result is the report that is being transmitted with this letter.

Working with an advisory group of 140 experts, the Commission examined California's programs, efforts by other states and academic studies. The Commission concluded that:

- The State's oversight structure is too fragmented to allow effective coordination and integration of long-term care services.

- Many of the State's policies favor expensive institutionalization at the expense of the home- and community-based services preferred by consumers.
- Despite new federal regulations, consumers continue to take issue with the quality of care in skilled nursing facilities.
- Regulatory change has not kept pace with the changing demands placed on residential care facilities.

To address these problems, the Commission first and foremost recommends that the State consolidate its long-term care programs in a single state agency that can provide a coordinated continuum of care. In addition, the Commission believes that the State's efforts should focus on consumer-oriented, outcome-based assistance in the least restrictive setting appropriate for each person. To achieve this, the State must aggressively pursue federal waivers, reform its own conflicting policies and increase resources in areas that can help people avoid institutionalization.

The State already has begun to take steps toward improving long-term care services. The recently recrafted Older Californians Act sets out a policy of providing consumer-friendly services that are easy to access. In addition, the State is embarking on a pilot project in five geographic areas to provide integrated services at the local level. This movement holds great promise -- but the further steps described in this report are necessary for progress to continue.

The State faces many competing demands, especially after several years of recession-strapped budgeting. But as the economy moves more fully into recovery and resources increase, the State can afford to re-examine its priorities. As the population that will need long-term care increases, the State should create opportunities to deliver more and better services in a less costly manner. The Commission believes this report can help policy makers do so.

Sincerely,


Richard R. Terzian
Chairman



Long-Term Care:

*Providing Compassion
Without Confusion*

December 1996

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Executive Summary



Executive Summary

Almost 13 million Americans have chronic health problems that require long-term care -- a constant and costly demand on a health care system that was never designed for prevention and maintenance but instead for identifying illnesses, treating symptoms and sometimes producing cures. The result of this mismatch between need and design is that people often go without help, face conditions that deteriorate prematurely and sometimes are pressed into expensive institutional care before necessary. The magnitude of the problem is large: California spends more than \$5 billion on long-term care services for fewer than half of the 1.5 million people who need assistance.

"Long-term care" focuses on managing on-going conditions over time. Services may include *medical assistance*, such as administering medication or performing rehabilitative therapy. But more typically it involves *personal care*, such as help with bathing and eating, and *supervision*, such as protecting a person from wandering away or inadvertently injuring themselves. The emphasis of long-term care is on enhancing a person's ability to function and enjoy a quality of life rather than on curing a condition. It takes place in a variety of settings -- in homes, in institutions, in community programs -- and is provided by a variety of caregivers -- licensed health care professionals, trained workers, family and friends.

As the Baby Boom generation moves into its declining years and begins to balloon the elderly population, the pressure is building to change the

approach to long-term care. In California, the Little Hoover Commission has had a standing commitment to improving the quality of long-term care for the elderly. The Commission has not been a lonely voice in this regard. Dozens of groups and reports at the federal, state and local levels have called for restructuring long-term care services to increase both effectiveness and efficiency.

The same sources who decry today's long-term care services produce similar lists of what a good system would look like: consumer-driven, community-based, social model, choices among least-restrictive options, affordable services, uniform access. And many argue that at least some of these goals can be obtained without massive infusions of new resources, although all maintain a larger slice of the resources pie is easily justified for this growing, vulnerable segment of the population.

Despite the general consensus about what is wrong and what the desirable end result is, little progress has been made toward restructuring long-term care services in California. That the demand for long-term care will increase is a certainty. How the State should respond is the question. The following report is designed to help policy makers shape the answer. It's findings are:

State Structure

Finding 1: The present state structure for long-term care oversight is not conducive to a coordinated continuum of care and fails to focus state efforts on consumer-centered, least-restrictive, best-value services.

A person in need of long-term care faces a bewildering maze of policies, bureaucracies and programs. Strictly regimented funding streams and fragmented service programs skew decisions toward high-cost, less consumer-desired solutions. Although the State Plan on Aging describes a coordinated continuum of care options that strives to keep consumers in their homes and communities, the State's segmented structure for overseeing long-term care frustrates the implementation of this federally required plan. The result is consumer confusion, costly choices and premature erosion in the quality of life for many individuals. At a time when the population most likely to need long-term care services is expanding rapidly, the State can ill afford to maintain its present system.

Recommendation 1-A: The Governor and the Legislature should consolidate the multiple departments that provide or oversee long-term care services into a single department.

Interdepartmental cooperation is a hit-and-miss proposition that usually lacks mission unity and aggressive leadership. If the State is serious about creating an effective long-term care system -- and with looming demographics that promise an explosion of those who need such care, the State should be concerned about that goal -- then it must reorganize departments into a single entity to oversee all long-term care. The new department should take advantage of the opportunities presented to create a consumer-centered philosophy that maximizes choice, effectiveness and efficient use of multiple resources.

Recommendation 1-B: The Governor and the Legislature should mandate that the new state department establish an effective one-stop service for consumers to obtain information, preliminary assessment of needs and referral to appropriate options.

What consumers have identified repeatedly as their most pressing need is a reliable source of information so they may understand the choices that are available to them. While the State has the backbone for such a system in place, with the 33 regional Area Agencies on Aging and a special 1-800 number, the resources are not available for personalized, one-stop counseling. In particular, the ability is lacking to access information about programs and individuals by computer so that counseling is person-specific. Over time, as the State makes progress on integrating programs, these referral centers should also serve as program entry points, with unified applications and common eligibility screening.

Recommendation 1-C: The Governor and the Legislature should require departments involved in long-term care to pursue federal waivers and options that will infuse flexibility into programs and funding.

The State has been slow to embrace opportunities to escape federal micromanagement, lagging behind other states in applying for and winning waivers. Although the process for securing waivers is lengthy, it is an investment the State must make if it is to create a long-term care system that focuses on consumer needs rather than one that is driven by artificial -- and often conflicting -- program constraints. Waivers are also a key tool for shifting long-term care services away from high-cost medical models to consumer-preferred, lower-cost community-based social models of care. Specific examples include Wisconsin's cash-and-counseling program, Oregon's targeted removal of people from skilled nursing facilities, and further replication of the On Lok and Social Health Maintenance Organization models.

Recommendation 1-D: The Governor and the Legislature should adopt a multi-pronged strategy for coping with the expected rising demand for and cost of long-term care services.

As the economy expands and state revenues increase, policy makers should give serious consideration to enlarging allocations for long-term care services. But there are other steps that would stretch resources, including further stimulation of the purchase of private long-term care insurance through tax credits; more effective educational outreach about people's financial options for the future; and elimination of program incentives that favor high-cost services.

Recommendation 1-E: The Governor and the Legislature should ensure that the State's policies are consumer-focused by establishing an advisory committee that can have a persuasive voice in policy formation, program implementation and quality assurance.

Consumers who actually use long-term care services can provide valuable input on what components are needed to make an effective system. They also can ensure that the focus of both policy and programs remains on the consumer and not on the convenience of bureaucracy. One option is to convert the existing California Commission on Aging to a body that includes consumers of long-term care services and to provide it with adequate resources to work closely with the restructured, single department in charge of long-term care services.

Recommendation 1-F: The Governor and the Legislature should develop a program for quality assurance and control that is outcome-based and consumer-oriented rather than prescriptive and process-oriented.

Policy makers should take several steps to shift oversight from a prescriptive system to an outcome-based system:

- √ The regulation-creating process and regulations themselves should be recrafted to emphasize outcome over process. This will lead to less rigid, less prescriptive regulations that may be more difficult for regulators to enforce and industry to understand but that should increase the opportunity for care that is centered on an individual's specific needs.
- √ More resources should be directed toward increasing training and professionalism of regulators so that less-prescriptive regulations

can be enforced with flexibility regarding method but consistency regarding results.

- √ The check-and-balance structure for enforcement activities should be strengthened by creating a formalized, effective role for public interest and advocacy groups. This will include ensuring open access to information and records, a role for such groups in negotiations and the ability to seek effective legal redress for problems.

In addition, policy makers should focus on improving accountability and credibility for the State's oversight functions. Two possible steps:

- √ Any structural reform should be accompanied by efforts to minimize conflicting roles. Complaint investigations could be shifted to either the Attorney General's Office or the Department of Consumer Affairs. Similarly, the ombudsman program could be housed in these departments. Such a change, if implemented, should be monitored for several years and then assessed for effectiveness.
- √ Increasing the resources available to the ombudsman program, which is stretched too thin over many important duties, would allow increased training and more effective outreach to identify a larger pool of volunteers. Added funding could be diverted from fines collected for violations of regulations.

Community Care

Finding 2: The State's policies and programs do little to encourage the use of community-based services, and too small an effort is made to protect people from premature deterioration that can result in costly institutional placements.

In many areas of state concern, prevention is an investment that saves long-range costs -- but prevention rarely wins priority over reactive services when resources are limited. In the case of long-term care, the bulk of government dollars is spent on institutionalization, and preventive services that would keep people out of high-cost institutions are stretched thin. Statutes are in place that favor community-based care, and exemptions and waivers for licensing regulations provide limited tools to keep people in home-like environments. But by and large, the state bureaucracy blocks rather than enables community solutions, and policy makers provide little financial support for preventive programs. Programs

that have proven their worth but that suffer from financial neglect include:

- √ Support services for family caregivers.
- √ Adult day care and adult day health care clinics.
- √ In-Home Supportive Services.
- √ Adult Protective Services.

Recommendation 2-A: The Governor and the Legislature should revamp the present highly segmented licensing structure for long-term care service providers to allow a more seamless delivery of service, to allow aging in place whenever possible and to emphasize social models over medical models.

Creating a unified licensing plan that would allow service providers to add-on optional services or provide various types of care in a single setting is a key requirement for moving long-term care toward integrated, consumer-focused service. Those who fear the consolidation of the existing separate licensing systems should have their concerns addressed by requiring any new system to be outcome-based, flexible in implementation, consistent in interpretation and supportive of social models of service delivery. Barriers raised by federal funding and oversight requirements for skilled nursing facilities should be addressed through waivers, demands for federal law reform or, if no other course is feasible, separation from other forms of long-term care licensing.

Recommendation 2-B: The Governor and the Legislature should designate a point person to develop funding streams and provide technical support for adult day care and adult day health care programs.

These programs can play a critical role in providing relief for caregivers and increasing the number of functionally impaired people who can remain at home and out of costly institutions. The State should provide leadership in securing Medicare reimbursement for services by pushing for changes in federal law and waivers. In addition, the State should focus on educating the public about the services available and enhancing the opportunity for development of more programs.

Recommendation 2-C: The Governor and the Legislature should increase funding for family caregiver respite and support services.

For more than a decade, the Caregiver Resource Centers have documented their value in providing services that allow people with brain impairment to remain home and under the care of family and friends. But funding constraints have kept the waiting lists long, limiting this program's ability to serve as a safety net for the long-term service continuum of care. The California Senior Legislature, which has the responsibility of proposing laws to assist the State's seniors, is backing a statewide respite care program as one of its priorities for 1997. Expanding the existing program would meet their goals.

Recommendation 2-D: The Governor and the Legislature should encourage counties, through funding and other incentives, to form Public Authorities to improve delivery of services under the In-Home Supportive Services program.

The problems with the In-Home Supportive Services program have been well documented and widely acknowledged for years. Improvements have been non-existent, due to lack of funding and governmental abhorrence to becoming involved to a point of being named the employers of caregivers. The Public Authority mechanism, while largely untested, has the ardent support of consumers as a means of improving the quality of care. This mechanism should be given every opportunity to succeed.

Recommendation 2-E: The Governor and the Legislature should require counties to provide multiple modes of services so In-Home Supportive Services recipients who do not want to act as employers have options, including care through agencies, that will meet their needs.

While many IHSS recipients want to retain control over their service provider choices, others neither desire nor can handle the role of employer. Just as recipients who want to be employers should have that choice, recipients who need management assistance for their caregivers should not be left without a program to meet their needs.

Recommendation 2-F: The Governor and the Legislature should increase funding and expand the state role in standardizing adult protective services throughout the state.

Society needs an effective mechanism for protecting people who are functionally impaired and threatened with abuse, neglect or exploitation. The present county-administered programs are not uniform throughout the state and lack the resources to provide effective service. The

California Senior Legislature has made increasing the funding and effectiveness of this program, as well as enhancing elder abuse prevention and treatment programs, as two of its top 10 priorities for 1997.

Recommendation 2-G: The Governor and the Legislature should clarify mandated reporting laws to turn them into a more effective tool for protecting vulnerable citizens.

Mandated reporting laws vary with regard to what should be reported, by whom, to whom and what resulting action is required. Providing uniformity to this system would make it more understandable both to those who are required to comply with the provisions and those who are seeking protection from them.

Skilled Nursing Care

Finding 3: Federal mandates for skilled nursing facilities have brought an improved process to monitoring quality of care -- but many previously identified issues remain unresolved and others are developing as the role of these institutions shifts to a higher level of care.

Under recently issued federal regulations, skilled nursing facilities (SNFs) are judged by their ability to provide the least restrictive, most socially stimulating environment that a person's condition, desire and needs allow. The State's process of holding SNFs to this standard holds great promise. But many of the problems identified in previous Little Hoover Commission reports continue to exist and have immense negative impact on people's lives. As the role of SNFs shifts more from long-term custodial care for chronically ill people to short-term rehabilitative care for recently acutely ill people, the State has an opportunity to recast the policies and programs that make these institutions the most costly, least consumer-desired long-term care option.

Recommendation 3-A: The Governor and the Legislature should take steps to move medical care in long-term care settings from the costly reactive model to the more economical, preventive model, including encouraging the use of allied health professionals when appropriate.

There is little value in protecting the turf of professionals who do not want to provide service in a long-term care setting but who are loathe to

see their competitors gain a foothold. Allied health professionals, such as dental hygienists, nurse practitioners and physician assistants, can play a valuable role in providing preventive health care and alerting the appropriate professionals to the needs of residents in skilled nursing facilities. They should be given the opportunity to do so.

Recommendation 3-B: The Governor and the Legislature should strengthen the opportunities, incentives and requirements for high quality performance by skilled nursing facility staff.

It is difficult to operate effectively in a setting that is understaffed, has incomplete or inadequate training and provides no opportunity for advancement. The following steps would address those concerns:

- Eliminate the doubling of hours for licensed nursing professionals, explore moving to a system that requires adequate staff for proper care rather than a certain number of hours, and/or set higher standards for staffing. The Older Women's League has recommended one caregiver for each eight residents at a minimum.
- Add more gerontology and human relations issues to the certified nurse assistant (CNA) training curriculum and provide more effective oversight to ensure that training is of high quality and actually occurs.
- Create a career ladder for CNAs by establishing progressive educational standards and work experience that would lead to licensed nursing status.

Recommendation 3-C: The Governor and the Legislature should enhance the State's enforcement capability by eliminating counterproductive provisions in the citation and fine system, directing more frequent use of alternative tools and creating a more effective civil liability remedy.

Specific steps that policy makers should take include:

- Eliminating the waiver of fines for B citations and the halving of fines for payment prior to appeal. The Department of Health Services told the Commission it supports both of these reforms.
- Encouraging the Department of Health Services to use more frequently facility decertification, delicensing and frozen

admissions, as well as creating a fee system that assesses a facility at a higher rate when frequent violations require more frequent inspections.

- Fines, set in the mid-1980s, should be increased. In addition, consumers should be empowered to sue for civil remedies with the potential for large enough financial damages to act as a deterrent for poor quality care.

These and similar reforms are supported by the California Senior Legislature in its 1997 list of priorities and the California Advocates for Nursing Home Reform.

Recommendation 3-D: The Governor and the Legislature should create a more responsive complaint investigation and resolution process that is separate from the licensing and technical advice function.

The reality is that the Department of Health Services is neither adequately funded nor staffed to be responsive to consumer complaints -- and the perception is that their interest is more aligned with encouraging industry to comply than providing aggressive enforcement. In addition, the current process is heavily weighted toward due process for industry rather than adequate concern for consumers. Restructuring the process and placing it at some distance from the licensing function -- such as at the Attorney General's Office or in the Department of Consumer Affairs -- would address these issues. This reform could be tracked and assessed for effectiveness over time.

Recommendation 3-E: The Governor and the Legislature should eliminate duplicate regulations and streamline the oversight process while ensuring that no deterioration in the quality of care occurs.

It is counterproductive to have more than one set of regulations governing an industry and to layer complexity with redundancies. Regulations should be focused on outcomes, allow for flexibility of methods, lend themselves to consistency of interpretation and be easily understood by industry, consumers and state workers.

Residential Care

Finding 4: Regulatory changes have not kept pace with the changing role of residential care facilities.

Residential Care Facilities for the Elderly (RCFEs) are a consumer-favored option for long-term care because of the home-like setting, lower cost and individual freedom provided. Although conceived as a non-medical approach to long-term care, their function has grown increasingly complex as residents have been given the right to remain in place with greater and greater need for care. While new regulatory categories have been added piecemeal to broaden the role of RCFEs, no comprehensive re-examination of where this service fits in the long-term care continuum has occurred. But as a key service that can keep people from premature institutionalization and foster at least partial independence, RCFEs deserve attention and reform that will support expanded availability to people with long-term care needs.

Recommendation 4-A: The Governor and the Legislature should restructure state policies regarding RCFE rates.

With market forces driving prices for 70 percent of the residents in RCFEs, state policies to artificially suppress rates for SSI/SSP recipients have had counterproductive affects, including lack of access. In addition, many people who are not poor enough for SSI/SSP benefits but too poor to pay \$1,500 a month are left with no options for out-of-home care other than expensive skilled nursing facilities. Policy makers should take several steps:

- Eliminate the ceiling on the rates RCFEs may charge SSI/SSP recipients.
- Petition the federal government to increase SSI.
- Increase the state-funded SSP portion of the monthly benefit.
- Craft a Medi-Cal benefit using the personal care waiver that will allow RCFEs to collect money for services beyond food and shelter that help keep residents out of skilled nursing facilities where the Medi-Cal bill would be much higher.

Recommendation 4-B: The Governor and the Legislature should revamp the regulatory structure for RCFEs.

An earlier recommendation calls for the complete restructuring of licensing to allow more flexibility and integration of long-term care services. This is particularly true for RCFEs, which would benefit from regulations that are size-specific and that more easily accommodate add-on services to a core package of basic care.

Recommendation 4-C: The Governor and the Legislature should encourage more clarity and consistency in enforcement efforts by dedicating more resources to staff training and enhanced technical support services.

Fairly enforcing regulations that avoid micromanagement and encourage innovative approaches requires state staff who are trained and kept abreast of state-of-the-art developments in long-term care. And the potential for high quality of care is enhanced by sharing with facilities the State's expertise on best methods and practices for complying with regulations.

Recommendation 4-D: The Governor and the Legislature should revise restrictions on RCFE medication practices while at the same time safeguarding consumer protections.

The elderly are a population that is already at risk for over-medication and incorrect usage of medication. But a system that requires event-by-event phone calls to physicians for permission to provide residents with over-the-counter cough medicine and aspirin seems to serve no one's best interests.

Recommendation 4-E: The Governor and the Legislature should couple a strengthened process for protecting residents from unwarranted evictions with the creation of a limited probation period when a resident can be asked to move without cause.

While residents should be protected from summarily being forced from a facility, RCFEs also should have tools at their disposal to ensure that residents can live together comfortably.

Recommendation 4-F: The Governor and the Legislature should request that the federal government restructure its health information collection process to include specific data on residential care facility residents.

The federal government should be encouraged to use the Census process to collect data on people who live in different types of out-of-home arrangements. In addition, the federal government's American Housing Survey suffers from the problem of lumping together everyone who lives with more than five unrelated people (including college dorms and half-way houses) rather than examining information by specific categories.

There is little mystery about what an effective, consumer-preferred long-term care system would look like. For years, if not decades, advocates have described a continuum of care that would provide freedom of choice and the least-restrictive type of assistance as a person moves from independence to assisted living to total dependence. Unfortunately, there has been little progress toward such a system.

The Little Hoover Commission believes the timing of this report -- which synthesizes the best-practices trends across the nation -- should enhance the opportunities for reform. The State already has taken good-faith steps toward a home- and community-based ethic of long-term care by creating an integrated services pilot project for five areas of the state and revising the Older Californians Act. The State can continue down this path by providing the oversight structure and leadership to nurture these initial steps.

Introduction



Introduction

The high-pitched siren of an ambulance, the green-garbed surgeon operating beneath bright lights – these are the visible components of the health care system that goes into action when illness is acute and symptoms cry out for instant attention. But the setting is less dramatic for people who face daily struggles in their own homes or in out-of-home care facilities. There, health care is a minute-by-minute, day-after-day process of helping someone live with pain, physical limitations or mental disabilities.

Almost 13 million Americans have chronic problems that require ongoing assistance – a constant and costly demand on a health care system that was never designed for prevention and maintenance but instead for identifying illnesses, treating symptoms and sometimes producing cures. The result of this mismatch between need and design is that people often go without help, face conditions that deteriorate prematurely and sometimes are pressed into high-cost institutions before necessary. As the Baby Boom moves into its declining years and begins to balloon the elderly population, the pressure is building to change the approach to long-term care.

In California, the Little Hoover Commission has had a standing commitment to improving the quality of long-term care for the elderly. In the mid-1980s, the Commission issued reports on skilled nursing facilities and residential care facilities, in both cases contributing to major legislative reforms of standards and oversight.

In 1991, the Commission re-examined these areas and added a third, in-home care, in a series of three reports that called for further reforms and improved state oversight. In particular, the Commission found that long-term care services were fragmented across many state departments and services were difficult for citizens to access. The Commission called for the State to ensure that citizens have a choice along a continuum of various care options, with a single point of access for assessment and referral.

The Commission has not been a lonely voice in this regard. Dozens of groups and reports at the federal, state and local levels have called for restructuring long-term care services to increase both effectiveness and efficiency. Perhaps the most succinct summation comes from a discussion paper titled "Long-Term Care Reform: Rethinking Service Delivery, Accountability and Cost Control" that was put together for a General Accounting Office/Kaiser Family Foundation forum in July 1993:

Few experts believe that future long-term care needs can be met, much less paid for, simply by delivering more units of the care we provide now. Today both care providers and persons needing assistance express widespread frustration with the organization of, access to and delivery of long-term care services. At the same time, federal and state officials are increasingly concerned about the ability of the public sector to pay for services even now, long before the great demographic changes of the next century occur.

What's the problem with the current long-term care system? There's no simple answer. At the heart of it, however, is that services are not organized with the disabled person in mind as the consumer. Nor is the system organized to achieve well-defined objectives or to maximize effective management of budgets. In addition, the system is biased in favor of institutional and medical approaches to care. As a result, disabled persons may get institutional or medical services when other, less intensive, often lower cost services would be more appropriate. And significant gaps exist in nonmedical home- and community-based services.

What is at the root of the problem to our approach to long-term care? A major part of the problem is that existing long-term care programs are not a "system" at all but rather a hodgepodge of programs that were designed to meet health care and other needs, not long-term care needs.

The same sources who decry today's long-term care services produce similar lists of what a good system would look like: consumer-driven, community-based, social model, choices among least-restrictive options, affordable services, uniform access. And many argue that at least some of these goals can be obtained without massive infusions of new resources, although all maintain a larger slice of the resources pie is easily justified for this growing, vulnerable segment of the population.

Despite the general consensus about what is wrong and what the desirable end result is, little progress has been made toward restructuring long-term care services in California. Other priorities have occupied policy makers, including dealing with recession-wracked budgets, meeting the educational needs of a burgeoning school-age population and coping with growing incarceration costs.

However, as the economy grows stronger and resources begin to expand, the time may well be ripe to pay attention to some daunting demographics:

- In 1990, California had 4.2 million people 60 and older.
 - √ The State had the largest number of older people in the country.
 - √ About 10 percent of all older Americans lived in California.
 - √ Older citizens made up 14 percent of the State's total population.
- By the year 2040, California will have 14.1 million citizens who are 60 and older if current trends continue.
 - √ The State will continue to have the largest number of 60-plus citizens in the country.
 - √ About 16 percent of all older Americans will live in California.
 - √ Those 60 and over will make up 22 percent of the State's total population.¹

Although the fields of science and medicine continue to advance in the fight against disease and deterioration due to aging, there is little doubt that many of these older Californians will need long-term care services at some point in their lives.

In light of these statistics, the Little Hoover Commission has chosen to update and consolidate its prior efforts on long-term care for the elderly to assist policy makers as California moves into the 21st Century. The Commission's study has a double focus:

- The need for a fresh approach, invigorated leadership and restructuring of state functions to eliminate perverse incentives, lapses in coordination and gaps in services.
- The ongoing need to address long-term care issues that have existed for some time in the skilled nursing and the residential care industry and that should be resolved regardless of the outcome of any state bureaucracy restructuring efforts.

While recognizing that the disabled population often has interests similar to those of the frail elderly, the Commission has retained its historical focus on the needs of California's elderly citizens during the course of its study. The Commission, therefore, did not examine the broad spectrum of state services for the disabled.

Nonetheless, the Commission acknowledges that many representatives of both the disabled and the elderly are strongly supportive of an integrated system of long-term care services that responds to a person's abilities and level of need rather than age. In many instances, the findings and the recommendations in this report will satisfy the concerns of both groups.

The Commission began its study with a benchmark public hearing in February 1996 to review the status of skilled nursing facilities, residential care facilities and in-home care. A September 1996 hearing focused on the State's structure for oversight and community-based service options. Agendas for both hearings can be found in **Appendix A**.

An integral part of the Commission's study process was an active advisory committee, a body that doubled to almost 140 people (**Appendix B**) after an initial meeting of 70 advocates, experts and other interested parties laid out the parameters for the study. Dozens of members participated in 36 hours of working group sessions to explore issues concerning skilled nursing facilities, residential care facilities, personal care and long-term care overall.

In addition, the Commission reviewed academic literature, government reports and other documentation, as well as receiving input from dozens of citizens by phone, mail and Internet.

The result of the Commission's multi-pronged efforts is this report, which begins with a transmittal letter to the Governor and the Legislature and an Executive Summary. This Introduction is followed by a Background section that sets the context for discussion of specific findings. There are chapters for each of four findings: state structure, community-based services, skilled nursing facilities and residential care facilities. The report ends with a Conclusion, the Appendices and the Endnotes.

No demographic development is more definite than the massive explosion in the numbers of elderly over the next few decades. The bulging Baby Boom generation born between 1946 and 1965 will turn 65 between 2011 and 2030. Coupled with this growing geriatric population is an increase in the chronically disabled as medical

miracles allow infants, children and adults to survive what were once deadly conditions -- premature birth, disabling head trauma, massive strokes.

That the demand for long-term care will increase is a certainty. How the State should respond is the question. The Commission hopes the following report will help shape the answer.

Background

- ❖ *Long-term care includes medical assistance, personal care and supervision for people with chronic debilitating illnesses.*
- ❖ *About 13 million Americans require assistance with daily living activities -- more than half of them elderly people.*
- ❖ *About \$108 billion was spent nationwide on long-term care in 1993, with federal and state governments paying for about two-thirds of the cost.*
- ❖ *In California, where about 1.5 million people need assistance, the State spends about \$5 billion on long-term care.*
- ❖ *Nationwide reforms are focused on taking care of people in their own homes and communities rather than in costly institutional settings.*

Background

Long-term care is service provided to people who face limitations in their daily functioning because of chronic conditions. Almost 13 million elderly and disabled people in the United States need long-term care. They receive it from a variety of informal and formal sources, at private, insurance, public or no expense, and with oversight from various levels of government. This Background defines long-term care, presents data about who uses it and pays for it, summarizes federal and state government roles in long-term care and describes some current trends in both California and the nation.

What is Long-Term Care?

Long-term care may include *medical assistance*, such as administering medication or performing rehabilitative therapy. But more typically it involves *personal care*, such as help with bathing and eating, and *supervision*, such as protecting a person from wandering away or inadvertently injuring themselves. Unlike health services for acute conditions, long-term care focuses on managing on-going conditions over time. The emphasis is on enhancing a person's ability to function and enjoy a quality of life rather than on curing a condition.

Long-term care takes place in a variety of settings -- in homes, in institutions, in community programs. To understand the relationship between the different types of long-term care services, it is useful to visualize a straight-line progression from complete independence to total dependence -- although it is important to note that many individuals

move back and forth among care options as their condition changes. The straight-line progression might look like this:

- ***In-home care:*** When people are no longer able to function completely on their own, they may require some level of assistance where they live. Services at home can range from personal care delivered by a person with little or no training to medical care provided by licensed personnel from home health care agencies.
- ***Residential care:*** At some point, people with chronic conditions may require substantial non-medical assistance and supervision in a 24-hour-a-day setting outside of their home, such as in assisted living and residential care facilities.
- ***Community-based care:*** While living at home or in a residential care facility, people who are impaired may require services that can be obtained at an adult day care center or adult day health care clinic. These services are provided neither at home nor in institutionalized settings where a person has moved but in programs that treat a person while leaving them in a nearby, familiar 24-hour-a-day environment -- thus the designation "community-based" care.
- ***Institutional care:*** When round-the-clock medical attention is required, people move to institutions that are designed to monitor them continuously.

The progression from independence to dependence discussed above and the array of services connected to it are often referred to as a continuum of care. The goal of many long-term care advocates is to design a continuum of care that allows people to move smoothly from one level of service to another as their needs change.

Who Needs Long-Term Care?

Many different physical and mental ailments may impair a person's ability to function independently. A person's physical incapability may result from paralysis, birth defects, heart disease, stroke and other illnesses. Mental impairment may be a byproduct of retardation, catastrophic injury to the head, Alzheimer's Disease and other forms of dementia. Barriers to independent living may arise slowly, over time, as a disease progresses -- or they may come swiftly as the result of an disabling accident -- or they may be with a person from birth.

Oftentimes the same medical diagnosis may have a very different impact on a person's life. One person with Alzheimer's Disease may need constant supervision but may need no help dressing, bathing and eating; another may be so completely disoriented and incapacitated from Alzheimer's that no activity can be undertaken without assistance.

Conversely, completely different diagnoses may leave two people with the same level of need. Both a young quadriplegic and an elderly bedridden stroke-victim may need full assistance with eating, dressing and toileting.

Because it is difficult to categorize by illness or disability the types of people who need long-term care and the level of services required, other measures are used. These measures are:

- **Activities of Daily Living (ADLs).** ADLs include eating, bathing, dressing, getting to and using the bathroom, getting in and out of bed or a chair, and mobility.
- **Instrumental Activities of Daily Living (IADLs).** IADLs include going outside the home, keeping track of money, preparing meals, doing light housework, using the telephone and taking medicine.²

Using ADLs and IADLs, a person can be assessed by their ability to perform each of these activities under four circumstances: independently, with minimal assistance, with moderate assistance or with full dependence on help. Definitions, however, are not standardized and the assessment process involves too much subjectivity to argue that there is a well defined system for determining a person's need for long-term care.

While 40 million Americans are disabled, only about 30 percent of them -- close to 13 million, as Table 1 indicates -- need long-term care. The federal government estimates that about 5.1 million of the 12.8 million people needing long-term care are severely disabled, requiring intensive assistance with three or more daily activities. This includes the 2.4 million people cared for in institutions.³

In California, it is estimated that 1.3 million citizens in 1991 had one or more functional limitations that meant they required long-term assistance. The number is expected to rise to 1.6 million by the year 2000 and 2.2 million by 2020.⁴

While functional impairment can occur at any age, the chances of being disabled rise rapidly with age. Only 1 percent of those under 45 have

Age	Institution	Community or home	Total population
Elderly (65 +)	1,640,000	5,690,000	7,330,000
Adult (18-64)	710,000	4,380,000	5,090,000
Child (0-17)	90,000	330,000	420,000
Total	2,440,000	10,400,000	12,840,000

Source: United States General Accounting Office

Although the phrase long-term care brings to mind elderly people lying in nursing home beds, many people who need long-term care are neither elderly nor institutionalized.

functional limitations. Those between 65 and 74 have a 13 percent rate, while those over 85 have a 55 percent rate. The likelihood of entering a skilled nursing home is 50 percent for those 65 and older⁵.

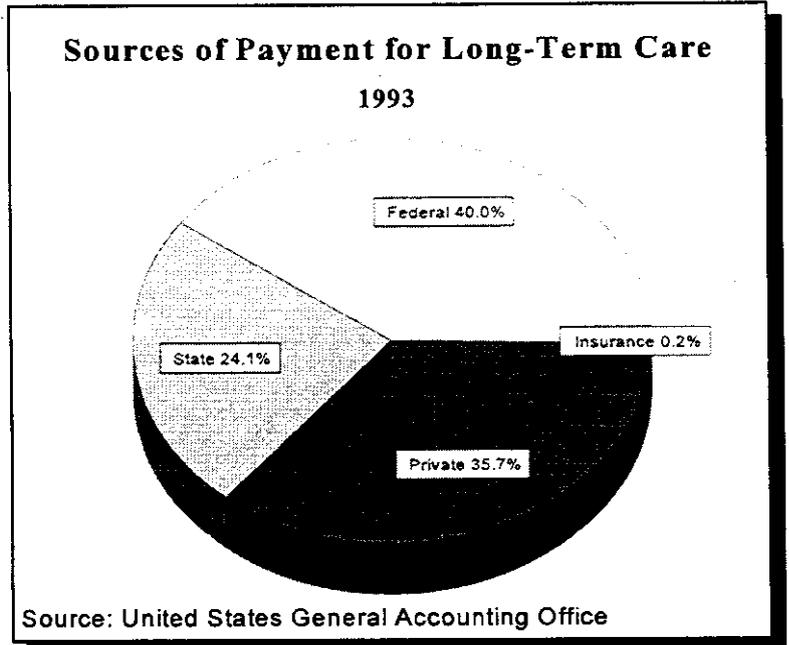
Who Pays for Long-Term Care?

The cost of long-term care services is mostly paid for by government. That is largely because government often covers the highest cost services, those provided in skilled nursing facilities, through the Medi-Cal program once a person has exhausted income and resources. The Medicare program pays for limited skilled nursing care after hospital stays. But charges in residential care facilities are not directly paid by government. In-home care may be provided through Medicare on a limited basis or state-run programs, like California's In-Home Supportive Services -- but it largely is provided at private expense or on a volunteer basis.

The federal government estimates about \$108 billion was spent nationwide on long-term care in 1993. The chart, which gives the breakdown of who pays for long-term care, indicates that 64 percent is funded by government sources while most of the remaining cost is covered out of pocket by people. Insurance coverage provides two-tenths of 1 percent of the funding for long-term care.

For the public portion of the cost, the federal government foots most of the bill, with the states providing matching dollars in many instances. Medicaid alone paid \$42 billion in federal and state dollars in 1993 -- \$26.1 billion for nursing homes, \$9.2 billion for nursing care for people with retardation and \$6.7 billion for home care.⁶

In California, the State spends about \$5 billion on all long-term care services. This includes more than \$2 billion for nursing homes, \$1 billion for in-home care, \$1.3 billion for developmental disability services and about \$68 million for community-based care.⁷ In some ways the State's funding for long-term care is generous; for instance, the State's In-Home Supportive Services program will pay relatives to provide care while other states prohibit payments to family members. In other ways,



State and federal governments pay for almost two-thirds of all long-term care, while insurance is the funding source for less than 1 percent.

however, the State is parsimonious; the State's Medi-Cal rate for skilled nursing facility care is far less than most states pay.

Despite these large expenditures in California and across the nation, most people who need long-term care either receive it from friends and relatives on a non-paid basis or manage without. Only slightly more than one-third of the severely disabled elderly (those with three or more ADL problems) live in institutions -- and 90 percent of those with lesser disabilities live at home.

At home, 70 percent of the disabled are cared for by volunteers who receive no pay -- family, friends and neighbors.⁸ Surveys have found that eight out of 10 caregivers provide unpaid assistance averaging four hours a day, seven days a week.⁹

With the overwhelming majority of people who need long-term care managing with no or free assistance, the large expenditures end up covering services for only a minority of the impaired. About 82 percent of the dollars go to nursing homes, even though only 16 percent of long-term care services are delivered in these institutions.¹⁰ The average cost of a nursing home stay in 1993 was \$39,000 a year.¹¹

The expenditures for long-term care are expected to more than double in the next 25 years.¹² This will be particularly burdensome as the number of working-age citizens declines, eroding the taxpaying base that provides support for services of all types.

For the last 20 years, California has had more workers to support long-term care needs; in the next

few decades, there will be far fewer as the trend reverses. In 1970 in California for every 100 working-age citizens, there were 83 Californians either too young or too old to work. The ratio decreased by 1990, leaving only 66 non-working Californians for each 100 workers. But by 2040, when those 60 and older will constitute 22 percent of the State's population, the number of non-workers will rise to 95 per 100 workers.¹³

Demands for government involvement in long-term care are rising just as resources are diminishing. But even with today's level of commitment,

<i>Type</i>	<i>Amount</i>	<i>% of total spending</i>	<i>Number of people</i>
Nursing facility	\$26.1 billion	62%	1.6 million
Intermediate care	\$9.2 billion	22%	149,282
Community/ Home-Based Waiver	\$2.9 billion	7%	135,000
Personal care	\$2.5 billion	6%	47,167
Home health	\$1.3 billion	3%	1.1 million
Total	\$42 billion	100%	3.0 million

Source: Public Policy Institute, April 1995

Almost two-thirds of Medicaid spending goes to nursing homes where about one-half of the people who receive Medicaid-funded long-term care are served.

government plays a significant role where its dollars are most heavily invested. Skilled nursing facilities, for instance, are heavily regulated by both the federal and state governments. Other types of assistance receive varying levels of government support and oversight.

Federal Government Role

The federal government has five major sources of funding for long-term care:¹⁴

- ***Medicare.*** This program (Title 28 of the Social Security Act) generally pays for acute medical care for the aged and some disabled; however, some home health visits and limited skilled nursing facility care are covered but only after a hospital stay. Of \$138.8 billion spent in 1993, \$15.8 billion was for long-term care services.
- ***Medicaid.*** This program (Title 19 of the Social Security Act) pays for medical care for low-income persons and is known as Medi-Cal in California. The long-term care services provided include skilled nursing facility care, community-based health and social services, facilities for the mentally retarded and chronic care in hospital settings. Of \$77.4 billion spent in 1993, \$24.7 billion was for long-term care.
- ***Social Services Block Grants.*** This source of funds (Title 20 of the Social Security Act) assists families and individuals in maintaining independence. Since states have flexibility in spending these funds it is not known how much of the \$2.8 billion spent in 1993 covered long-term care services.
- ***Rehabilitation Act.*** This act supports vocational rehabilitation and independent living services for the disabled, including attendant and personal care. In 1993, \$2.2 billion was spent, with about \$54 million going to long-term care.
- ***Older Americans Act.*** This funding is intended to foster the development of a comprehensive and coordinated service system for the elderly. Services include nutrition, home and community-based social services, protective services and the long-term care ombudsman program. About \$1.4 billion was spent in 1993, with \$765 million devoted to long-term care services.

Each of the federal funding programs is restricted to certain types of uses, and in each case a state must agree to provide specific services to specific categories of people in order to receive the funding. The rigidity of this system makes it difficult to design programs that meet local and individual needs, and it often results in perverse incentives that drive decision-making in ways that are not focused on the needs of the consumer -- issues that will be examined in Finding 1.

To accommodate experimentation and innovation, the federal government allows waivers on a state-by-state basis. Typically, a state will suggest an alternative way of using funds and then must prove to the federal government's satisfaction that the original goals of a program will still be met, and that people will not be deprived of an expected level of service. In addition, the cost must not be more than 100 percent of the projected cost to serve individuals if the waiver were not granted. States have the option of targeting certain populations, geographic areas and income thresholds.

In 1981, the federal government created a specific waiver program called the Medicaid Home and Community-Based Service Waiver Program. By 1994, all states (except Arizona, which instead has a demonstration program) had programs under the waiver. Services provided under this waiver may include case management, personal care, adult day care, respite care and homemaker chores.¹⁵

In 1987, the federal government added another waiver program targeted at the elderly. Under the first home- and community-based service waiver, a state could only provide services to one person for each skilled nursing facility bed that went unused. Under the new waiver, a state could take the funds saved by not using one bed and serve as many people as possible with that funding. To implement this, the state and federal government agree on an overall amount that will be spent on long-term care based on historical spending patterns and then the state has complete flexibility as long as it remains under that limit. According to the General Accounting Office, the only state to try this type of waiver -- Oregon -- eventually returned to the original waiver program because of the difficulty of staying under the limit.¹⁶

In 1990, the federal government added an "option" for those states looking for an alternative to the budget neutrality provisions of the waivers. States may provide the elderly with a package of home and community-based services, but overall spending is capped each year, so the program is not an entitlement because the funding is limited.¹⁷

At various times, waivers have been difficult to obtain or relatively easier to win, depending on the bureaucratic environment. Many states -- including California -- have implemented alternative programs successfully, some more aggressively than others. In California, 26 Medicaid waiver programs exist, 11 of them involving long-term care.

The federal government, then, is a major provider of funds and sets the parameters for service in connection with those funds. In addition, in some areas of long-term care, quality control and oversight is regulated by the federal government. The states add their own funding, administer programs required by the federal government and, in some cases, support home-grown approaches to long-term care.

California's Role

California's programs that provide or oversee long-term care are spread across several state departments -- and in some instances the State merely acts as a funnel, transferring funds to the counties to administer programs. The major functions by department include:

- The **Department of Health Services** provides funding for skilled nursing and intermediate care facilities through the Medi-Cal program, the State's version of Medicaid. Approximately 102,000 people reside in skilled nursing facilities on any given day, with the State paying about \$1.99 billion annually for the care provided to about 70,350 of them. In addition, Medi-Cal pays for some care under the In-Home Supportive Services program and in adult day health care settings.

Besides acting as a payor for long-term care services for people with limited means, the Department also directly oversees the quality of care in the State's 1,498 nursing care facilities through a licensing and annual survey process that is federally mandated.

- The **Department of Social Services** oversees the In-Home Supportive Services (IHSS) program and Adult Protective Services, both of which are administered by counties. The IHSS program provides personal care services to aged, blind and disabled low-income people so that they may remain safely in their own homes rather than being institutionalized. Depending on the person's eligibility, the program is paid for through a combination of federal, state and county dollars. Approximately 200,000 people will receive services in 1996-97, for a program cost of \$845 million and administrative cost of \$150 million. The Adult Protective Services program provides assistance to functionally impaired adults who are victims of abuse, neglect or exploitation. Oversight from the State is in the form of general parameters for services that should be provided.

In addition, the Department licenses and inspects non-medical, out-of-home care facilities. These include 4,700 Adult Residential Facilities with a capacity of 40,000; 5,200 Residential Care Facilities for the Elderly with a capacity of 116,000; and 23 Residential Care Facilities for the Chronically Ill with a capacity of 272. The Department also licenses 500 Adult Day Care operations with a capacity of 24,315 and 40 Adult Day Support facilities with a capacity of 1,400.

- The **Department of Aging** administers programs funded under the federal Older Americans Act, as well as some funded by the State. The programs include the Multipurpose Senior Services Program and Linkages, which provide case management to prevent premature institutionalization; Adult Day Health Care and

Alzheimer's Day Care Resource Centers, which provide health services and day care for impaired adults and respite for their caregivers; Health Insurance Counseling and Advocacy Program, which provides assistance on long-term care insurance issues; the Ombudsman program, which uses trained volunteers to provide oversight and assistance to people in out-of-home care facilities; and a variety of case management, nutrition, transportation and information services.

- Other departments that provide long-term care services include the Department of Developmental Services, the Department of Rehabilitation and the Department of Mental Health.

The State also has several advisory bodies on issues, like long-term care, that affect the elderly. They include:

- √ The **California Commission on Aging** is a 25-member body, with 19 members appointed by the Governor and three each by the Senate Rules Committee and the Speaker of the Assembly. The members serve three-year terms. The Commission meets the federal requirement for an advisory body to the Department of Aging, is by statute the principal advocate for California's seniors and has administrative responsibility for the California Senior Legislature and the Triple A Council of California.
- √ The **California Senior Legislature**, an elected body of citizens 60 years of age and older that parallels the state Legislature and is responsible for proposing laws each year to help senior citizens.
- √ The **Triple A Council of California**, a body with representatives from the 33 Area Agencies on Aging (Triple A's) that cover the state and coordinate senior services underwritten by federal funding.

In addition to the state structure for long-term care oversight, there are many private-sector groups in California that voice their concerns about long-term care issues, including consumer advocate groups and industry associations.

While California is the state with the largest number of both the nation's elderly citizens and those who need long-term care, the State is not outstandingly innovative compared to other states when it comes to program and system reform. When experts discuss trends in long-term care, they often look to Oregon, Wisconsin, New York and other states -- but not California. The next two sections will summarize long-term care developments nationwide and special programs in California.

Nationwide Reform

The major trend in states that are restructuring their long-term care services is to emphasize in-home and community-based care rather than institutionalization. This is the result of two pressures: consumer preference and cost containment. Repeated studies have shown that people who need assistance would rather receive it in familiar settings than move to nursing homes. And nursing homes, which take the lion's share of public funds expended on long-term care, are an expensive way to deliver care unless a person actually needs round-the-clock nursing attention. Experts believe that many existing residents of nursing homes, who receive 24-hour-a-day care, could be served in home or community settings if adequate but limited assistance were available.

The major barriers to carrying out reform that could shift consumers to the less costly and more desirable settings are the restrictions that the federal government places on funding. Both the Medicare and Medicaid programs heavily emphasize medical solutions -- such as skilled nursing care in an institution -- rather than social model solutions that rely on preventive health care and low-cost assistance by people not necessarily licensed as health care professionals to keep people healthy enough to remain at home and out of hospitals.

With waivers from the standard federal programs and the adoption of options that Congress has made available, several states are making progress. Among them are:

■ ***Oregon.*** In 1981, Oregon created a single long-term care state agency to administer consolidated state and federal funding for services to the elderly and disabled. The state serves 25,000 people in home and community settings.¹⁸

Oregon was the first state to institute a program under the federal government's Medicaid Home and Community-Based Waiver Program and it has been the only state to actively relocate nursing home residents to community settings.¹⁹ It has accomplished this partly by encouraging the creation of residential care home, assisted living facility and adult foster home alternatives, in some cases by the same nursing home operators who were losing clientele. Before the program began, the state estimates that 85 percent of the skilled nursing home residents were there for functional, rather than medical, reasons. Today Oregon has 1,000 fewer Medicaid-funded nursing home residents than a decade ago -- despite 28 percent growth in the over-65 population.

The program places primary responsibility for administration of services on the Area Agencies on Aging, which are a single point of entry for the state's long-term care consumers. In addition to traditional long-term care services, eligibility for food stamps, medical and cash assistance for the elderly and the disabled are all handled through the same department.

Central to the program is case management -- assessment of needs, problems and resources; care planning and arrangement for formal and informal services; ongoing monitoring to assure services are appropriately delivered; and reassessment to adjust care to changing needs.

Long-term care services can be provided in out-of-home placements, such as residential care homes, adult foster homes and assisted living facilities. In-home care is provided by either formal providers under contract with the state or by someone selected by the consumer under the Client Employed Provider program. In addition, services can be obtained at adult day health care clinics.²⁰

An academic assessment of the Oregon program concludes that it has produced a system that is client-driven and community-based. But the study also says that Oregon may be unique among states for its strong political leadership, well-organized senior activists, dedication to experimentation and commitment to consumer preferences.²¹

■ **Washington:** In Washington, a single state agency is responsible for all long-term care services. The state's programs include Medicaid waivers and two state-funded programs for people who do not qualify for Medicaid. The state has made an aggressive effort to keep people out of institutions, concentrating on home and community-based care.

■ **Wisconsin:** In 1982, Wisconsin formed a state-funded alternative to nursing home care called Community Options Program (COP), expanding it statewide in 1986. Each person at risk for nursing home placement is assessed to determine if they can live in the community with some level of assistance. A care plan is developed and individuals are informed of available options.

Because this program is state funded, it has been limited -- serving roughly 7,400 people in 1994, with substantial waiting lists. More than 90 percent of the people served require a level of care that would entitle them to Medicaid funding in a nursing home.²²

<i>Data</i>	<i>Oregon</i>	<i>Washington</i>	<i>Wisconsin</i>
Nursing beds per 1,000 over age 65	36	49	75
Aged/disabled in community/home care	16,330	22,040	24,525
Nursing facility care	7,631	17,428	30,497
% of all long-term care in community/home setting	68%	56%	N/A

Source: United States General Accounting Office

In these three states, the number of nursing facility beds declined 1.3 percent between 1982 and 1992. During the same period nationwide, beds increased 20.5 percent. The number of people receiving community-based services in Oregon and Washington nearly doubled.

Wisconsin recently added a Medicaid waiver program that provides similar services using the funds that would have paid for the consumer's nursing home stay: respite care, supportive home care, home modifications, adult day care, case management, adaptive equipment and others. In addition, the program gives eligibility to those who have twice as much income as the State's SSI rate, broadening the pool of people who are provided services.²³

The Wisconsin program is known as "cash and counseling" because people are assessed, determined to be eligible for funding that would otherwise have gone to a nursing home, and then provided with an array of options that allows them to remain at home or in a community setting using an equivalent or lesser amount of funding.

■ **New York:** Placing a moratorium on new nursing home beds in 1977, New York has a longstanding commitment to community-based care. There are several components to its home-based care program:

- √ The Personal Care Program serves more than 50,000 people in New York City alone and offers services by health care paraprofessionals in the consumer's home.
- √ The Nursing Home Without Walls program provides care at home for up to 75 percent of the cost of nursing home care.
- √ The State Office for Aging operates a program for frail elderly who are not Medicaid eligible using state and federal Older Americans Act funding.
- √ Skilled nursing care and rehabilitative services are provided by certified home health agencies, who receive reimbursement from Medicare, Medicaid and private insurance.

With the largest home care population in the nation and Medicaid costs for home care that are rising 18 percent annually, New York has begun to look for ways to cap and contain costs.²⁴

■ **Texas:** By obtaining a Medicaid waiver for home care in 1993 that was equivalent to 22,000 nursing home beds, Texas has dramatically increased the number of people who receive long-term care services outside of nursing homes. In 1980, 30,000 people received community care while 65,000 were in nursing homes. In 1993, 75,000 received community care while the nursing home population remained at 65,000.²⁵

■ **Maine:** By 1997, Maine expects to have a Medicare/Medicaid managed care program for the elderly and disabled. Regional service delivery networks will be responsible for the management, coordination

and integration of services, including primary, acute and long-term care, underwritten by combined funding streams.²⁶

■ **Minnesota:** Under a five-year demonstration project, Minnesota is integrating long-term care and acute care for elderly patients who are eligible for both Medicaid and Medicare. The program is called Long-Term Care Options Project and is structured to test whether integrated services can be delivered more economically.²⁷

■ **Colorado:** This state provides a home care allowance of up to \$330 per month to elderly residents with disabilities. The person may purchase care from an outsider or reimburse friends and relatives for care.²⁸

■ **Pennsylvania:** A state-funded program in Pennsylvania allows nursing-home-eligible consumers to receive home and community-based care instead -- but only as long as the cost remains at 45 percent or less than the nursing home care would be. In an average month, the program serves 3,400 people, but budget limitations result in a large waiting list. In addition, the state has an attendant care program funded by federal grants that covers almost 2,000 people with disabilities. The waiting list for this program is also long, resulting in a two-year wait to receive services.²⁹

■ **Massachusetts:** This state has been a forerunner in providing long-term care services at home, but budgetary constraints have slowly eroded the progress made in the 1980s. Although 45,000 people received in-home care in 1988, only 34,000 received it in 1994.³⁰

The Health Care Financing Administration, which oversees both Medicare and Medicaid, is testing several programs in multi-state sites. Two will be described below under California's innovative programs (PACE and SHMO). The Community Nursing Organization approach tests the impact of nurse-directed home health care and nurse case management on costs and integration of care. In addition, the EverCare demonstration project pairs physicians and geriatric nurse practitioners to oversee nursing home residents. The goal is to reduce hospitalization. A fixed monthly rate is paid with the case managers at full financial risk for acute care services for the enrollees.³¹

California's Innovations

While California is not among the states that experts tout as making good use of federal waivers, the State does have 11 programs that operate under Medicaid waivers regarding long-term care. The 11 programs cover up to 53,451 consumers, with the largest number -- 35,105 -- providing home services for the developmentally disabled. Most of the programs are much smaller:³²

- √ The Program of All-inclusive Care for the Elderly (PACE) incorporates all acute and long-term care services in one program, funded by Medicare and Medicaid, with the provider at full financial risk if costs rise above capitated rates. Core services include adult day health care, multidisciplinary team case management and home personal care services. From the consumer perspective, the program's primary focus is to keep the consumer healthy and at home as long as possible, avoiding both hospitalization and skilled nursing home care. With sites in Sacramento and Oakland, California has two out of 10 sites nationwide that have an enrollment of about 3,000. The program is modeled after San Francisco's On Lok program, which will be described in Finding 1. The three waivers in California combined allow up to 644 enrollees.

- √ California also has one of the nation's four Social Health Maintenance Organizations in Long Beach. The program pools Medicare, member premiums and Medicaid funding to provide acute care, prescription drugs and long-term care benefits such as homemaker, transportation and home health services. Like the PACE model, this program relies on avoiding high-cost institutionalization through preventive care and aggressive case management. Enrollees are limited to 627.

- √ A special program covers up to 4,550 patients with AIDS and AIDS related conditions, providing case management, homemaker services, counseling and other in-home services.

- √ The In-Home Medical Care Waiver with 375 enrollees, Model Home and Community-Based Services Waiver with 200 enrollees and the Skilled Nursing Facility Waiver with 450 enrollees all focus on services and family training and support that allow nursing-home eligible consumers to remain at home.

- √ The Multipurpose Senior Services Program Waiver, serving up to 8,000, is operated by the Department of Aging under an agreement with Department of Health Services. Nursing-home-eligible people who receive SSI payments are provided case management and other services to try to retain them in their homes.

The State will add another approach to long-term care services under legislation that became effective in 1996. Five pilot projects in different parts of the state will concentrate on local integration of all services and funding streams for long-term care. The State, which plans to request a federal waiver for the experimental program, recently began the bidding process that will determine how and where the pilots will be developed. Many long-term care advocates look to these five pilots to set the stage for complete integration of long-term care services and a movement to community-based care throughout the state.

The Department of Health Services told the Commission it also is researching assisted living services that are provided in other states under Medicaid programs. The programs typically include personal care, homemaker, chore, medication oversight and therapeutic social and recreational services provided in a home-like environment, either in licensed facilities or in the consumer's own home. The Department plans to submit a recommendation to policy makers in January 1997.³³

With the expansion of innovative programs and many examples of nationwide trends to emulate, California is poised for reforming the way it meets the needs of the elderly and the disabled. The following four findings focus on the barriers that may continue to block reform. The recommendations provide further steps that policy makers can take to reshape the long-term care system into an effective, consumer-oriented continuum of care.

State Structure

- ❖ *Long-term care programs and policies are fragmented among various levels of governments and constrained by multiple layers of regulations.*
- ❖ *The present system is neither consumer-driven nor consumer-focused, resulting in confusion and inappropriate -- or no -- services for many people.*
- ❖ *Consumers would like a single, credible source of information, referral and assessment, as well as a uniform eligibility process.*
- ❖ *Accountability should shift from monitoring processes to focusing on outcome, and oversight should be consistent with regard to goals while allowing flexibility of method to reach those goals.*

State Structure

Finding 1: The present state structure for long-term care oversight is not conducive to a coordinated continuum of care and fails to focus state efforts on consumer-centered, least-restrictive, best-value services.

A person in need of long-term care faces a bewildering maze of policies, bureaucracies and programs. Strictly regimented funding streams and fragmented service programs skew decisions toward high-cost, less consumer-desired solutions. Although the State Plan on Aging describes a coordinated continuum of care options that strives to keep consumers in their homes and communities, the State's segmented structure for overseeing long-term care frustrates the implementation of this federally required plan. The result is consumer confusion, costly choices and premature erosion in the quality of life for many individuals. At a time when the population most likely to need long-term care services is expanding rapidly, the State can ill afford to maintain its present system.

In a society that values youth, little emphasis is placed on the aging process, what to expect and what resources are available. As a result, when people suddenly find themselves incapacitated, few know where to turn or have a plan in place for how to cope. This is no less true for those who are struggling to assist an elderly relative, especially if they are geographically removed from the person in need of care. In fact, misconceptions abound:

- An American Association of Retired Persons poll found that 79 percent of the elderly believe that Medicare covers the cost of care in skilled nursing facilities. It does not, except for a limited time after hospitalization to treat an acute condition.³⁴
- Studies also have found that many are unaware that they must become impoverished to be eligible for skilled nursing facility care at public expense under the Medicaid program, known as Medi-Cal in California.
- Even fewer are aware that no public support is provided for those who want to live in residential care facilities, a lower level of care that can extend a person's independence while safeguarding them from the perils of remaining at home with diminished abilities.
- Few people know the difference between the various levels of care options, especially the many distinctions between residential care facilities and skilled nursing facilities and the fact that different government agencies regulate them.

A common occurrence is a sudden event -- perhaps a fall or a medical crisis such as a stroke -- that causes a person and his relatives to realize that remaining at home alone is no longer a safe option. Sometimes there is no particular event but instead a growing awareness that memory loss or physical weakening is endangering the person. Several scenarios may occur at this point.

Many Options, Little Help in Choosing

If a person is hospitalized for treatment, the hospital's discharge planner may help find an out-of-home placement or arrange for in-home assistance. Or a relative may arrange to use one of the private information-and-referral services that are beginning to be available. These are neither licensed nor regulated by government, so the consumer has little to guide him in making a choice or relying on the advice given. The relative also may turn to a home health agency, which is licensed by the State, and arrange for in-home medical attention from visiting nurses -- a costly route if only supervision and minor personal care is needed.

A person may call the local Area Agency on Aging if they know about it. The State contracts with 33 agencies to cover the entire state geographically (in urban areas, these often coincide with county lines, while rural areas usually share an agency). These agencies are supposed to develop a coordinated system of long-term care services, provide information and referral for people and perform other functions to assist older Californians. Those most familiar with the agencies, known as Triple A's, say their record is spotty. Some Triple A's do a good job of helping people, while others provide little information and assistance.

Some offer case management services and specialized assessment programs; others do not.

Recently, the State provided an 800 telephone number (1-800-510-2020) that hooks people into a local referral service. Operators who answer the phone are trained to ask questions and then refer people to appropriate sources for help, such as local health clinics, legal aid societies, advocacy groups, and licensing agencies.

The endangered person may come to the attention of county social services or welfare workers through an abuse or neglect report and be referred to In-Home Supportive Services, a county-run program that uses state, federal and local funding to provide help at home for impoverished functionally impaired people. In most counties, the people in need of assistance will be assessed, assigned a number of hours of eligibility for help and then be told to find their own caregiver at minimum wage. This burden sometimes is overwhelming and it can lead to unreliable situations.

If continued residence in the person's own home seems impossible, the consumer may simply turn to the Yellow Pages and find that yesterday's convalescent hospitals have turned into today's specialized, separate categories: residential care homes, nursing homes and retirement homes. Each provides an opportunity for price sticker shock (about \$3,500 a month for nursing homes, \$1,500 for residential care homes) and confusion.

In short, the choices that one faces when long-term care is needed are many and the sources for information are scattered.

Nursing homes are regulated by the Department of Health Services and can be paid for by the government if a person is poor enough in both income and assets. Residential care homes are overseen by the Department of Social Services and are paid for by the resident. If the resident receives SSI/SSP payments, the home cannot charge more than the monthly check -- unless the resident's family chooses to voluntarily supplement the low rate. Those with only SSI/SSP checks may find their choices limited or non-existent. Retirement homes and other "assisted" living arrangements may or may not fall under various state licensing categories, depending on what they promise in the way of service.

In short, the choices that one faces when long-term care is needed are many and the sources for information are scattered. Although the State's new 800 number may eventually become a widely recognized resource, it still will not provide a single point of comprehensive assessment and listing of options that are designed around a person's particular situation. Instead, it will serve as a way to find other sources that must be called and checked out.

Complicated Program Constraints

Just as information is difficult to obtain, funding and program constraints make understanding and selecting options a bewildering experience. More importantly, these constraints influence choices in a way that has little to do with the person's individual situation and need for care. The following three statements describe some of the problems with today's long-term care services:

■ ***Not all government programs have the same eligibility criteria.*** A person may be eligible for some types of assistance and not others. And each program has its own application process and mechanisms for assessing need. This may mean that a person will go through repeated processes of proving they are disabled and in need.

For instance, a person receives Medicare coverage at age 65 (or sooner with some specific medical conditions) and regardless of income. However, Medi-Cal coverage kicks in when a person's assets and income fall below a certain level -- although partial coverage called "share-of-cost" can be obtained by people with slightly higher incomes. Medicaid nationwide provides long-term care for about 12 percent of the elderly and 15 percent of the working-aged disabled.³⁶ Each program covers different services under different payment schemes.

Yet a separate program is the Supplemental Security Income/State Supplementary Payment program, which provides a monthly stipend to the impoverished aged, blind and disabled population and provides automatic eligibility for Medi-Cal and for In-Home Supportive Services (IHSS). People can receive IHSS services, however, even if they are not SSI/SSP recipients.

The Department of Aging provides case management for low-income seniors through the Multipurpose Senior Services Program and for others through Linkages. Both programs are restricted in the number of people they serve because of limited resources -- and in some geographic areas they are not available at all despite the presence of people who meet the criteria for service. Similarly, many nutrition and hot meal programs have no income test but availability may be restricted because of resources.

In general, a person who needs multiple services will have to go through multiple application and in-take processes with different criteria determining eligibility.

■ ***Not all government programs pay the same level for service, so cost-shifting occurs.*** In California compared to the rest of the nation, Medi-Cal is well-known for paying low rates for medical care and nursing home services (for instance, New York's program pays twice as much for a day of care). The nationally run Medicare program pays 66 percent

more for a nursing home day than Medi-Cal; private pay rates average 40 percent more than Medi-Cal.³⁶

These facts, combined with the point that neither government program is at total risk for patient outcome, allows the potential for cost-shifting and perverse incentives. A skilled nursing facility, for instance, receives a much higher daily rate for a Medi-Cal resident who has deteriorated to the point of being transferred to an acute-care hospital and then has returned to skilled nursing care under Medicare reimbursement. Some consumer advocates have argued that skilled nursing facilities would provide better bed-sore prevention, hydration and nourishment monitoring -- common problems that send residents to hospitals with acute conditions -- if the facility had to pay for the hospitalization. Instead, skilled nursing facilities receive a daily stipend to hold the bed open while the resident is in the hospital, and then receive a higher reimbursement rate for a time when the person returns from the hospital. At least one government report acknowledges this perverse incentive.³⁷

The built-in problems associated with the current system becomes particularly evident when the experience of On Lok is examined. A program that operates under federal and state waivers, On Lok collects a set amount of Medi-Cal and Medicare dollars for each patient and uses the funds to provide intensive preventive care and in-home services to stave off institutionalization as long as possible. Since the program must pay for any expensive hospitalization and skilled nursing facility care that is incurred, focused effort is devoted to maintaining the patient's health in their home environment and avoiding the institutional placements. The

The Story of On Lok

The typical enrollee is a frail 83-year-old with eight medical problems, difficulty with two or three Activities of Daily Living and taking four or five medications a day. Sixty percent have some form of dementia and 50 percent are incontinent. And despite the fact that each enrollee by definition needs continuous nursing care, only 5 percent are in skilled nursing facilities.

This is On Lok (in Chinese, "inner peace"), a comprehensive program that has been providing care to the frail elderly in San Francisco since 1973. Under federal Medicaid and Medicare waivers that the program obtained on its own in the mid 1980s, On Lok receives a capitated amount of about \$3,200 a month to provide complete acute and chronic medical care to enrollees who are certified as needing to be placed in skilled nursing facilities.

The combined Medicaid/Medicare rate is about 90 percent of the average payment to skilled nursing facilities in the state and 95 percent of what Medicare presumes medical care would cost for a similarly elderly and frail population. On Lok has complete flexibility to use the funds, typically paying for extensive in-home assistance and aggressive preventive health care measures.

How does On Lok make ends meet since it is at risk for all medical costs until the death of the enrollee? The key, says Executive Director Jennie Chin Hansen, is keeping hospital care to a minimum through careful attention to daily needs. On Lok has a hospital utilization rate of 1,400 days per 1,000 enrollees, while the national average for all people over 65 -- a much healthier population -- is 2,400 days per 1,000 people.

Another factor is staving off out-of-home placement as long as possible. Skilled nursing facilities have a role in long-term care, Chin Hansen says, but some 30 percent of people there today might not need to be if they had the proper assistance to remain home. On Lok provides that help, focusing on nourishing meals, social activities, family involvement, necessary transportation and preventive health care. "We see the person as a total individual -- and then we use the funding to meet their needs," Chin Hansen says.

On Lok, with only 435 enrollees, is a success story that is beginning to begat imitators. PACE (the Program of All-Inclusive Care for the Elderly) is replicating the On Lok model at 10 sites around the nation, including Sacramento and Oakland in California. A total of about 3,000 people are covered.

program shows substantial savings, its operators report, largely because of the infrequent use of hospitalization.

■ ***Public support is easier to obtain for "high-end" services rather than for simple support measures that allow a person to retain independence or health.*** There are several examples:

- √ Medi-Cal will cover the cost of skilled nursing facility care but not residential care facility occupancy. As a result, if people cannot come up with the \$1,500 per month for residential care, they may remain in their homes until they have deteriorated to the point of needing to move to a skilled nursing facility at a much higher cost to the State. Many argue that earlier intervention with a lower level of assistance would stave off skilled nursing facility usage for a longer period.
- √ Medicare will cover the cost of medical services on an expensive fee-for-service basis at a doctor's office. But the same service delivered more cheaply and more conveniently in an Adult Day Health Care Center is not reimbursed.
- √ Medicare will cover the cost of prescription drugs for chronic illness and durable medical equipment in institutional settings, but will not do so if the person is able to obtain treatment in a home setting.³⁸
- √ A Medicare surgical patient can go to a skilled nursing facility after hospital treatment at Medicare expense -- but not if the surgery was performed in a less costly outpatient facility or if the hospital stay was less than three days.³⁹
- √ Architectural barriers, like the lack of a ramp for a wheelchair or bars in a bathroom, may make it unsafe for a person to remain in his or her home. Medi-Cal, the program that bears the cost if a person moves to a skilled nursing facility, cannot cover the cost of such modifications.
- √ For the past few years, Medi-Cal has provided coverage for in-home care, but only if the services are obtained through an agency. People who use relatives or friends -- typically at lower expense -- under the In-Home Supportive Services program are limited to the hours available under the county/state-funded portion of the program.
- √ Oral hygiene for people in skilled nursing facilities must be provided by dentists or under the direct supervision of dentists. Facilities have difficulty finding dentists that will come in, especially since rooms are not set up for this specialized service. Often residents are not easily moved out of facilities. Dental hygienists who might fill this gap in services cannot do so except under the direction of a dentist, an arrangement that is not

usually made. As a result, skilled nursing facility residents often go without dental care, which in turn can affect their nourishment intake and other health aspects of their lives.

The problems outlined above -- consumer confusion and program constraints -- are not a surprising revelation. They are commonly recognized -- and have been for years -- by the people who need services and their families, researchers, bureaucrats, policy makers and advocates.

Common Concerns, Solutions

Many of the organizations and individuals involved with long-term care have similar complaints and wish lists for improvements. For instance, the federal Health Care Financing Administration (HCFA) -- the federal agency that oversees Medicare and Medicaid spending -- itself recognizes the problems with long-term care in a report titled "The Role of Medicare and Medicaid in Long-Term Care: Opportunities, Challenges and New Directions." The report finds that:

*...the present Medicare and Medicaid service delivery systems consist of a number of self-contained benefits rather than a comprehensive system of care suited to meeting the complex needs of persons with disabilities. These systems are, moreover, professionally driven rather than beneficiary-centered and directed.*⁴⁰

The report continues with observations about the problems of coordination "within and across" the two programs, especially relating to benefit coverage and eligibility criteria. The problems are often complicated by the fact that the two programs are created and amended by different legislative authorities and have fundamentally different administrative structures.⁴¹

The HCFA report also notes that the coverage guidelines for Medicare "complicate decisions regarding choice of the appropriate setting for care....Principally, they fail to acknowledge that persons with chronic illness may often make a number of transitions between community-based and institutional settings."⁴²

The HCFA report identifies the key principles of a beneficiary-centered system: integrated funding, case management that seeks consumer and family involvement and control, integrated data systems and interdisciplinary teams of caregivers.⁴³

Taking a broader perspective, the United States General Accounting Office told the U.S. Senate that long-term care:

...has been patched together from multiple funding streams, both federal and state. Literally dozens of categorical funding streams

provide long-term care to specific populations such as chronically ill children, persons with AIDS, persons with developmental disabilities, persons with mental illness and the frail elderly....To negotiate services, an individual may need to contend with the myriad of federal and state long-term care programs that provide services, sometimes with different eligibility requirements.⁴⁴

The federal government is not alone in recognizing shortcomings. In testimony prepared for the Little Hoover Commission, the Director of California's Department of Aging summed up the problems with the State's system:

By lack of integration and fragmentation of social and medical services, we have frustrated consumers and their families. We are not "user-friendly." We ought to have one-stop accessibility to services; an elimination of multiple eligibility forms; and a shift to low-cost, low-tech services. And if you had been able to join us at any of our hearings, you would know that when staff uses the phrase "intake processes," the whole world of consumers and their families groan in lamentation.

Perhaps even more fundamental, the average consumer does not know what is covered by Medicare and/or by health insurance. Yet more basic, the consumers think their payments of income taxes entitles them to health and long-term care without regard to income or assets.⁴⁵

The Director called for reforms that remove barriers to service, establish uniform assessment processes and empower the consumer.

As part of the Little Hoover Commission study process, an advisory committee of more than 140 consumers, providers, advocates and other experts took part in multiple meetings to explore long-term care issues. One sub-group of the committee spent 12 hours identifying what consumers, providers and government want to achieve in long-term care and what barriers are stopping them. The group decided the key elements missing in an effective long-term care system for California were:

- ***A consumer-driven, consumer-focused policy that would ensure appropriate access to needed services.*** To address this concern, the group recommended consumer participation in the design, implementation and evaluation of programs. They also recommended that programs be outcome-oriented and canted toward social, rather than medical, models. Policies should emphasize consumer choice and full access for those with service needs, regardless of income or geography.

- ***A single source for information, assessment and referral.*** The group found that government is the best source for "objective" data, such as who owns facilities and what licensing

requirements are, while the private sector is more credible with "subjective" information about quality of care and other issues. Key criteria for a single information source would be reliability, consumer-friendly, neutral and uncontrolled by providers, and funded by adequate resources.

- **Funding at adequate levels.** The group encouraged the use of foundation grants for project seed money and research and the use of incentives to increase purchases of private long-term care insurance. But

government will continue to be the main source of funding. They advocated removing perversities in the system that drive up costs without increasing service, uniform eligibility standards, pooling of funding streams that are now restricted and increasing the priority of long-term care in the competition for government resources.

- **Accountability that is both credible and responsive to consumer concerns.**

Government, providers and the private sector each have a role in ensuring accountability. Government needs to fully fund mandates, improve management information systems and remove duplication in systems. Providers should respond to incentives to improve care and be innovative. The private sector should

focus on effective means of monitoring quality of care.

The Challenge is Clear

Six advocacy organizations developed a joint policy statement in January 1995 to push for reform of long-term care services in California. Titled "The Challenge is Clear, the Time is Now," the statement calls for six steps:

- ✓ Designate a state agency with authority to reorganize the current fragmented system and categorical services; to integrate health and social services funding; to secure appropriate waivers; and to ensure that long-term care needs of the citizens of California are being met in the most efficient and cost-effective way.
- ✓ Create a structure that assures the participation of consumers, families, local representatives, service providers and advocates in the design and monitoring of the system.
- ✓ Develop minimum standards of service with outcome measures.
- ✓ Develop a sustainable management infrastructure that supports the delivery of a broad continuum of services and creates an integrated data collection system.
- ✓ Require local areas to designate an entity responsible for local system development and implementation.
- ✓ Design a system that builds upon the existing system of community care and that is supported by federal, state and local public resources, as well as private funding and fee-for-service revenues.

The six signatories to the policy statement are the California Association of Area Agencies on Aging, the California Commission on Aging, the California Foundation of Independent Living Centers, the California Senior Legislature, the Public Interest Center on Long-Term Care and the Triple A Council of California.

Many of the points made by the Commission's advisory committee have been previously embraced in other forums. A coalition of six advocacy organizations has signed a "call for the development and restructuring of California's long-term care system." Their statement of principles includes designing a system that has the flexibility to respond to the needs of individuals, families and caregivers; that provides for consumer

choice and self-determination; that involves consumers in designing and monitoring the system; and that focuses on preventive services and home and community-based support.⁴⁶

One of the six organizations, the California Commission on Aging, spearheaded a series of more than 45 public hearings around the state in the first half of 1996. In testimony about those hearings, the Commission's Chairman reported:

We heard loud and clear that seniors in need, as well as their family caregivers and their friends and neighbors who voluntarily help them, are frustrated with the way they can learn about and get the services they need to remain in their homes and communities and out of expensive institutions.⁴⁷

The Chairman reported that people testified that they wanted a place in their community where they could meet with a competent individual to learn about an array of services that would allow them to remain home as long as possible. They also indicated a desire for a single point of entry where they could learn what services they are eligible for and coordination that would allow them to move between different programs without having to requalify.⁴⁸

In addition to supporting reforms that address the concerns identified in their statewide hearings, the Commission on Aging's Chairman told the Little Hoover Commission:

The Commission [on Aging] envisions a system -- something we have referred to as a continuum of care system -- which would assist those in need to move from one set of services to another set without having to be requalified, without having to visit new agencies to determine what is available, and without losing their dignity in having to ask for assistance over and over again. And we firmly believe that such a continuum of care system is achievable -- achievable if we can remove turf issues from the service provider community; turf issues from among the bureaucrats who seem to be entrenched in what is, not what can be; and even turf issues with our lawmakers who feel they must add new pieces to the puzzle for which they can take credit for creating, rather than looking at how they might enhance implementation and make operative what already exists.⁴⁹

California is not the only state that is seeking an effective long-term care system. The United States General Accounting Office surveyed states in September 1994 and reported these common conclusions about long-term care:

- A person's ability to perform activities of daily living (ADLs) is the best way to identify persons with the greatest need for services. Most states couple this with a measurement for cognitive

disability and a factor for access to care from family to determine need.

- To determine what type of service is needed, most states believe that case management, a standard assessment instrument and active involvement in the process by the consumer are important.
- State agencies also believe that long-term care spending can be controlled by encouraging greater private-sector involvement. This includes incentives to purchase long-term care insurance and use of private residential care alternatives.⁵⁰

Agreement seems fairly broad-based about what needs to be accomplished -- and this consensus has existed for years, if not decades. Nonetheless, change in the long-term care arena tends to be incremental rather than on the scale required to make dramatic improvements. Many believe there are at least three factors that hold back the necessary reforms: California's state structure for overseeing long-term care, funding concerns and accountability issues.

State Structure

As cited in the Background, oversight of long-term care services is spread across several different departments. The Departments of Aging, Social Services and Health Services all house functions that serve the elderly. The Departments of Developmental Services, Rehabilitation and Mental Health provide services to the disabled and others who need long-term care. In the broader sense, the Departments of Transportation, Housing and others

Voices in Unity

Many advocates and experts in California have added their voices to the call for a more integrated long-term care system. Among them are:

- √ The Caregiver Resource Centers in California. These state government-funded programs that focus on non-institutional care have as a primary policy objective promoting "comprehensive, appropriate and affordable long-term care and support for family caregivers." The centers support eligibility requirements that are based on functional and cognitive limitations rather than age, financial resources, medical diagnosis or disability. They also believe a coordinated continuum of care options should emphasize the "least restrictive" level of care. Funding should come from a partnership between levels of government to maximize the impact of the funds and ensure "meaningful choices for consumers, their families and caregivers."
- √ In his book on health care choices in California, Lucien Wulsin Jr., a health expert and former long-time legislative consultant, concludes a chapter on long-term care by finding that "California already pays for large amounts of long-term care, but from many different pockets and with little program integration." He advises consolidation and integration of the State's many efforts.
- √ Writing in March 1991, the Senate Office of Research found that neither the federal government nor the state government are likely to provide universal long-term care any time soon because of cost. Energy should be focused, the office recommended, on improving the existing system by providing coordination of programs, extending the capacity of informal caregivers through support and preventing unnecessary institutionalization. The report recommended establishing a single department to oversee long-term care services and creating one-stop centers statewide for assessment, referral and eligibility screening. The report also noted that a Long-Term Care Reform Act was enacted in 1982 that would have folded all existing programs into a single Department of Aging and Long-Term Care. The act was never implemented, however, because the necessary federal waivers were not sought.

have a major impact on the elderly and the disabled when it comes to mobility, architectural accommodations and other issues.

While many of the departments with direct oversight of long-term care are in the same agency -- Health and Welfare Agency -- they historically have operated independently, and in some instances at odds with each other. In addition, some departments have been reluctant to embrace innovations. Some examples are:

- In the 1980s, consumer advocates pushed for the State to make use of Medi-Cal waivers and options -- as other states had successfully done -- to shift much of the In-Home Supportive Services (IHSS) program from a state General Fund base to a program funded 50-50 by the State and federal government. Many blamed the State's reluctance on the fact that money saved in the Department of Social Services, which oversees IHSS, was of little concern to the Department of Health Services, which would see its Medi-Cal costs rise and have to do the extensive work to achieve a federal go-ahead. The approach was eventually adopted in 1992 but not without significant help from the budgetary pressures caused by a statewide economic recession -- and not without procedural barriers that hampered the program's use during the first two years.
- Certified Nursing Assistants (CNAs) receive training, under the direction of the Department of Health Services, that heavily emphasizes that they have no role in distributing medications. Residential care facilities, however, may hire CNAs and expect them to assist residents with medications under Department of Social Services guidelines. The Department of Health Services sided with a CNA in a lawsuit who was fired for refusing to handle medications. The Department of Social Services' posture is that the residential care facility setting is different and CNAs should be able to play a different -- and appropriate -- role in that setting. As this report was being written, the two departments were working on an agreement in this area.
- Many have observed that the State has been reluctant to pursue waivers from the federal government. The On Lok program obtained its own waivers directly from the federal government because it could not get the State to respond. Advocates who have pushed for waiver programs over the years have been told there was no staff to do the paperwork. While the State now lists 26 Medicaid waivers, most of those have been developed in the last few years as the State has moved to place Medi-Cal recipients into managed care. There is general agreement in the consumer community that the State has lagged behind other states in obtaining federal permission to be innovative -- especially in light of the current receptiveness by the federal government to such requests.

- While the Department of Aging is the lead agency for issues affecting older Californians, its budget is tiny (\$142 million) compared to both the Department of Social Services (\$16 billion) and Department of Health Services (\$19 billion). Consumer advocates have complained that it is difficult for the Department of Aging to get the attention of the other departments at high levels for interdepartmental meetings to coordinate services.

That last point has been particularly significant, according to the Chairman of the California Commission on Aging. While the State Plan on Aging and the State's statutes provide direction for a comprehensive and integrated system of long-term care, no one appears to be directly responsible -- and therefore accountable -- for reaching goals. The Chairman told the Little Hoover Commission that the Commission on Aging does not have the clout to provide the coordination and responsiveness to consumers that it believes are critical to an effective long-term care system.

The State Plan on Aging -- required by the federal government as a condition for receiving federal funding for elder care programs -- calls for a long-term care service system that serves a broad range of individuals, provides the broadest scope of services possible, focuses on the community, provides for interorganizational relationships among public and private entities and makes optimal use of resources. Doing this, the plan says, requires an articulation of the leadership role at the state level, defining responsibilities and naming specific participants, and delineating the organizational structure that will support the desired services system.⁵¹

In addition to the State Plan on Aging support for an integrated long-term care system, the State's statutes envision a unified approach to services. Welfare and Institutions Code Section 9016 defines long-term care:

One-Stop Shopping for Care

The California State Plan on Aging is a federally required document that lays out the State's policies and priorities for serving elderly citizens. The 1993-97 version emphasizes an integrated approach to long-term care and says the most effective system would make it easier for people to know where to get information, reduce the burden placed on them by multiple assessments, help people transfer among service providers and monitor services to ensure quality and ongoing appropriateness.

The Plan identifies the following as necessary elements:

- ✓ **Information and assistance** that responds to requests, links people to services and provides follow-up.
- ✓ **Integrated intake** to avoid duplication in asking the consumer for information and to facilitate matching the person's needs to available services.
- ✓ **Uniform assessment** to obtain accurate information about the functional level of the consumer.
- ✓ **Case management** is used to identify the person's needs and to plan and coordinate available resources to address those needs.
- ✓ **Workable referral process** provides channels of communication and cooperation among service providers, intake workers and case managers.
- ✓ **Client program review** identifies the services the person has received in the past and is receiving now, current conditions and future options.

Long-term care means a coordinated continuum of preventive, diagnostic, therapeutic, rehabilitative, supportive and maintenance services that address the health, social and personal needs of individuals who have restricted self-care capabilities. Services shall be designed to recognize the positive capabilities of the individual and maximize the potential for the optimum level of physical, social and mental well-being in the least restrictive environment. Emphasis shall be placed on seeking service alternatives to institutionalization. Services may be provided by formal or informal support systems and may be continuous or intermittent. Long-term care may include licensed nursing facility, adult residential care, residential facility for the elderly, or home- and community-based services.

Many in the long-term care arena believe that the State's fragmented management structure -- spread across turf-conscious departments -- is a significant barrier to an effective system that cannot be overcome by simply encouraging coordination or mandating annual meetings. A decade ago at a Senate hearing on long-term care, witnesses called for a streamlined bureaucracy. One witness specifically recommended a single state agency so that effective coordination would be possible:

A single state agency responsible for case management and pre-screening could eliminate duplication which presently exists between programs, including assessments performed by numerous local agencies. For example, one case manager could perform assessments for both In-Home Supportive Services and Adult Day Health Care. A single state agency could develop consistent regulations and guidelines across programs, reducing any overlap or conflict.⁵²

Another witness at the same hearing added, "It makes good sense for a distinctly defined continuum of care to be regulated by an agency that understands case management, appreciates the need for blending of social and medical models, and can focus on the client who may need an array of services."⁵³

More recently in mid-1996, when the California Commission on Aging made recommendations to the Governor for amendments to bills re-crafting the Older Californians Act, the Commission called for a single state entity with comprehensive responsibility for policy development and for the planning and administration of long-term care services. The Commission's letter said:

California can no longer afford the inefficiency and waste of its current system of having departments, such as the Department of Aging, Social Services, Health Services, Mental Health, etc., providing separate services to the same individual without a comprehensive plan of care. Nor should such an individual consumer have to qualify separately for each department providing services.⁵⁴

It was a message that fit in with the trend of the Administration's own pronouncements in this area. In early 1996, the Governor's California Competes policy paper directed the Health and Welfare Agency to examine departments and programs within its jurisdiction with an eye to consolidation, increased efficiency and improved effectiveness. While the Administration has kept its thoughts under wraps, many administration and long-term-care-advocate sources shared with the Little Hoover Commission the belief that a single department overseeing all long-term care is a logical recommendation that the Governor may embrace.

Not everyone views the single-department approach with approval. Dozens of residential care facilities wrote to the Little Hoover Commission objecting to any move that would place them under the same roof as those who license skilled nursing facilities. Many fear that the intensive medical model -- complete with elaborate licensing requirements and exhaustive inspection processes -- will overwhelm and redirect the current social model found in residential care facilities.

Others argue that placing all the same people under a single department will not accomplish anything new. Neither practices nor perspectives will change -- merely business card titles and addresses.

And still others argue that many of the problems stem not from how the State is structured but from the many constraints placed on programs by federal funding and dictates. Changing how the State operates will not infuse new flexibility into programs or unleash tightly controlled funds.

But many others see the potential for re-energized leadership and thinking outside of the box. A single department could set and pursue broad goals of obtaining federal waivers, integrating services and maximizing flexibility. A single department could have clear policy objectives that combine the best elements of existing operations, including the social model of programs under the Department of Social Services and the outcome-based criteria recently enacted by the federal government and followed by the Department of Health Services. A single department could ensure that the policy focus is on the consumer's needs rather than on bureaucratic convenience.

Funding Issues

There are two aspects of funding that concern long-term care advocates: how much, and how it can be used. Since the population of elderly Californians is expected to expand rapidly and since they constitute a majority of those requiring long-term care services, many worry that government is not setting aside enough funding to cope with the need. And with the majority of spending concentrated on institutional care when all data points to people preferring at-home or community-based care, there is general consensus that funding priorities

need to be redirected by infusing flexibility into the use of government resources.

Providing more monetary support for long-term care services worries policy makers, who fear the number of people requiring care will rapidly expand when families and friends realize they no longer have to cope with the situation themselves. In reference to long-term care, this has been labeled the "out-of-the-woodwork" phenomena. Researchers, however, discounted this when an entitlement to skilled nursing facility care was floated as a concept. They found that consumers have no greater desire to live in institutions when they know the bill will be footed by the government. Most want to remain at home and with familiar caregivers as long as possible, regardless of who pays. This has proven true, for instance, in Canada, as one study indicated.⁵⁵

On the other hand, making more resources available for lower levels of long-term care has been found to expand the number of people seeking service. Increasing funding for in-home care is often talked about as a way of saving long-range costs by decreasing the number of skilled nursing facility residents. Researchers, however, have found that such increased resources tend to serve unmet needs that people have been coping with by remaining at home in discomfort or even danger rather than keeping people from entering skilled nursing facilities. Expanding such services neither keeps people from immediate institutionalization nor encourages family and friends to abandon their efforts. It simply improves the quality of life by taking care of needs that otherwise go unmet, researchers believe.⁵⁶

Recent academic research on the elderly in Massachusetts echoed these findings. The researchers drew several main conclusions:

- √ Informal care remained the predominant source of help even when formal, government-funded services were available.
- √ There was no evidence of a major or persistent trend of replacement of informal care by formal services.
- √ Formal services were most often used in conjunction with informal care.

The researchers found that when most consumers did switch to formal government programs for in-home care, they did so temporarily because of a disruption in their normal arrangements. They wrote:

It is important to restate that this study was conducted in a state with a well-established, publicly funded home care program, which would have made substitution of formal services for informal care easier. However, the fact that service substitution was temporary and related to the availability of the primary caregiver suggests that public funding for home care does not result in widespread and undesired (i.e. costly) service

substitution. Publicly funded services appear to be doing what they are intended to do: supporting and sustaining the informal caregiving arrangement or providing care during the disruption (usually temporary) of the regular arrangement in order to keep the elderly in the community. It cannot be denied that this substitution of formal services for previously provided informal care incurs costs that would not have been required had the informal care not been interrupted. However, the probable benefits of these services to both the care recipient, who desires to remain living at home, and to society, in containing the number of institutionalizations, appear to justify the costs.⁵⁷

Increasing funding for long-term care services is a mixed bag, then. Making skilled nursing facility care an entitlement at no private cost will not cause consumers to rush to enroll. But without further policy changes, providing more support for in-home services will increase spending without necessarily reducing government costs for institutionalization. In Oregon, for instance, a carefully targeted policy of reducing nursing home residency has shifted the balance of funding. Whereas the ratio of public dollars spent on community-based care versus nursing home care is one to five across the nation, in Oregon it is one to 2.6.⁵⁸

Recognizing the fervent competition among many justifiable interests for public dollars, many believe it will be difficult to carve out a bigger piece of the pie for long-term care services. But public dollars can be stretched in several ways:

- One is to encourage the use of privately purchased long-term care insurance. Covering only a tiny two-tenths of a percent of all long-term care costs, such insurance is a rarity today. But recently enacted federal law allows income tax deductions for the premiums, employers like the State of California are beginning to offer it as an option to workers, and California is also encouraging its purchase by allowing buyers to avoid impoverishing themselves to get Medi-Cal coverage once their policy's limits are reached.
- Another is to eliminate perverse incentives that force decisions toward high-cost care and duplicative systems that increase administrative costs. As many have suggested, setting up a system of single-point access to information, referral and assessment would allow consumers to make choices that suit their needs at a lower processing cost for the State. Sixteen states have adopted a single entry point for long-term care services, including California's neighbors, Oregon and Nevada.⁵⁹
- Finally, many advocates believe a powerful way for the State to get the best value out of present allocations is to pursue vigorously waivers, options and other creative solutions, distancing California as much as possible from the constraining

micro-management of the federal government. Taking steps to replicate On Lok's success, to experiment with "cash and counseling" as Wisconsin is doing, and to concentrate on keeping people out of nursing homes as Oregon has done would allow dollars from many programs to be combined and focused on consumer-centered options.

Accountability

When programs affect vulnerable citizens, the State has an interest in making sure they operate properly. In the case of long-term care services, several departments have oversight responsibilities. The Department of Social Services licenses and inspects residential care facilities and oversees the In-Home Supportive Services program. The Department of Health Services licenses and inspects skilled nursing facilities, as well as licensing or certifying other health facilities, home health agencies and certain types of health care workers. And the Department of Aging operates the Ombudsman program and oversees Adult Day Care centers. Specific issues in each of these areas will be examined in the remaining findings, but some concerns regarding accountability cross departmental lines and impact overall state policy.

Three strands of problems make accountability difficult: how to achieve flexibility and consistency simultaneously; how to balance individual choice against protecting people from themselves; and how to regulate effectively.

■ ***Flexibility and consistency:*** Much has been written about the counterproductive result of imposing rigid, specific rules on people -- this is, after all, the centerpiece of the past decade's private-sector reform movement of re-engineering businesses: freeing people to make good decisions to reach specific goals. In tightly constructed systems, people are neither allowed nor encouraged to think but instead are required to follow dictates. Those dictates may not prove suitable in all situations, and when they are rigidly followed the result may fall far short of an organization's goals. Instead of focusing on achieving desirable outcomes, both workers and bosses focus on process.

In the world of government oversight, the problem can be the same. Industries are forced to be accountable for process rather than outcome because regulators find it easier to measure, evaluate and examine process. An outcome may be difficult to describe precisely; a process is much easier to delineate and monitor. But as in the private-sector world, the prescribed process may not always yield a desirable outcome. In the worst case scenario, regulators may be proud that they have enforced a process and industry may feel safe from criticism because they followed the process -- but the end result may look like nothing that either side was trying to achieve.

It is tricky, however, to shift focus from process to outcome. Allowing people to meet overall goals in a variety of ways infuses flexibility into process, but also causes uncertainty. Many of the service providers who participated on the Little Hoover Commission's advisory committee complained in one breath that there is too much micro-management in the State's regulatory process -- and then in the next breath criticized the regulators for not adhering to clear, precise rules. Likewise, consumer advocates wanted tougher enforcement but recognized that layer upon layer of regulations often diverts attention from what is happening to the consumer and protects the provider from real accountability.

Most agreed that what they would like to see is outcome-based standards, flexible policies about how to meet those standards and statewide consistency on interpreting standards. Such consistency would be achieved by a high level of professionalism and training for front-line regulators so there is a clear understanding of overall goals and current knowledge about state-of-the-art techniques and options.

At least one potential glitch in any shift to such a system lies in the State's approach to regulations. The State requires precise regulations that are not subject to misinterpretation and has created a process to ensure that regulations are neither vague nor more burdensome than required to enact a law's provisions. The process includes review by the Office of Administrative Law, an office set up to ensure that regulations are specific and narrow.

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While the Little Hoover Commission's long-term care study did not include a comprehensive review of the State's regulatory process, the Commission did gather some preliminary evidence that the process itself may hinder a shift in the regulatory paradigm. For instance, state Department of Health Services officials said the federal nursing home oversight regulations -- widely recognized as outcome-based and consumer-centered -- could never be adopted as state regulations because they are not precise enough. In another example, other officials said it is easier to achieve reform by placing specific language in statutes because the regulatory process takes too long and outcome is too uncertain.

■ ***Individual choice versus protection:*** The State has an interest in protecting vulnerable citizens -- and some would argue that includes protecting them against their own foolish choices, as well as against abuse and mistreatment by others. The discussion of pros and cons is much the same as the dialogue on the right to die that is being explored nationwide. If a person wishes to remain in a facility, even when some standards would indicate it may not be safe for him to do so, should the

State intervene and force him to move? Should the person's right to choose be held sacred -- or is the State correct in interceding in recognition that choices can be unduly influenced by depression, family pressure, economics and other factors?

The complexity is illustrated by different approaches in three different departments. At the Department of Health Services, which oversees skilled nursing facilities, the consumers are often among the frailest, most vulnerable citizens in the State. Many suffer from dementia and other disabling cognitive limitations. In addition to wanting to protect these people, the State has a further obligation as a direct purchaser of services. Since taxpayers' dollars are used to underwrite a large amount of nursing home care, the State wants to ensure it gets good value for its investment. While many advocates criticize the State's resolve and results, all would agree that a comprehensive structure for oversight and enforcement is in place, although its effectiveness can be questioned.

At the Department of Social Services, where residential care facilities are regulated, the philosophy is less clear. People live voluntarily and to a large degree independently in residential care facilities -- and the State does not directly purchase care in these facilities. Yet the State's licensing and inspection process requires state intervention when a person's needs exceed the level of care allowed in residential care facilities -- regardless of whether the facility wants to continue to provide care and the resident wants to continue to live there.

Because people want to "age in place" -- eventually die in familiar surroundings -- the Department of Social Services faces severe criticism whenever they force an individual to move. In fact, the Department even is taken to task when it closes places that it has judged are unsafe. In one instance where not one but two residents had wandered from a facility and been killed accidentally, relatives of other residents were outraged at the resulting state closure. They insisted the deaths were aberrations, that the facility had provided excellent care and that finding a replacement home as good would be almost impossible. On the other hand, the Department is just as often criticized for failing to close unlicensed facilities and for not shutting down operations that fail to provide good care.

A third philosophy is followed at the Department of Aging's ombudsman program. The ombudsmen, usually volunteers, act as advocates for people in residential care facilities and skilled nursing facilities. Their training emphasizes respecting the individual's wishes even when that is at variance with the individual's apparent best interests.

In the Commission's discussions with advocates and other experts, it became clear that many believe that a consumer should have freedom

It is clear that many people believe that a consumer should have freedom of choice -- but the comfort level with that standard rapidly diminishes if there is imminent danger to the consumer.

of choice -- but the comfort level with that standard rapidly diminishes if there is imminent danger to the consumer.

■ **Effective regulatory methods.** Regulation apparently is a thankless assignment, especially when it comes to creating effective mandates that will protect people and ensure an enjoyable quality of life. All of the parties involved in long-term care rarely are satisfied with regulatory efforts. Consumers and their relatives complain that the State is unresponsive, careless and too protective of industry. Care providers believe regulations are unduly burdensome and expensive and that inspectors can be capricious to the point of sabotaging viable businesses. And the regulators themselves feel constrained by precise rules that refuse to yield to common sense or hard-earned experience.

Yet most would agree that protecting those who require long-term care services is not something that can be left to the vagaries of market forces. One expert on regulatory theory has written that nursing homes are an excellent place to test new mechanisms for making regulations more effective:

Nursing home residents are arguably the least powerful individuals in modern societies. Most of them have been rendered indigent by extended illness. They are mostly unable to vote with their feet as consumers or to give political speeches; they are generally even afraid to complain. They enjoy less freedom of movement than slaves: in the United States, 38 percent of them are physically restrained, mostly by tying them to chairs, and many more are chemically restrained...even prisoners can riot. Dependent clients, and especially the frail, elderly poor, either fail to pursue or even conceptualize grievances; they develop a "culture of silence."⁶⁰

Experts have studied regulatory structure and effectiveness for decades. There generally are three academic theories of regulation, which is defined as authoritative intervention in private decision-making: public interest theory, regulatory capture theory and the theory of corporatism. Under public interest theory, it is presumed that restrictions on how individuals conduct their business are necessary because the marketplace will fail to force them to act properly. Regulatory capture theory involves how those who are regulated invest time and money in influencing the regulations rather than in complying with them. They "capture" the regulators through building long-term relationships, offering the hope for a future industry job and arguing that the economic viability of the industry as a whole is threatened if regulators are too firm. Corporatism theory refers to arrangements where private interest groups are given a direct role in the implementation of regulations in exchange for acceptance of constraints (such as licensing boards).⁶¹

As the then-president of the American Enterprise Institute for Public Policy Research testified to Congress in 1995, the pitfalls of regulation are well-known:

...the tendency of regulatory requirements to grow without limit in number and detail; the tendency of single-purpose agencies to be overzealous, extravagant and sometimes abusive in the pursuit of these purposes; and the tendency of policy to be manipulated and distorted by special interest groups -- [these problems] are predictable and routine rather than the product of crazed bureaucrats or the election of one or another party to control of the Executive Branch.⁶²

Mechanisms for coping with the flaws of regulation are less easy to agree on. Rotating regulators out of assignments assures that they do not become too aligned with those they are regulating -- but it also wastes the benefit of accumulated expertise. Limiting discretion of regulators ensures that they do not do "favors" but it also results in micromanagement and lack of focus on outcomes. Almost any mix of carrot-and-stick tools will be criticized by consumers as too wrapped up in incentives and by industry as too concerned with penalties.

Some research, however, points to two concepts that are useful when constructing regulatory frameworks: the involvement of public interest groups and "reintegrative shaming."

In both a book and articles, regulatory experts Ian Ayres and John Braithwaite argue that regulation can be flexible and outcome-based if a third party -- with equal clout -- is added to the usual players, government and industry. The two believe that regulation works best when there is the "evolution of cooperation" between regulator and regulatee; otherwise, too much energy and resources are wasted on avoiding detection and punishment. But, they say, "the very conditions that foster the evolution of cooperation are also the conditions that promote the evolution of capture and indeed corruption."⁶³

Ayres and Braithwaite call their solution tripartism, selecting a third party, such as a public interest or advocacy group, to join government regulators and industry at the table. The third party would have equal access to information, equal ability to negotiate and equal standing to sue or prosecute when regulations are violated.

While no one used the label tripartism, several advisory committee members told the Little Hoover Commission that regulation of long-term care services should be strengthened by giving more power to the private sector to access information, sue in court for substantial fines and, in general, serve as an outside-of-government "eye" on what is happening. At least one statewide organization, California Advocates for Nursing Home Reform, tracks the State's regulatory efforts, but the organization has no formal role other than as persistent gadfly.

The other tool for increasing regulatory effectiveness is a conscious effort to shame industry into doing a good job -- but only in a supportive fashion. In a study of Australian nursing home inspections, researchers Braithwaite and Toni Makkai identified three attitudes displayed by

regulators: tolerant of lapses in hopes of winning cooperation, intolerant in a stigmatizing fashion that focused on punishment, and intolerant in a manner that firmly required correction but did not indicate disrespect. The researchers found that future compliance with regulations dropped significantly when nursing homes were made to feel guilty and not respected; it dropped slightly less when tolerance allowed the homes to “get away” with violations.

The best result came from “reintegrative shaming,” combining criticism with respect and the prospect of “forgiveness”:

The effective inspectors are those who believe in strong expressions of disapproval combined with strong commitments to burying the hatchet once such robust encounters are over, to terminating disapproval with approval once things are fixed, to tempering disapproval for poor performance on one standard with approval for good performance on other standards, to avoiding humiliation by communicating disapproval of poor performance within a framework of respect for the performer.⁶⁴

The researchers noted that reintegrative shaming is most successful when an ongoing relationship has been established and a baseline of respect exists.

Many long-term care service providers complained within the Commission’s advisory committee forum that state regulators treat them arbitrarily and with disrespect. And consumer advocates told the Commission there is much too much tolerance by state regulators of violations. But in observations of inspections and discussions with state managers, the Commission noted that they strive to set a tone of respect and firmness and express both approval of and support for state employees who are professional in their approach to regulating care providers.

Nonetheless, there appears to be a mixture of roles in state government that undermines the credibility of efforts to provide effective oversight for long-term care. Many people have complained that having the same people providing both licensing activities and complaint investigation in the same operation affords too many opportunities for favoritism. Others are concerned that a department that is responsible for licensing and nurturing the economic viability of an industry cannot also effectively and aggressively protect the public. Examples of problems and perceptions that are specific to the skilled nursing facility and residential care facility industries will be discussed in Findings 3 and 4.

State officials recognize the duality of their roles. The Department of Social Services provides limited technical support to help licensees bring their operations into compliance with regulations, but the Department says it does not see its main function as helping businesses learn how to be successful. Similarly, the Department of Health Services runs seminars on select topics for providers when they find industry-wide

compliance problems, and they host an annual recognition event for skilled nursing facilities that demonstrate “best practices.” But the main focus of the licensing and certification unit is assuring quality of care through enforcing compliance with standards.

Another department’s program that is engaged in accountability for long-term care faces similar criticism for conflicts. The State Long-Term Care Ombudsman program uses volunteers who are trained by the State to monitor conditions in skilled nursing facilities, residential care facilities and other care arrangements. Some consumers have complained that the volunteers are too cozy with the facilities; others have said that the volunteers are not effective at making complaints that will be followed up by state licensing officials. Industry has complaints about ombudsmen, as well. Some say the volunteers are poorly trained and do not know what they are doing, while others feel the ombudsmen act like they are another arm of licensing with the power to punish regulation violations.

While this study did not focus on the operation of the Long-Term Care Ombudsman program, there did appear to be general consensus on two problems with the program: There is neither enough funding nor enough volunteers to cover effectively all the institutions and populations that are supposed to be monitored.

Keeping actual conflicts and perceptions of mixed roles to a minimum is important for effective regulation. Some consumer advocates have suggested that stronger enforcement and more responsive reaction to complaints would result from separating licensing functions from complaint investigations. Alternatives to the current system include shifting performance oversight to the Attorney General’s Office, where legal action can be taken, or to the Department of Consumer Affairs. Similarly, if the State moves to a single-department approach to long-term care programs, keeping the ombudsman program independent by placing it in a department like Consumer Affairs is an option worth exploring.

Regulating in a manner that will achieve a high quality of care for diverse individuals is not easy but it is a critically important goal. As one expert summarized:

The challenge is to create a regulatory climate that will fairly reward good outcomes and penalize poor ones in a context that will permit, even encourage, innovation. Focusing on outcomes will permit more opportunities to compare across modalities of care and will encourage approaches that integrate the efforts of both clinically and socially oriented care. It is both misleading and dangerous to suggest that medical care has little to offer those receiving long-term care. It is more realistic to portray medicine’s role as necessary but not sufficient and to establish a climate in which collaborative efforts are directed to improving or at least preserving function for as long as possible.⁶⁵

Summary

With no single source of reliable information and an array of complicated programs that are often at odds with each other, long-term care services in California are neither well organized nor easy to access for consumers. Consensus is broad and longstanding on many of the attributes that make up an effective and equitable long-term care system. Despite repeated calls for reform, California has made little progress on molding a well-run system. At least part of the reason is an inhospitable state structure for long-term care oversight, funding concerns and accountability issues. But there are steps policy makers can take to begin reforming long-term care services.

Recommendations

Recommendation 1-A: The Governor and the Legislature should consolidate the multiple departments that provide or oversee long-term care services into a single department.

Interdepartmental cooperation is a hit-and-miss proposition that usually lacks mission unity and aggressive leadership. If the State is serious about creating an effective long-term care system -- and with looming demographics that promise an explosion of those who need such care, the State should be concerned about that goal -- then it must reorganize departments into a single entity to oversee all long-term care. The new department should take advantage of the opportunities presented to create a consumer-centered philosophy that maximizes choice, effectiveness and efficient use of multiple resources.

Recommendation 1-B: The Governor and the Legislature should mandate that the new state department establish an effective one-stop service for consumers to obtain information, preliminary assessment of needs and referral to appropriate options.

What consumers have identified repeatedly as their most pressing need is a reliable source of information so they may understand the choices that are available to them. While the State has the backbone for such a system in place, with the 33 regional Area Agencies on Aging and a special 1-800 number, the resources are not available for personalized, one-stop counseling. In particular, the ability is lacking to access information about programs and individuals by computer so that counseling is person-specific. Over time, as the State makes progress on integrating programs, these referral centers should also serve as program entry points, with unified applications and common eligibility screening.

Recommendation 1-C: The Governor and the Legislature should require departments involved in long-term care to pursue federal waivers and options that will infuse flexibility into programs and funding.

The State has been slow to embrace opportunities to escape federal micromanagement, lagging behind other states in applying for and winning waivers. Although the process for securing waivers is lengthy, it is an investment the State must make if it is to create a long-term care system that focuses on consumer needs rather than one that is driven by artificial -- and often conflicting -- program constraints. Waivers are also a key tool for shifting long-term care services away from high-cost medical models to consumer-preferred, lower-cost community-based social models of care. Specific examples include Wisconsin's cash-and-counseling program, Oregon's targeted removal of people from skilled nursing facilities, and further replication of the On Lok and Social Health Maintenance Organization models.

Recommendation 1-D: The Governor and the Legislature should adopt a multi-pronged strategy for coping with the expected rising demand for and cost of long-term care services.

As the economy expands and state revenues increase, policy makers should give serious consideration to enlarging allocations for long-term care services. But there are other steps that would stretch resources, including further stimulation of the purchase of private long-term care insurance through tax credits; more effective educational outreach about people's financial options for the future; and elimination of program incentives that favor high-cost services.

Recommendation 1-E: The Governor and the Legislature should ensure that the State's policies are consumer-focused by establishing an advisory committee that can have a persuasive voice in policy formation, program implementation and quality assurance.

Consumers who actually use long-term care services can provide valuable input on what components are needed to make an effective system. They also can ensure that the focus of both policy and programs remains on the consumer and not on the convenience of bureaucracy. One option is to convert the existing California Commission on Aging to a body that includes consumers of long-term care services and to provide it with adequate resources to work closely with the restructured, single department in charge of long-term care services.

Recommendation 1-F: The Governor and the Legislature should develop a program for quality assurance and control that is outcome-based and consumer-oriented rather than prescriptive and process-oriented.

Policy makers should take several steps to shift oversight from a prescriptive system to an outcome-based system:

- √ The regulation-creating process and regulations themselves should be recrafted to emphasize outcome over process. This will lead to less rigid, less prescriptive regulations that may be more difficult for regulators to enforce and industry to understand but that should increase the opportunity for care that is centered on an individual's specific needs.
- √ More resources should be directed toward increasing training and professionalism of regulators so that less-prescriptive regulations can be enforced with flexibility regarding method but consistency regarding results.
- √ The check-and-balance structure for enforcement activities should be strengthened by creating a formalized, effective role for public interest and advocacy groups. This will include ensuring open access to information and records, a role for such groups in negotiations and the ability to seek effective legal redress for problems.

In addition, policy makers should focus on improving accountability and credibility for the State's oversight functions. Two possible steps:

- √ Any structural reform should be accompanied by efforts to minimize conflicting roles. Complaint investigations could be shifted to either the Attorney General's Office or the Department of Consumer Affairs. Similarly, the ombudsman program could be housed in these departments. Such change, if implemented, should be monitored for several years and then assessed for effectiveness.
- √ Increasing the resources available to the ombudsman program, which is stretched too thin over many important duties, would allow increased training and more effective outreach to identify a larger pool of volunteers. Added funding could be diverted from fines collected for violations of regulations.

Community Care

- ❖ *There is no consistent state-level effort to encourage home and community-based care in lieu of institutionalization.*
- ❖ *Adult Day Care and Adult Day Health Care programs provide local options for treatment but are limited because of lack of funding.*
- ❖ *Family caregiver programs provide respite services and counseling, but waiting lists are long and resources are few.*
- ❖ *Long-standing problems with the In-Home Supportive Services program continue to affect quality of care, but recent legislative changes hold out hope for improvement.*
- ❖ *County-administered adult protective services programs have proven an inadequate safety net because of lack of funding and statewide standards.*

Community Care

Finding 2: The State's policies and programs do little to encourage the use of community-based services, and too small an effort is made to protect people from premature deterioration that can result in costly institutional placements.

In many areas of state concern, prevention is an investment that saves long-range costs -- but prevention rarely wins priority over reactive services when resources are limited. In the case of long-term care, the bulk of government dollars is spent on institutionalization, and preventive services that would keep people out of high-cost institutions are stretched thin. Statutes are in place that favor community-based care, and exemptions and waivers for licensing regulations provide limited tools to keep people in home-like environments. But by and large, the state bureaucracy blocks rather than enables community solutions, and policy makers provide little financial support for preventive programs. Programs that have proven their worth but that suffer from financial neglect include:

- √ Support services for family caregivers.
- √ Adult day care and adult day health care clinics.
- √ In-Home Supportive Services.
- √ Adult Protective Services.

The imbalance between institutional and community-based care is difficult to tally accurately because of the fragmented nature of the State's programs. But California spends about \$2 billion annually on long-term care in skilled nursing facilities, providing services to about

70,350 people. In comparison, about \$850 million is spent on the In-Home Supportive Services program, which reaches almost 200,000 people, with another \$200 million for a variety of services underwritten by the Department of Aging that reach thousands more consumers in their homes and communities. An additional \$4 million is spent on Alzheimer's Centers and \$5 million to support family caregivers of brain-damaged adults.

The California statistics are not out of line with the national experience. For instance, in 1991 the federal Medicaid program spent \$20.7 billion on nursing home care or about 27 percent of all expenditures. The same year Medicaid expenditures on home health care were \$4.1 billion, or about 5.3 percent of all Medicaid spending.⁶⁶

A key difference between the State's financial support for institutional care and community-based care is the "unlimited" nature of institutional care from the consumer's perspective. A person who is eligible for skilled nursing care and who is poor will have the cost covered by Medi-Cal for all necessary services and for however long such care is needed. The In-Home Supportive Services program, while an "entitlement" that covers all eligible persons, nonetheless provides a limitation on the number of hours and the cost of services provided. Similarly, support for family caregivers is limited to the funding provided each year by policy makers and there are long waiting lists for services.

These budget allocations may make it appear that the State places a priority on institutional care. But actually the State's statutes regarding long-term care place heavy emphasis on home- and community-based care. This was true of both the original Older Californians Act and in its new version, which replaces the original effective January 1, 1997. The Older Californians Act, which places renewed emphasis on home- and community-based services, has several

The Older Californians Act has several goals: to shift control of programs and funding from the State to local areas, to integrate social and medical services, to provide a single, easily accessible point of access to services and to provide effective case management.

goals: to shift control of programs and funding from the State to local areas, to integrate social and medical services, to provide a single, easily accessible point of access to services and to provide effective case management. How these goals will take shape is still unknown, especially since there is no additional funding to make the changes.

Among other things, the Older Californians Act directs the State's Department of Aging to ensure "to the extent possible" that services provided by multiple state departments are coordinated and integrated. The Act continues, "That integration may include, but not be limited to, the reconfiguration of state departments into a coordinated unit that can provide for multiple services to the same consumers."

The Act defines the Department's mission as providing leadership to the area agencies on aging in developing systems of home- and community-based services that will maintain consumers in their own homes or in least-restrictive, home-like environments. The program standards the Department will adhere to and enforce include:

- √ Flexibility to respond to the needs of individuals, families and caregivers.
- √ Consumer choice and self-determination.
- √ Consumer involvement in the design and evaluation of the long-term care system.
- √ Equity and accessibility for all.
- √ Consistent statewide policy, with local control and implementation.
- √ Support for preventive services and home- and community-based services.
- √ Appropriate cost containment and fiscal incentives.

The call for integrated and community-based services in the new law is welcomed by consumer advocates. But the framework the law provides will need to be accompanied by substantial changes in the way the State does business if reform is to be effective. One area that many have targeted is the way the State licenses long-term care providers.

Licensing Categories

The lack of flexibility in California's approach to licensing programs may force a person to move to settings with higher levels of care before it is really necessary to do so. This is so even though the State has been responsive to the changing needs of long-term care consumers by adding exceptions and waivers to what are generally strictly regimented care options. But these innovations often lag behind growing need.

For instance, some terminal care is available to residents of Residential Care Facilities for the Elderly (RCFEs) through the secured-perimeter Alzheimer's program and the hospice program. But in general people who require medical care -- even at low levels that could be provided by home health agency personnel coming into an RCFE -- must move on to skilled nursing facilities.

This may mean that people with diabetes who can no longer do the finger prick test for blood sugar levels on their own must move to a full medical-model facility. Or someone who needs inhalant therapy several

times a day but otherwise is capable of managing with minor assistance may not be allowed to remain in an RCFE.

Another example occurs when a person cannot arrange for a caregiver under the In-Home Supportive Services program. Multiple efforts to find someone reliable and well-trained to provide needed service may eventually frustrate relatives' ability to help keep a person in his own home. This, too, may lead to premature placement in a skilled nursing facility.

From the State's perspective, keeping people in settings that are not skilled nursing facilities as long as possible is at least partly driven by economics -- alternative settings are cheaper and usually not paid for by the government. But there is also a human component to this problem. It has long been recognized that relocating frail elderly or severely disabled people can have a negative impact on their ability to function and survive. Known as transfer trauma, this phenomenon has been studied with different results. Some studies have found increased morbidity and mortality; others have found positive outcomes if the move is handled well and living conditions improve. But in general, moving to an entirely new and unfamiliar environment is very difficult and often dangerously depressing for people who are ill.⁶⁷

Rigid licensing categories not only directly impact consumers, they also affect the decisions made by care providers. The creativity that many community-based programs try to bring to long-term care is hampered by a state structure that requires them to deal with multiple licensing entities -- and the multiple reporting, tracking and auditing requirements that come with fragmented but rigid regulations.

For instance, the On Lok program, which offers a combined approach to caring for enrollees, has day health center licenses, primary medical care clinic licenses and a home health agency license. In addition, because it is paid for its enrollees on a capitated (per-person) basis, it must comply with Department of Corporations filing provisions that are designed for managed care health plans that typically cover thousands of enrollees -- rather than the 485 On Lok has. The result is that On Lok faces multiple and duplicative inspection processes and in some cases must set up separate bookkeeping mechanisms that add no value to On Lok's purposes other than satisfying regulatory requirements.⁶⁸

Participants on the Little Hoover Commission's advisory committee who are long-term care service providers said that if dual licensing were not so difficult and expensive they would be able to fashion solutions that would allow residents to age in place for a longer period. For instance, large residential care facilities could also become adult day health care centers, providing a licensed source of medical care for residents who no longer can attend to their own medical needs but who are far short of needing round-the-clock medical assistance in a skilled nursing facility.

In addition to meeting the needs of the residents, such an arrangement would give the residential care facilities an additional source of revenue (from Medi-Cal reimbursement of adult day health care services) to underwrite better care. Such a dual arrangement would also limit the transportation costs and problems most adult day health care centers face.

But beyond wishing that licensing processes were more amenable to allowing providers to offer multiple types of service, the Commission's advisory committee members worried that any move to consolidate licensing would bring the medically oriented, arduous inspection process that affects skilled nursing facilities into play for residential care facilities. And while desiring more effective oversight for all types of long-term care services, consumer advocates on the advisory committee did not want to see the medical-orientation and what they perceive as anti-consumer due process entanglements of the skilled nursing oversight system imposed on community-based, home-like service providers. Any reform would have to be carefully constructed to focus on outcomes rather than processes, the advisory committee cautioned.

For the most part, service providers have focused on modifying their own licensing categories rather than finding an overall solution. For instance, the California Association of Adult Day Services advocates a "levels of care" approach to licensing that would allow adult day programs to offer only core services or to offer augmented and specialized services with different add-on licensing approvals. This would allow consumers to receive multiple types of services in a single setting. The association's "Levels of Care Initiative" document states:

Levels of Care Proposal

The California Association for Adult Day Services envisions all centers having a single type of license to deliver a core package of services. Additional services would be provided under a certification process. The **Core** services would include:

- ✓ Screening, assessment and creation of a service plan.
- ✓ Personal care assistance with toileting, walking, eating, etc.
- ✓ Health-related services, such as monitoring medications, providing first aid, consulting with physician in charge, etc.
- ✓ Social services, including linkages to other programs, education for family, support for caregivers.
- ✓ Therapeutic activities, such as exercises to promote independence and group activities.
- ✓ Nutrition, including meals, snacks and fluids.
- ✓ Transportation to and from the center.
- ✓ Emergency care planning.

Augmented services would include:

- ✓ Nursing services, such as administration of medication and oxygen and monitoring vital signs.
- ✓ Psychosocial services, including counseling and assessment for depression.
- ✓ Rehabilitative services, such as physical therapy, occupational therapy and speech therapy.

Specialty services would include:

- ✓ Intensive nursing services, including providing injections, managing catheters, nasogastric tubes, etc.
- ✓ Specialized supportive services, such as intensive counseling and behavioral management.
- ✓ Intensive psychosocial services.
- ✓ Intensive rehabilitative services.

A levels of care approach to service delivery is based on the notion that the needs of persons with chronic disabilities change over time. It may be subtle or dramatic. In response to the variety of needs among adults with chronic disabilities, adult day services programs have developed to provide a range of services from respite-only adult day care to adult day health programs in a community clinic setting.⁶⁹

The desirability of integrating licensing for long-term care services is not a new concept. In 1986, the Senate Subcommittee on Aging conducted a hearing to explore licensing models that would provide a real continuum of long-term care services. Several service providers, including On Lok, testified about the problems with trying to offer integrated services. The executive director for the Jewish Homes for the Aged in Los Angeles told the subcommittee that the program offered only partial adult day care services and had set up a minimal assisted living housing arrangement separately from its main operations largely because of the demands of multiple licensing processes. He identified the disincentives for holding multiple licenses as:⁷⁰

- "The endless bureaucratic entanglements and delays associated purely with the licensing application process," which he said can take anywhere from several months to years to complete.
- Hidden costs to comply with the different policies and procedures established by each separate license. Typically, separate bookkeeping systems are required for each licensed activity.
- Dealing with separate licensing agencies, usually at different times of the year, that do not coordinate inspections, audits and demands for corrective action.

A representative for the California Association of Homes for the Aging echoed those concerns. He described continuing care retirement communities as a model that allows consumers to move from complete independence through assisted living to complete care without having to relocate. But licensing under separate state agencies is costly and duplicative. Saying that the pieces of a high-quality long-term care program exist and are individually well formulated, he concluded:

Will we continue on this same course of targeting to distinct sub-populations based on categorical funding programs, thus reinforcing the existing fragmented system and increasing the possibility of duplications in effort? Or can we adopt a generic model and pool resources to better serve disabled adults and their families? This is basically a call for this constellation of services and programs to be consolidated into a continuum; regulated and licensed by a single agency and funded through consolidated sources. The benefits are obvious: cost savings through reduced redundancy and duplication and efficient administration; caring

*for the state's frail elderly and their families in a humane and orderly manner.*⁷¹

Most people testifying favored slow and well-studied reform that would lead to a more welcoming licensing structure. The executive director of On Lok said that such an effort should be ongoing as different models of care evolve over time.⁷²

As a result of the hearing, the subcommittee made recommendations, including establishing a task force to review regulations, central coordination of all state programs and the development of multidisciplinary team licensing -- consolidating the process of granting, evaluating and renewing licenses rather than consolidating the licenses themselves.

Ten years later, people are still discussing such changes. Task forces meet to discuss the feasibility of a matrix -- or add-on model -- of licensing and to review regulations for overlap and obsolete requirements. But little progress has been made to make the licensing process friendlier to programs that want to provide an integrated array of social and medical services. The reasons are many: fear of change, departmental turf concerns and federal barriers, to name a few.

Adult Day Programs

Programs that are particularly affected by state licensing policies are the different types of adult day services, which is one reason the statewide association is pushing for reform (as described above). But a more pressing concern for most of these programs is financial viability.

Adult day care and adult support centers are licensed by the Department of Social Services to provide organized social services and protective supervision in a community setting. Adult day health care programs, on the other hand, are overseen by the Department of Aging under licensing requirements from the Department of Health Services. Alzheimer's Day Care Resource Centers provide respite to primary caregivers, training and education under the oversight of the Department of Aging.

These programs provide services that are intended to keep frail people healthy and at home. The highest level program can provide all of the care of a skilled nursing facility -- but the consumer goes home at night. The programs rely on an organized, comprehensive, team approach combining input from staff, the consumer and family. The statewide organization describes the approach:

The programs bridge medical and social services by viewing the person as a multidimensional person living within a larger community that includes both formal and informal support. Center staff work closely with participants, community

*resources, family members and other caregivers on an intensive, daily basis.*⁷³

Advocates for the programs say that statistics indicate that services from a day program may help delay institutionalization three years or longer.

The cost is comparatively low. For \$54.30 a day, Medi-Cal requires programs to provide transportation to and from the consumer's home, skilled nursing services, meals, personal care and other activities for at least six hours. This compares to the \$80 per day that Medi-Cal pays for skilled nursing home care.

Service providers say the reimbursement rate makes it difficult for programs to survive -- and almost impossible for new ones to be created. There are about 84 day health care programs, 110 day care centers and 16 specialized Alzheimer's programs, largely concentrated in the San Francisco Bay Area and Los Angeles area. Most people who could benefit from these services do not have access to them simply because of geography. Recently, rural programs have run into problems because of new tough requirements that all consumers in the service area be provided transportation to and from the program no matter how geographically remote. This means programs are faced with increased transportation costs or restricting service to areas where they can provide transportation.

Those connected with adult day care identified the following priorities during the Little Hoover Commission advisory committee meetings:

- Increase Medi-Cal reimbursement rates and change the federal Medicare program so that it covers medical services at adult day health care centers. Also create a source for start-up funding.
- Increase expertise about and focus on adult day care programs at the Department of Aging.
- Streamline regulations.
- Reverse the transportation rule.

Advocates say these types of programs need to be promoted to both consumers and policy makers so that they are not overlooked as efficient, life-enhancing methods for coping with long-term care needs in non-institutional ways.

Family Caregiver Programs

California's Caregiver Resource Centers take a different tack from most long-term care programs. They focus on the people who provide care rather than on the consumer who needs care. Under a

1984 law, the State provides funding for a statewide program of assistance for those caring for adults with brain damage, regardless of cause. The program's target audience for information, supportive services and training are the families, unpaid caregivers and professionals who work with the patients.

Services at 11 nonprofit centers include:

- Centralized information, advice and referral services, documentation of service needs and specialized training for caregivers.
- Planning and problem-solving consultations with families and caregivers about long-term care alternatives, diagnostic problems, legal and financial problems and patient care.
- Emotional support and mental health services to help families, patients and others cope with the consequences of brain impairment.
- Respite care services to give families a break from full-time caregiving.

The funding has held constant for the past few years, despite growing need and long waiting lists, at \$5 million. Of that amount, \$1.3 million is used to pay for in-home and out-of-home respite care. Experts say giving caregivers a break is critical to avoid burnout, depression, premature placement of patients in skilled nursing facilities, and -- far worse but not uncommon -- suicide. Respite care not only gives the caregiver time off, but it also provides the patient with a change, either in companionship with in-home respite care or in scenery with out-of-home respite care.

Who Are the Caregivers?

The Family Caregiver Alliance performed a year-long study of family caregivers in 1988-89, interviewing 1,337 people who care for brain-impaired adults and who contacted one of the Caregiver Resource Centers for assistance. They found the following, as reported in "Who's Taking Care? A Profile of California's Family Caregivers of Brain-Impaired Adults":

- √ The typical patient is male, average age 70, married and living at home with spouses or other relatives, with an income between \$12,000 and \$16,000.
- √ The typical caregiver is usually female, married to the patient and average age 61.
- √ Causes of the brain damage that created the need for care were stroke 23 percent, degenerative disease/dementia 65 percent, traumatic brain injury 8 percent and other 4 percent. Alzheimer's Disease alone accounted for 38 percent. While the time the patients had problems ranged from one to 38 years, the average length of disability was six years.
- √ Patients averaged 14 problems, some related to cognitive deficits (inability to communicate, concentrate) and some to the inability to perform activities of daily living (bathing, feeding, dressing). The older the patient and caregiver, the more problems were reported.
- √ Caregivers had high levels of depression: 68 percent showed clinical signs of depression and 61 percent felt burdened by their responsibilities. Older caregivers as a group were in worse health than the general population of elderly.
- √ The most needed services were consultation/planning 79 percent, in-home respite care 54 percent, legal/financial consultation 40 percent and counseling 26 percent.

The resource centers are allowed to authorize up to \$425 monthly for respite care, but most cap the service at \$350 so that more people can be served. On average, caregivers who are covered receive about nine hours of respite time per week. Caregivers may be provided vouchers to receive respite care through established programs (such as day care centers) or they may be given funding directly to arrange their own respite care.⁷⁴

Almost as important as respite care is the information the centers provide on such things as how to turn someone in bed, mood swings (both the patient's and the caregiver's), the disease process and how to find support groups.

The Family Caregiver Alliance, which is the research and consulting arm of the state-funded program, has conducted several studies to determine the characteristics and needs of brain-damaged adults and their caregivers. The results of one large, year-long study are summarized in the box on the previous page. Another smaller study of 284 caregivers in the Bay Area painted a picture that makes it clear why life is so difficult for these people:

Their patients range in age from 18 to 93, with the average 67. Many wander (48 percent), cannot be left alone (78 percent), awaken the caregiver at night (77 percent) and are stubborn or combative (84 percent). Two-thirds need help to bathe or take medications, three-fifths cannot dress themselves, half cannot go to the bathroom alone and one-third need help to eat.

They have been providing care an average of five years, 59 hours a week, with 28 hours paid help and less than two hours help from other kin outside the patient's household. Many feel tired (59 percent), are usually tense or anxious (42 percent) and feel quite burdened (46 percent). One-fifth had not had a vacation in five years.⁷⁵

The biggest problem facing the program is financial constraints. In 1994-95, the program reached 9,235 caregivers with one or more services. The same year a total of 820 families received respite care. As of January 1, 1996, 3,000 families were on a waiting list for respite care -- a waiting list so lengthy that sometimes patients die or go to institutions before they get to the top of the list.⁷⁶

Stressing the importance of the caregiver program, one advocate told the Little Hoover Commission:

Aging issues are family issues. Families, not institutions, are the major providers of long-term care in this country. Public policies must promote comprehensive, appropriate and affordable long-term care and support for family caregivers. Respite care is just one of a range of services that families need to keep them together at home and out of more costly institutional settings.⁷⁷

In-Home Supportive Services

The In-Home Supportive Services program is a giant among the non-institutional long-term care programs, costing more than \$845 million in direct services, with another \$150 million for administration, and reaching almost 200,000 people a year. But despite its relative wealth, this program, too, faces severe fiscal limitations that directly impact the quality of care people receive.

The program, administered by counties under oversight from the Department of Social Services, provides the following types of services to people who are low-income and who have been assessed as needing assistance with activities of daily living:

- √ Personal care services, such as bladder and bowel care, feeding, bathing, dressing and walking.
- √ Domestic services, including light house work and laundry.
- √ Assistance with food shopping, meal preparation and clean-up.
- √ Protective supervision to safeguard the consumer from injury and hazards.
- √ Transportation, including to medical appointments.

The Little Hoover Commission reviewed this program in 1991, concluding that limited funding and inherent structural flaws prevented the program from providing effective services.⁷⁸ The report cited as key problems the fragmentation of responsibility, with all levels of government trying to escape the burden of being the employer of caregivers; the prevalence of relying on the disabled consumer to manage the care, in some cases inappropriately; and the low quality of care stemming from many factors, including lack of standards and training for workers, who are often low paid and transient.

After meeting with the Commission's advisory committee, consulting with state officials and hearing from many IHSS recipients, the Commission found that none of these problems have been resolved. There have, however, been several developments since 1991:

■ ***Medi-Cal funding for IHSS was obtained:*** In 1991, the IHSS program in California was completely funded with state General Funds. Other states, however, had made use of a Medicaid waiver to provide the same type of services with a combination of state and federal funds. The Little Hoover Commission's report recommended that California apply for a waiver as a means of stretching state dollars further, bringing in federal funding and improving services. As the Commission report was issued, policy makers enacted legislation requiring the Health and Welfare Agency to investigate the feasibility of obtaining a waiver.

At about that same time, the State began to move programs to county control and funding responsibility under a process called realignment. Also at that time, the State's multi-year recession began to squeeze the resources available for all service programs.

When the Medi-Cal waiver came through, the State had two separate IHSS programs: 1) The so-called IHSS Residual Program is funded 65 percent by the State and 35 percent by counties. 2) The Personal Care Services Program is funded 50.23 percent by the federal government, 32.35 percent by the State and 17.42 percent by the counties.⁷⁹ A primary difference in who uses each program is that the Residual Program allows payments to family members; in addition, it allows protective supervision services, which the Medi-Cal program does not. Today about 65 percent of IHSS recipients receive care through the Medi-Cal-funded program.

While long-term care advocates are pleased with the implementation of the waiver program (after a shaky and expensive start when the program required intensive use of health care professionals even for personal care), they are less so with the fact that the expanded funding base allowed the State to cut back on its level of commitment to the program. Advocates had sought the dedication of the extra resources to improved and greater levels of service.

■ ***The Public Authority mechanism was created.*** The 1991 Commission report also encouraged the creation of non-profit entities to run controlled registries of screened and available workers, provide training and offer dispute resolution services. In 1992 this law was enacted but follow-up regulations made the public authorities liable as employers of the caregivers. The problems were resolved, consumer advocates believe, with budget language passed in the summer of 1996 that made it clear caregivers will continue to be paid through the State's payroll mechanism, that the public authority will face no increased tax liabilities and that recipients will maintain control of care provider selection.⁸⁰

The Public Authority mechanism, already existing in three San Francisco Bay Area counties, is embraced enthusiastically by IHSS consumers. Set up by counties at arms' length, the Public Authorities serve as umbrella organizations to engage in collective bargaining with caregivers (even though the caregivers are employed directly by the IHSS consumer), deal with consumer complaints and try to improve the availability and training of caregivers. Run by boards that are heavily populated with IHSS recipients, the Public Authorities have the practical goal of making the program work better for consumers. Like most components of the long-term care system, the major potential barrier to success will be the lack of funding to carry out the variety of necessary chores.

■ ***The controversial managed care mode became the Task Frequency mode of service.*** In its 1991 report, the Commission recommended that non-severely impaired, low-hour cases be handled by

contract agency workers. The recommendation included the caveat that such arrangements must contain suitable safeguards to ensure consumer freedom of choice and high performance standards.

From 1992 to 1995, the State authorized a demonstration project in Tulare County to assess the ability of a privatized managed care program to deliver services to IHSS recipients that met the needs of all clients at costs similar to existing services and with the same quality of care. The reviews of the project were decidedly mixed:

- √ Consumer advocates, who disliked the concept of recipients not being in charge of their own workers and who were wary of reduced hours that were supposed to deliver the same level of service through better trained workers, felt vindicated by a California State University assessment that services were less efficient, more costly on a per case and per hour basis, and lower in quality level for personal care, although household care seemed similar to other IHSS programs.⁸¹
- √ The managed care provider, however, was much happier with an assessment it paid for that highlighted the fact that overall program costs declined, abuse rates declined, hospitalization rates declined, skilled nursing facility placements declined and consumer satisfaction with services was comparable to satisfaction rates in other counties.⁸²

The Legislature responded to the demonstration and to a ruling by the federal government that its funding could not be used for managed care IHSS by creating in mid-1996 the "task frequency" mode of service. The mode requires the county to provide case management services, allows service to be delivered on a task-frequency basis rather than an hourly basis and will rely on state formulated performance and quality standards.⁸³

The recent legislative changes, which have not had a chance yet to affect in any broad way IHSS service delivery, make it difficult to assess whether the IHSS program will need further reform to become an effective, quality component of the long-term care system. The Public Authority mechanism holds the hope of giving consumers an opportunity to find qualified, pre-screened workers. The Task Frequency mode, if embraced by counties, promises relief for IHSS recipients who do not desire or who are not able to act as employers, locating, hiring, training, managing and firing workers (and even the most ardent advocates for self-directed management of IHSS services conceded to the Commission that some 15 percent of recipients need assistance in obtaining and managing workers).

One thing is clear: Responsibility for the program should not continue to pass from bureaucracy to bureaucracy like a hot potato that no one is willing to own. The Department of Social Services told the Little Hoover Commission that it must move cautiously in creating and imposing

performance standards, worker screening and training for fear it will be ruled by courts to be the employer -- a designation the State wants to avoid at all costs since it would require increased worker wages, benefits and working conditions.⁸⁴ Similarly, counties do not want to be on the hook as the employer for fear of liability when accidents occur or workers abuse or injure consumers.

The result of government's refusal to "own" the program is that, despite repeated criticisms in a variety of forums, IHSS continues to operate inefficiently and ineffectively with very little accountability. The Commission received multiple complaints from consumers in 1991, and much the same type of concerns were expressed during the course of this study. One San Francisco Bay Area woman wrote extensively about the poor quality of care she received under a managed care arrangement that further injured her health. Her complaints resulted in no care at all, with no assistance from county employees in locating replacement care providers and no assistance from the State in enforcing her entitlement to care under the program. Her tale is hardly unique.

Other states, such as Oregon, appear able to provide consumers with enough choices to bring market forces to bear on the issues of quality and reliability. As the Public Authority and Task Frequency mechanisms develop in California, long-term care analysts should look for signs that they bring consumers actual, rather than illusory, freedom of choice and service that meets needs rather than hour or cost allowances.

Adult Protective Services

Federal law mandates that adults of any age and income be provided protective services when abuse, neglect or exploitation is occurring. In California, the service is provided by the counties with very little guidance or oversight by the State. The Little Hoover Commission's advisory committee identified the following problems with Adult Protective Services:

- Lack of statewide consistency and accountability because of the lack of standards and regulations enforced by the State.
- A need for more resources and staffing. This is one of the many social programs that has been cut heavily by counties as resources have diminished. Many reports of abuse now go without investigation or response because of a lack of staff. The State's annual report for 1995 indicated 53,548 reports of abuse, a decline from the 1994 figure of 57,628 that the State largely attributes to a decrease in county staff to take and respond to complaints.⁸⁵
- Varying mandated reporting laws. Many health care officials are required to report a variety of types of abuse when they encounter it. Participants felt laws should be improved regarding

who reports, to whom, what is reported and what processes must take place once a report is made. For instance, one option would be to include financial experts and require reporting of financial exploitation. A Department of Health Services task force is working on the issue, and at least one bill introduced in the last legislative session would have unified all mandated reporting requirements, whether they affect children or adults.

- Training for county Adult Protective Services workers. Not all people who are responding to complaints have adequate information about options, linkages to various programs and the needs of those with functional impairment.
- Visibility of service. There is a need for a greater level of awareness of Adult Protective Services so that the general public will know who to call when they witness abuse or problems.

Like the IHSS program, Adult Protective Services was reviewed by the Little Hoover Commission in 1991. The Commission found then that the program was overloaded, underfunded and not standardized.⁸⁶ The situation has not improved. State officials confirmed to the Commission that Adult Protective Services has suffered cutbacks and service limitations in the last few years at the hands of counties with diminishing resources. While a Senate subcommittee focused in 1996 on areas that need reform, funding was not increased and no one predicts that improvement is close at hand.

Summary

Home- and community-based services can maintain a person's ability to have some degree of independence, remain at home or in home-like settings and enjoy a quality of life that is not always possible in institutions. Services that allow this include:

- √ **Case management**, which helps consumers understand their options and receive appropriate services.
- √ **Personal care**, which is assistance with bathing, dressing, walking, feeding, grooming and other daily living functions.
- √ **Homemaker**, which includes household activities, shopping and transportation to medical appointments.
- √ **Adult day care**, which provides out-of-home stimulation for the consumer and sometimes rehabilitative therapy.
- √ **Respite care**, which provides relief for the caregiver to avoid burnout.

California has programs that provide these services, but like many states its policies and funding do not make them a priority -- despite the fact that there is widespread agreement that they should be. As one report summarized:

Despite the fact that eight times as many people with disabilities live in the community as in nursing homes, the current financing system is heavily skewed toward institutional care. Spending for nursing homes in 1991 was about six times as great as spending for home care. Many people with disabilities can receive appropriate care at home. With home care services, their functional status, physical health, and mental and social well-being improve. Ninety-five percent of the elderly with chronic disabilities prefer home care to institutionalization.⁸⁷

Recommendations

Recommendation 2-A: The Governor and the Legislature should revamp the present highly segmented licensing structure for long-term care service providers to allow a more seamless delivery of service, to allow aging in place whenever possible and to emphasize social models over medical models.

Creating a unified licensing plan that would allow service providers to add-on optional services or provide various types of care in a single setting is a key requirement for moving long-term care toward integrated, consumer-focused service. Those who fear the consolidation of the existing separate licensing systems should have their concerns addressed by requiring any new system to be outcome-based, flexible in implementation, consistent in interpretation and supportive of social models of service delivery. Barriers raised by federal funding and oversight requirements for skilled nursing facilities should be addressed through waivers, demands for federal law reform or, if no other course is feasible, separation from other forms of long-term care licensing.

Recommendation 2-B: The Governor and the Legislature should designate a point person to develop funding streams and provide technical support for adult day care and adult day health care programs.

These programs can play a critical role in providing relief for caregivers and increasing the number of functionally impaired people who can remain at home and out of costly institutions. The State should provide leadership in securing Medicare reimbursement for services by pushing for changes in federal laws and waivers. In addition, the State should focus on educating the public about the services available and enhancing the opportunity for development of more programs.

Recommendation 2-C: The Governor and the Legislature should increase funding for family caregiver respite and support services.

For more than a decade, the Caregiver Resource Centers have documented their value in providing services that allow people with brain impairment to remain home and under the care of family and friends. But funding constraints have kept the waiting lists long, limiting this program's ability to serve as a safety net for the long-term service continuum of care. The California Senior Legislature, which has the responsibility of proposing laws to assist the State's seniors, is backing a statewide respite care program as one of its priorities for 1997. Expanding the existing program would meet their goals.

Recommendation 2-D: The Governor and the Legislature should encourage counties, through funding and other incentives, to form Public Authorities to improve delivery of services under the In-Home Supportive Services program.

The problems with the In-Home Supportive Services program have been well documented and widely acknowledged for years. Improvements have been non-existent, due to lack of funding and governmental abhorrence to becoming involved to a point of being named the employers of caregivers. The Public Authority mechanism, while largely untested, has the ardent support of consumers as a means of improving the quality of care. This mechanism should be given every opportunity to succeed.

Recommendation 2-E: The Governor and the Legislature should require counties to provide multiple modes of services so In-Home Supportive Services recipients who do not want to act as employers have options, including care through agencies, that will meet their needs.

While many IHSS recipients want to retain control over their service provider choices, others neither desire nor can handle the role of employer. Just as recipients who want to be employers should have that choice, recipients who need management assistance for their caregivers should not be left without a program to meet their needs.

Recommendation 2-F: The Governor and the Legislature should increase funding and expand the state role in standardizing adult protective services throughout the state.

Society needs an effective mechanism for protecting people who are functionally impaired and threatened with abuse, neglect or exploitation. The present county-administered programs are not uniform throughout the state and lack the resources to provide effective service. The California Senior Legislature has made increasing the funding and effectiveness of this program, as well as enhancing elder abuse

prevention and treatment programs, as two of its top 10 priorities for 1997.

Recommendation 2-G: The Governor and the Legislature should clarify mandated reporting laws to turn them into a more effective tool for protecting vulnerable citizens.

Mandated reporting laws vary with regard to what should be reported, by whom, to whom and what resulting action is required. Providing uniformity to this system would make it more understandable both to those who are required to comply with the provisions and those who are seeking protection from them.

Skilled Nursing Care

- ❖ *Federal quality assurance standards that have been in the implementation stage for several years offer hope for more rigorous oversight of skilled nursing facilities.*
- ❖ *While some improvement in fine collections has occurred, the state citation system lacks a strong enough bite to make providing quality care not merely a humane practice but also a sound business decision.*
- ❖ *Inadequate staffing requirements, artificial barriers to the use of some types of health care providers and a less-than-robust response to consumer complaints continue to plague the skilled nursing care system.*
- ❖ *Overlapping state and federal regulations are an all-but-incomprehensible maze for consumers, facilities and state enforcers.*

Skilled Nursing Care

Finding 3: Federal mandates for skilled nursing facilities have brought an improved process to monitoring quality of care -- but many previously identified issues remain unresolved and others are developing as the role of these institutions shifts to a higher level of care.

Under recently issued federal regulations, skilled nursing facilities (SNFs) are judged by their ability to provide the least restrictive, most socially stimulating environment that a person's condition, desire and needs allow. The State's process of holding SNFs to this standard holds great promise. But many of the problems identified in previous Little Hoover Commission reports continue to exist and have immense negative impact on people's lives. As the role of SNFs shifts more from long-term custodial care for chronically ill people to short-term rehabilitative care for recently acutely ill people, the State has an opportunity to recast the policies and programs that make these institutions the most costly, least consumer-desired long-term care option.

In 1987, Congress passed a nursing home reform package known as OBRA 87 (Omnibus Budget Reconciliation Act of 1987) that focused on improving the quality of care and life for skilled nursing facility residents. The new outcome-based directives required nursing homes to assess residents as they entered the facility, plan a course of action that would meet the multiple needs of residents and take actions that were responsive to residents' wishes, capabilities and changing status. Among the reforms OBRA 87 required were:⁸⁸

- Protection for patients' rights, including restrictions against chemical and physical restraint without informed consent, accommodation of needs, privacy, access to information, the freedom to express grievances and expect a timely response without retaliation and the right to be fully informed about nursing home actions, policies and care planning.
- Staffing requirements, including the presence of a registered nurse for at least eight hours a day, a licensed nurse 24 hours a day and sufficient staff to allow residents to maintain functionality.
- Training requirements, including 75 hours for nursing home aides, documentation of training and competency, and listing of all incidents of abuse or neglect in a state registry.
- Initial and annual assessments of residents to determine their needs and create a care plan that provides for the highest practicable physical, mental and psychosocial well-being of the resident, with deterioration in a resident's condition only when it is clinically unavoidable.

California Record

In California, the first response by the State was to insist that state regulations were already more comprehensive and that, therefore, the federal mandate could be ignored. In a lawsuit that became known as the Valdivia case, consumer advocates demanded that the State enforce the new federal requirements.⁸⁹ A preliminary injunction was issued against the State and eventually in 1993 an

Gathering Information

Under federal regulations, skilled nursing facilities must fill out a Minimum Data Set (MDS) and Resident Assessment Profile for each person as they enter the facility. Topics covered in the MDS are:

- Cognitive patterns
- Communication/hearing patterns
- Vision patterns
- Physical functioning and structural problems
- Continence
- Psychosocial well-being
- Mood and behavior patterns
- Activity pursuit patterns
- Disease diagnoses
- Health conditions
- Oral nutritional status
- Oral/dental status
- Skin condition
- Medication use
- Special treatments and procedures

Topics covered by the Resident Assessment Profile include:

- Delirium
- Cognitive loss/dementia
- Visual function
- Communication
- Activities of daily living function/rehabilitative potential
- Urinary incontinence/ indwelling catheter
- Psychosocial well-being
- Mood
- Behavior
- Activities
- Falls
- Nutrition
- Feeding tubes
- Dehydration/fluid maintenance
- Dental care
- Pressure ulcers
- Psychotropic drug use
- Physical restraints

agreement was reached that required the State to enforce the federal regulations.

The State's resistance was matched by the federal government's lethargy. While OBRA 87 originally required the implementation of the new program by 1990, the federal government was still issuing major portions of enabling regulations in July 1995. State officials, who began enforcing the regulations as they emerged, told the Little Hoover Commission that even now there are elements of the program still missing but that in general the structure is well in place to inspect skilled nursing facilities for compliance with federal mandates.

The time of transition -- overlaying the new federal system on to the state one, which has been supplemented rather than supplanted -- has not always gone smoothly, as evidenced by several studies:

- A January 1994 audit of the licensing and certification unit for the Department of Health Services found problems with the way fees were set, a failure on the part of the department to complete inspections of long-term care and home health facilities within the federally mandated one-year period, lateness in investigating 50 percent of complaints received and antiquated information systems.⁹⁰
- The Legislature ordered the State Auditor to review the Orange County record of enforcement on standards for skilled nursing facilities after advocacy groups, ombudsmen, whistleblowing state workers and individual consumers complained in 1993 that the State's operation there had all but ceased to exist. The result was a July 1995 report that confirmed the Orange County office was failing to use its enforcement authority properly, was consistently late in investigating complaints -- but had begun improving its performance in the past two years.⁹¹
- An annual report card by a consumer group called California Advocates for Nursing Home Reform has consistently criticized the Department of Health Services for failing to use the tools it has to aggressively enforce high standards of care. However, the 1995 report card upgraded the Department's enforcement efforts from a D to a C, calling 1995 a time of transition and looking to new federal enforcement tools to help the Department become more effective on behalf of consumers.

The State also was scrutinized from the outside by the agency in the best position to determine if California is doing a good job of meeting federal mandates. The Health Care Financing Administration (HCFA) evaluation of the State's efforts for October 1, 1994 through September 30, 1995 struck a positive note initially by praising California's efforts:

Fiscal year 1995 brought significant changes to the survey and certification process as new Long-Term Care enforcement

regulations were implemented. The success of the implementation depended upon the total commitment of state survey agencies and close coordination with HCFA. The California survey agency managed the implementation, which required extensive training of the survey and management staff, as well as provider and consumer organizations, in an outstanding manner.⁹²

But the evaluation found that the State did not meet federal standards, "narrowly missing the acceptable performance level." The evaluation said there was "relatively close agreement" between the State's survey results and the federal government's recheck of the institutions -- but the statistics cited gave little comfort to consumer advocates who reviewed the report. It said that in 21 of the 34 facilities reviewed by the federal government in the footsteps of the state surveys, HCFA took its own enforcement action -- and in 14 of the 21 facilities that the State had cleared, HCFA determined there was substandard care.

Continued training and experience with the new system, however, will undoubtedly lead to more conformity with the federal government's expectations. In reviewing the survey process, the Little Hoover Commission noted that there are multiple elements that provide a solid structure for performing rigorous and productive assessments of skilled nursing facilities.

For instance, the survey team has a well-orchestrated list of duties it must accomplish and statistical sampling criteria that it must meet -- but the system also has room for flexibility when a survey team member notes something unusual or unexpected.

SNF Swat Team

They gather quietly in the far end of the parking lot until all of the members of the team are present. And then they move in, posting a sign on the door of the skilled nursing facility as they enter to announce to the world that the Department of Health Services has arrived to conduct a week-long federally mandated inspection.

They are not completely unexpected since it has been almost a year since the last annual inspection. But the appearance of a half dozen people, armed with notebooks and prior-year records and ready to fan out in all directions, is enough to make the best-run facility nervous.

The Little Hoover Commission spent the better part of four days in September with an inspection team on an annual survey of a Sacramento skilled nursing facility. Other than safeguarding resident confidentiality, the inspection team shared its entire process with Commission staff. While recognizing the very fact that Commission staff was present made this survey different from others, there were some general observations that the Commission believes are valuable:

- ✓ The collaborative team approach to annual surveys enhances consistency and credibility. Team members shared their findings, bounced reactions off of each other and used consensus, not to water down, but to strengthen their findings.
- ✓ Team members conduct themselves professionally, but with a sense of purpose that is consumer-focused. They discuss small nuances as well as big-picture concepts; patiently talk to mentally impaired residents, upset family members and wary staff with equal courtesy; and look for the most meaningful way to report their observations that will both force and encourage the facility to provide better care.
- ✓ The process, which begins by reviewing the facility's prior year trends in citations, has built-in flexibility because the team purposefully reassesses its focus areas part way through the survey. This allows a dynamic approach that combines past history with present observations.

Perhaps even more encouraging are the new higher standards for the Plan of Correction that facilities must submit in response to citations. In past years, Plans of Correction appeared to mostly consist of rote statements pledging to do in-service training on whatever the problem was. Under the federal system, the Plan of Correction must explain 1) how they will handle the problem with residents who were found to be affected, 2) how they will identify other residents who have the potential for being affected by the same problem, 3) what measures the facility will put into place to ensure similar problems do not occur in the future for anyone and 4) how the facility will monitor its corrective actions to ensure that they have effectively changed the system.

While the new system holds out great hope for the future, whether it will live up to its potential cannot yet be determined. However, the Little Hoover Commission noted in its current study that many past problems and recommendations remain valid, new problems are arising and potential solutions are emerging.

Ongoing Problems

The Little Hoover Commission examined the State's oversight of skilled nursing facilities in 1983, 1987, 1989 and 1991, in each case issuing critical reports with recommendations for reforms. In addition, the Commission conducted an oversight hearing in 1993 and put together a package of legislation based on that hearing and prior recommendations. Despite some progress, particularly in the area of patients' rights, many of the recommendations remain unfulfilled and the same problems persist.

In some instances, incremental reform has occurred but the underlying conditions still warrant further reform. For instance, for years the Commission has complained that the State's computer resources are so antiquated that fines cannot be tracked and collected adequately. During this study, the Commission found that dramatic improvements have been made in the State's computer abilities -- but fines continue to be waived or halved in accordance with law, watering down their impact on the industry and their ability to satisfy consumer demands for equity, justice or retribution.

After reviewing materials, discussing key issues on skilled nursing facilities with the Commission's advisory committee and meeting with experts, the Commission believes the following problems still persist and are well documented in its prior reports:

- The citation and fine system continues to be undermined by procedural delays and penalty reduction mechanisms. Fines do not serve as adequate deterrents when they are too low compared to injuries sustained; arbitrarily cut in half for prompt payment; and completely waived on the first incident.

- The State's response to complaints continues to be slow and unsatisfactory for residents and their families, placing more emphasis on due process rights for the industry than on the importance of being responsive to consumers. In this study as in previous ones, the Commission was inundated with consumer complaints about nursing home performance and the difficulty of getting the State to take what the consumers felt were appropriate action. The State has made strides in providing materials to citizens to explain their rights and how to exercise them, but their primary focus is not consumer service, nor are they adequately funded or staffed to provide such service.
- Staffing of skilled nursing facilities, which is set at 3.2 hours per patient per day, is too low to provide adequate care -- especially since these hours are averages and can be filled by different levels of professionals. The state provision that allows the hours worked by registered nurses and licensed vocational nurses to be doubled on paper is particularly contrary to common sense since residents' needs do not change simply because a registered nurse is present instead of a nursing assistant. With the exception of the skilled nursing facility industry, no one the Commission spoke to or heard from favors the continuation of this mechanism.
- The lack of adequate pay and career advancement opportunities for Certified Nursing Assistants (CNAs) leads to continual turnover and disruption of the quality of care in nursing homes. While much progress has been made in standardizing training, key elements -- such as anger management, understanding the needs of the elderly, listening skills, stress management -- still may be missing. In addition, the quality of training is difficult to monitor accurately. And, finally, the State's process for certifying and renewing certifications for CNAs is often backlogged.

Growing Issues

The nature of long-term care is changing, as has been described in the beginning sections of this report. Consumers are pushing for more home- and community-based care, and settings that are not paternalistic, dehumanizing and devoid of consumer control. Concurrently, skilled nursing facilities are turning their attention to what has become known as subacute care -- the more-lucrative treatment required by people who have been recently hospitalized but are not yet ready to return to their homes. At the same time, citizens are demanding more accountability -- as taxpayers for the money they spend on long-term care and as consumers for the quality of care that is provided in facilities.

These trends suggest three areas that may be ripe for reform: the use of allied professionals in facilities, the need for civil liability remedies and the desirability of streamlining regulations.

■ **Allied professionals:** Much of what occurs in skilled nursing facilities is driven by the fact that funding comes from two medically oriented systems: Medicaid and Medicare. These systems often require the highest level medical professional to be in direct charge of all treatment and decisions. But few highly paid, top-ranked professionals desire a practice that includes nursing home residents for several reasons: low reimbursement rates from government programs, the inconvenience of traveling to facilities that are not equipped for diagnosis and treatment, and the barriers to nursing home residents coming to the professional's office.

On the other hand, these same professionals are territorial in their concern that alternative types of health care providers -- known as allied professionals -- not be allowed to give treatment independently. The result is that dental hygienists, nurse practitioners and other educated and trained professionals are often blocked from providing needed services in skilled nursing facilities.

For almost a decade, dental hygienists have engaged in a pilot project in skilled nursing facilities to demonstrate that residents' quality of living can be improved with direct care to the residents and oral care training for facility staff provided by hygienists. Despite their documented success and the popularity of the program with skilled nursing facilities, the dental hygienists have not been able to get past dentists' opposition to win the ability to operate independently in these facilities.

The California Dental Association is surveying its membership to determine the level of involvement with skilled nursing facilities, plans to develop training modules for skilled nursing facility staff and plans to encourage dental schools to discuss gerontological issues as part of their curriculum. But none of these actions address the fact that most skilled nursing facilities do not have a means of providing their residents with regular, reliable dental care.

It is beyond the focus of this study to delve into scope-of-practice issues, trying to determine who is qualified to deliver what type of treatment. But as pressure mounts to shift the focus of skilled nursing facilities away from medical models, it appears sensible to open the doors to different kinds of treatment providers, especially when there is a documented void in care.

■ **Civil liability remedies.** Experts cite the ability of citizens to sue for malpractice -- and win large awards -- as one reason many other types of medical facilities have adopted stringent quality control mechanisms, effective peer review and other measures that have improved the quality of care. The same dynamic has not been in play for skilled nursing facility residents. Since most of the residents are elderly, the age-dependent calculations that are used to figure the size of awards usually render such suits unattractive to lawyers who operate on a contingency fee basis. Thus citizens by and large are left to rely on the deterrence power of the State-invoked penalties, which can be quite

small in comparison to a facility's budget or a large facility-owning corporation's overall cash flow.

One new mechanism for making regulatory compliance more attractive to facilities is the federal government's use of the False Claims Act. In a 1996 case that was settled out of court, the federal government sued a facility for providing inadequate care to three residents and then billing the government through Medicaid and Medicare for normal charges. The government's posture was that by submitting the claims, the facility was certifying that it had rendered care consistent with state and federal requirements.⁹³

It is unknown whether the federal government will make such suits a standard practice. If so, it would simply add another governmental mechanism for deterring noncompliant care. But many consumer advocates told the Little Hoover Commission that empowering residents and their families to pursue civil remedies for claims of harm, with proportionately serious financial remedies, would add an effective weapon to the drive for higher quality care. And as described in Finding 1 under the discussion about regulatory effectiveness, providing the private sector with access to the quality control process would strengthen the opportunities for regulations to work as intended.

■ **Streamlining regulations:** While not everyone agrees on the degree of regulatory effectiveness, it is difficult to dispute that the skilled nursing facility industry faces multiple layers of regulations, especially since the implementation of OBRA 87. Federal and state requirements sometimes overlap, sometimes conflict and sometimes are outdated. The industry shared the following comments with the Commission:

- √ The need for paperwork and documentation is time consuming, not always clearly stated and often focused on process rather than resident outcome.
- √ Regulations known as "specificity of care" requirements use absolute standards of weight deviation and input and output volumes that do not allow for professional judgment, specific case variations and desirable outcome.
- √ Some requirements are outdated, calling for equipment that is no longer used or standards that are no longer generally practiced.
- √ Regulations do not allow for innovation, industry advances and other flexibility.
- √ Some regulations require the nursing home to ensure things that are not within its power to provide. For instance, informed consent is supposed to be obtained from the resident by the physician -- but it is the facility that is held responsible for it being accomplished.

- √ Some regulations duplicate requirements in other areas of state law, such as building standards, and are unnecessary.

Both the industry and the Department of Health Services are engaged in reviews of state and federal regulations to see what streamlining can be accomplished. While consumer advocates have legitimate concerns that reform in the regulatory arena not mean a lessening of standards, common sense argues that no one benefits from a convoluted, multi-layered regulatory scheme that is difficult for industry to follow, consumers to understand and the State to enforce.

Summary

Regulation of skilled nursing facilities is undergoing transition as outcome-oriented federal mandates begin to mold state oversight and industry practices. Many of the provisions of federal law hold great promise for improving conditions in skilled nursing facilities. But many problems remain, some documented in prior studies and others growing more evident as the long-term care industry grows and changes. While it is too early to judge the eventual impact of federal requirements, state policy makers can still take steps to improve conditions in facilities that house some of the State's most vulnerable citizens.

Recommendations

Recommendation 3-A: The Governor and the Legislature should take steps to move medical care in long-term care settings from the costly reactive model to the more economical, preventive model, including encouraging the use of allied health professionals when appropriate.

There is little value in protecting the turf of professionals who do not want to provide service in a long-term care setting but who are loathe to see their competitors gain a foothold. Allied health professionals, such as dental hygienists, nurse practitioners and physician assistants, can play a valuable role in providing preventive health care and alerting the appropriate professionals to the needs of residents in skilled nursing facilities. They should be given the opportunity to do so.

Recommendation 3-B: The Governor and the Legislature should strengthen the opportunities, incentives and requirements for high quality performance by skilled nursing facility staff.

It is difficult to operate effectively in a setting that is understaffed, has incomplete or inadequate training and provides no opportunity for advancement. The following steps would address those concerns:

- Eliminate the doubling of hours for licensed nursing professionals, explore moving to a system that requires adequate staff for proper care rather than a certain number of hours, and/or set higher standards for staffing. The Older Women's League has recommended one caregiver for each eight residents at a minimum.
- Add more gerontology and human relations issues to the certified nurse assistant (CNA) training curriculum and provide more effective oversight to ensure that training is of high quality and actually occurs.
- Create a career ladder for CNAs by establishing progressive educational standards and work experience that would lead to licensed nursing status.

Recommendation 3-C: The Governor and the Legislature should enhance the State's enforcement capability by eliminating counterproductive provisions in the citation and fine system, directing more frequent use of alternative tools and creating a more effective civil liability remedy.

Specific steps that policy makers should take include:

- Eliminating the waiver of fines for B citations and the halving of fines for payment prior to appeal. The Department of Health Services told the Commission it supports both of these reforms.
- Encouraging the Department of Health Services to use more frequently facility decertification, delicensing and frozen admissions, as well as creating a fee system that assesses a facility at a higher rate when frequent violations require more frequent inspections.
- Fines, set in the mid-1980s, should be increased. In addition, consumers should be empowered to sue for civil remedies with the potential for large enough financial damages to act as a deterrent for poor quality care.

These and similar reforms are supported by the California Senior Legislature in its 1997 list of priorities and the California Advocates for Nursing Home Reform.

Recommendation 3-D: The Governor and the Legislature should create a more responsive complaint investigation and resolution process that is separate from the licensing and technical advice function.

The reality is that the Department of Health Services is neither adequately funded nor staffed to be responsive to consumer complaints -- and the perception is that their interest is more aligned with

encouraging industry to comply than providing aggressive enforcement. In addition, the current process is heavily weighted toward due process for industry rather than adequate concern for consumers. Restructuring the process and placing it at some distance from the licensing function -- such as at the Attorney General's Office or in the Department of Consumer Affairs -- would address these issues. This reform could be tracked and assessed for effectiveness over time.

Recommendation 3-E: The Governor and the Legislature should eliminate duplicate regulations and streamline the oversight process while ensuring that no deterioration in the quality of care occurs.

It is counterproductive to have more than one set of regulations governing an industry and to layer complexity with redundancies. Regulations should be focused on outcomes, allow for flexibility of methods, lend themselves to consistency of interpretation and be easily understood by industry, consumers and state workers.

Residential Care

- ❖ *About 10,000 residential care facilities house more than 155,000 people, providing supervision and non-medical services.*
- ❖ *Government does not pay directly for residential care, but it does impose a limit on what facilities may charge if the resident is an SSI/SSP recipient -- and, at about \$23 a day, the limit means that facilities receive less than a motel that provides no service.*
- ❖ *Rigid licensing distinctions make it difficult for facilities to offer services that would allow residents to age in place.*
- ❖ *While eager to avoid the complicated oversight system that skilled nursing facilities operate under, residential care facilities want clear guidelines with consistent interpretations.*

Residential Care

Finding 4: Regulatory changes have not kept pace with the changing role of residential care facilities.

Residential Care Facilities for the Elderly (RCFEs) are a consumer-favored option for long-term care because of the home-like setting, lower cost and individual freedom provided. Although conceived as a non-medical approach to long-term care, their function has grown increasingly complex as residents have been given the right to remain in place with greater and greater need for care. While new regulatory categories have been added piecemeal to broaden the role of RCFEs, no comprehensive re-examination of where this service fits in the long-term care continuum has occurred. But as a key service that can keep people from premature institutionalization and foster at least partial independence, RCFEs deserve attention and reform that will support expanded availability to people with long-term care needs.

California has 5,234 licensed RCFEs with a capacity of 116,082. Another 4,691 facilities house adults between the ages of 18 and 64, with a capacity of 39,259, and 23 facilities provide residential care for up to 272 people with chronic life-threatening illnesses (largely AIDS). Thus there are almost 10,000 facilities that house more than 155,000 people. These facilities range in size from under six beds to more than 100 and in appearance from homes tucked away on residential streets to apartment-like complexes on bustling streets. Nine or 10 is the average bed size, but 70 percent are six beds or fewer.⁹⁴

Residential care facilities provide a range of services that stop just short of medical care. Services include providing meals, shelter, laundering, transportation, supervision of medications and limited assistance with the activities of daily living (dressing, grooming, eating, bathing, toileting and walking). Residents cannot be bedridden nor can they require 24-hour nursing care. The facilities are responsible for the safety of residents, but residents are free to come and go as they desire.

Among the issues raised regarding RCFEs during this study were:

- √ State policies regarding monthly rates.
- √ The growing difficulty of determining what constitutes service that requires licensing.
- √ The problems with uniformly regulating an industry that ranges from under six beds to more than 100.
- √ Restrictions regarding medications.
- √ Policies about evictions.
- √ The lack of credible statistics on RCFEs.

Going Rates

Unlike skilled nursing facilities, the State is not a direct purchaser of services in Residential Care Facilities. But that has not stopped the State from intervening in the pricing structure for RCFEs.

RCFEs may charge whatever the market will bear -- but if the resident is an SSI/SSP recipient, then the facility may only charge that person the SSI/SSP benefit rate minus about \$90 for personal spending. (Supplemental Security Income is a federal program of cash assistance to the aged, blind and disabled who have limited income and resources. The companion State Supplementary Program puts state funds into the mix.)

A Picture of RCFEs

The State does not track who lives in RCFEs, what their conditions are and what kind of services they receive. But in July 1994 the Institute for Health and Aging at UC San Francisco reported on a 1993 statistical sampling of RCFEs. The report made the following generalizations:

- √ The typical resident is a white female in her late 70s or early 80s. About 20 percent do not have relatives within an hour's drive; but half have two or more relatives within that distance.
- √ About 40 percent report their health as fair to poor. Between 40 and 50 percent suffer from depression. Cognitive problems are present in up to one-third. The average number of chronic conditions -- such as arthritis, hypertension and bowel and bladder problems -- is two per resident. More than a third have at least two limitations in activities of daily living. The average number of medications taken is four.
- √ At least one-third of residents receive SSI/SSP. About 12 percent have incomes of \$25,000 or more.
- √ Single room rates range from \$1,000 to \$1,600 per month, with double occupancy rates ranging from \$700 to \$1,000.
- √ Most RCFEs are operated by for-profit ownership. At least one-third of the owners also own other RCFEs. About half of facilities, except in the under-six-bed category, have been in operation for more than 10 years.

At current rates that means somewhat less than \$700 per month -- or about \$23 a day (as one Commission advisory committee member commented, not even as much as a hotel charges). This compares to monthly rates for non-SSI/SSP recipients that range from \$1,300 to \$2,000 statewide, with a median rate of \$1,512 (the median is slightly higher in Northern California's urban counties -- \$1,850).⁹⁵

The result of the disparity between the artificially limited \$700 rate and the \$1,500 median rate is that facilities limit the number of SSI/SSP recipients that they will accept -- if any -- and then subsidize care with higher private-pay rates than would otherwise be necessary. SSI/SSP recipients, who make up about 30 percent of all RCFE residents, are used as "fillers" in facilities with empty beds. Or they cannot find space at all in some Northern California counties, according to consumer advocacy groups.

The state policy has had several unintended consequences. Families of SSI/SSP recipients, until recently, were not allowed to voluntarily supplement their relative's ability to pay as a means of procuring a better level of care or environment. This set them apart from people who could afford to pay much higher rates and consigned them to finding care in RCFEs that often would not have been their first choice. The State recently changed this policy, but now consumer advocates fear that the "voluntary" nature of supplementary payments may turn into mandatory "blackmail" -- or that discontinuance of such payments at any time might lead to evictions.

The policy of holding down rates for one group of people has also created a gap in who can afford RCFE service. People who collect Social Security or pensions that are above the SSI/SSP eligibility level but below the ability to fund private-pay rates -- roughly \$750 to \$1,400 per month -- have no choices.

Several options have been offered by various experts:

- The Institute for Health and Aging at UC San Francisco has suggested that restructuring the RCFE rate system may require an increase in the basic SSP rate coupled with subsidizing specific personal care assistance through Medi-Cal personal care benefits.⁹⁶ A different source has suggested that such a subsidy could range from \$500 to \$1,400 a month.⁹⁷
- The Community Residential Care Association of California believes the federal government should be lobbied to increase the federal portion of the SSI/SSP grant specifically for people living in licensed community care facilities.⁹⁸
- Others have suggested providing half of the state-paid skilled nursing facility rate to purchase care for RCFE residents who would otherwise be placed in skilled nursing homes at state expense.

For many people, residential care facilities are a last stop before skilled nursing facility placement, the most costly service from the State's perspective and the most restrictive level of care from the consumer's viewpoint. Restructuring the way RCFEs are paid is one route to increasing their availability as a community care resource.

Licensing Categories

The people who operate RCFEs cite two factors with the potential for affecting their industry negatively: competition from other forms of housing that assist people but that do not have to obtain licensing, and complications from the Americans With Disabilities Act. Consumer advocates worry, as well, about unlicensed operations that may promise lots of care, fail to deliver when it is needed and then be accountable to no one since they are not within the purview of community care licensing. And policy makers are concerned about the licensing barriers that may prevent the expansion of living arrangements that are community-based and capable of keeping people from deteriorating to the point of needing skilled nursing care.

Care, supervision, case management -- these are the concepts that make a facility fall under the residential care facility licensing requirements. But some forms of independent living housing and congregate living facilities offer assistance with a variety of functions: meals, transportation, housekeeping and social activities. The key difference lies in whether a facility provides assessment, linkage to services and other actions designed to meet a resident's specific needs.⁹⁹

A facility can be deemed an unlicensed RCFE if it accepts or retains residents who demonstrate the need for care or supervision. To become licensed, a facility would need to meet standards that include a pre-admission appraisal, prohibiting residence by people who are bedridden or who cannot self-administer medications, providing an admission agreement outlining specific services and meeting increased building and fire safety requirements.

Because meeting these requirements can be expensive, assisted living facilities may try to avoid crossing the line by providing too much service. This, in turn, may mean that people cannot remain in their present living arrangements when their condition requires more assistance. A Senate Office of Research report in 1993 cited the confusion over when community care licensing standards kick in as a deterrent to the development of more community-based assisted living arrangements.

In addition to these concerns, the RCFE industry sees a legal conflict between state regulations that require them to reject some people as residents -- those with excessive medical needs -- when the Americans With Disabilities Act requires no discrimination and "reasonable accommodations" for people with needs that are not met by normal

operations. Industry advocates cited this as an area that may move into the courts in the future, especially if family members vigorously oppose the removal of a resident whom the State has deemed unsuitable for RCFE care.

As long-term care options develop and providers move to arrangements that offer integrated care, the lines between licensed and unlicensed care may blur. While expansion of options is a top priority, protection for consumers remains a concern. These two goals may require a fresh assessment of how licensing standards are applied in community-based settings.

A Matter of Size

Regulating facilities that range in size from under six beds to more than 100 presents the State with challenges. The State's top goal is to oversee quality of care for residents, not to protect the industry or nurture struggling businesses. But because of the growing numbers of citizens who need out-of-home assistance, the State does have a legitimate interest in maintaining and expanding accessibility to this type of care.

RCFE operators and other care providers who served on the Commission's advisory committee said that small facilities have difficulty complying with regulations that are often written with much larger facilities in mind. Few regulations make a distinction between what is required of various sizes of facilities.

Advisory committee members from the industry also complained that the Department of Social Services performance in overseeing RCFEs is erratic. Policies may be interpreted differently by different regional offices and the attitudes and actions by individual analysts assigned to

Home-Like Settings

The deviations in look, atmosphere and comfort in Residential Care Facilities varies greatly since the category can range from a bedroom in the service provider's home to huge nursing-home-like complexes. In addition, the facilities can be plain or plush depending on the resources and clientele.

The Department of Social Services provided the Little Hoover Commission with a tour of different facilities in the Sacramento area. The distinctions were marked:

- ✓ A home in a quiet part of South Sacramento resembles its neighboring ones from the outside with the exception of a handicapped-accessible ramp leading to the door. Inside is a spotless home shared by six elderly residents, one past the century mark. The owner, who lives elsewhere but frequently provides the required overnight supervision, knows her residents intimately and treats them like family, worrying about their conditions, keeping connected with relatives and frequently talking to physicians.
- ✓ Most of the action at a spartan facility that houses some 80 people centers on a large, open day room with a TV and tables for activities. Rooms, usually shared, bear personalized decorations and furniture, but the wide halls and communal eating area are reminiscent of a skilled nursing home. The facility is clean but there is little feeling of intimacy or family for its residents.
- ✓ Soft colors and pleasant interiors mark a decidedly upscale facility that is home for 65 residents. The monthly tab can run more than \$2,000 and the acceptance fee is \$3,500. Rooms are small but private, and the communal areas are spotless and unused looking.
- ✓ The odor is strong and not quite identifiable at the largest facility on the tour, home to 186 people in a multi-level building originally constructed to be a skilled nursing facility. Different wings have scheduled activities at different times, but a strong impression is left of people sitting and waiting for time to pass. There is little to remind one of home.

an RCFE are not always consistent. They also noted that they have far fewer due process safeguards than do skilled nursing facility operators who are overseen by the Department of Health Services. And they were particularly critical of the lack of assistance available to a facility that wants to comply with regulations but has difficulty understanding the State's requirements.

The Department of Social Services, however, is recovering from several years of deep personnel cuts and has embarked on a course of standardizing policies and providing intensive training for the people who inspect RCFEs. The Department also has an interdisciplinary team that reviews appeals of inspection findings. In addition, policy makers recently provided the funding for the Department to double its tiny staff of technical assistance personnel -- the unit that can provide help to RCFEs in understanding what actions must be taken to comply with state regulations.

While the State does not need to take on the responsibility of incubator to develop high-quality RCFEs, it can play an important role in improving the quality of care in an industry that is disproportionately made up of small businesses with few resources. The Department of Social Services was undergoing a review of regulations to streamline processes and eliminate unnecessary rules as this report was being written. Many of the people who participated in this study believe a positive outcome of that effort would include treating small RCFEs separately with due consideration for their size.

Other Issues

Other issues raised during the course of the Commission's study included medications, the eviction process and the lack of solid information about RCFEs.

■ **Medications:** RCFEs can assist with medications, but not administer them. For instance, an RCFE may remind a resident that it is time to take their medication and have a safe, locked area where medications can be stored and tracked. But it is up to the resident to actually take the medication, measure it out if that is necessary and in other ways control the process.

Several RCFE operators complained that the restriction against RCFEs helping with medication is so broad that aspirin and over-the-counter cough medicines cannot be provided without specific, event-by-event doctor's authorization. This may make a middle-of-the-night cough or headache difficult to cope with.

Consumer advocates expressed concern that RCFEs not slip into a category that might allow them to influence whether chemical restraints -- psychotropic drugs -- are administered, an area that has been a problem in skilled nursing facilities and that has led to strong informed-

consent provisions for residents. Recent studies indicate that RCFE residents take a large number of drugs. More than one-third use at least one psychotropic drug and 10.5 percent take two to four different psychotropic drugs.¹⁰⁰

Many academic studies have shown that the elderly are particularly prone to misuse of drugs and unmonitored combinations of drugs that may threaten their health. But loosening regulations regarding limited types of over-the-counter medications made sense to many people on the Commission's advisory committee.

■ **Evictions:** Consumer advocates say that tenants have more protection from their landlord's evicting them than RCFE residents do from a facility forcing them to relocate. They pushed for legislation in 1996 that would have applied standards similar to those that are used in skilled nursing facilities: that a resident only be evicted for failure to pay or if his stay is a danger to health and safety. The measure also would have required facilities to inform residents of their right to contest evictions.

RCFE operators argue, however, it is to their advantage to keep a facility full so business pressures keep unnecessary evictions from occurring. They say that state regulations give them very little protection from residents who damage facilities or who persist in disruptive behavior.

This is a particularly sensitive area for small RCFEs. Since small facilities offer a home-like environment, it is important for a resident to be a good "match" for the operator and the other residents. Operators said it is sometimes difficult to tell upon admission whether someone will fit in. But usually within a few weeks, problems will surface if they are going to.

Based on anecdotal evidence, it appears that regulations in this area are neither strong enough nor clear enough to protect both the consumer and the provider.

■ **Information:** Academics who study gerontology issues and try to provide accurate data to policy makers say there is a lack of information about long-term care for the elderly in general and Residential Care Facilities specifically. In skilled nursing facilities, residents' condition and attributes are recorded in the federally required Minimum Data Set (although at this point the data is not routinely turned over to the State where it can be shared with researchers). Nothing similar is required of RCFEs, although regulations do require them to make a pre-admission assessment of each resident.

Filling in this gap of knowledge could be accomplished in several ways:

- √ RCFEs could be asked to provide resident-specific data or aggregate data once a year to the Department of Social Services.

- √ The federal government could be asked to amend its methods in the Census count and the annual American Housing Survey to require separate questions about people living in RCFEs and other types of assisted living facilities.

Summary

Residential care facilities are a critical component of the community-based efforts to keep people with long-term care needs in home-like environments. But these types of facilities receive far fewer resources, state attention and encouragement to deliver services in creative ways than is necessary to ensure that their potential is maximized. Policy makers can take several steps in the area of rates, licensing and operations to enable RCFEs to make a larger contribution to providing long-term care options.

Recommendations

Recommendation 4-A: The Governor and the Legislature should restructure state policies regarding RCFE rates.

With market forces driving prices for 70 percent of the residents in RCFEs, state policies to artificially suppress rates for SSI/SSP recipients have had counterproductive affects, including lack of access. In addition, many people who are not poor enough for SSI/SSP benefits but too poor to pay \$1,500 a month are left with no options for out-of-home care other than expensive skilled nursing facilities. Policy makers should take several steps:

- Eliminate the ceiling on the rates RCFEs may charge SSI/SSP recipients.
- Petition the federal government to increase SSI.
- Increase the state-funded SSP portion of the monthly benefit.
- Craft a Medi-Cal benefit using the personal care waiver that will allow RCFEs to collect money for services beyond food and shelter that help keep residents out of skilled nursing facilities where the Medi-Cal bill would be much higher.

Recommendation 4-B: The Governor and the Legislature should revamp the regulatory structure for RCFEs.

An earlier recommendation calls for the complete restructuring of licensing to allow more flexibility and integration of long-term care services. This is particularly true for RCFEs, which would benefit from

regulations that are size-specific and that more easily accommodate add-on services to a core package of basic care.

Recommendation 4-C: The Governor and the Legislature should encourage more clarity and consistency in enforcement efforts by dedicating more resources to staff training and enhanced technical support services.

Fairly enforcing regulations that avoid micromanagement and encourage innovative approaches requires state staff who are trained and kept abreast of state-of-the-art developments in long-term care. And the potential for high quality of care is enhanced by sharing with facilities the State's expertise on best methods and practices for complying with regulations.

Recommendation 4-D: The Governor and the Legislature should revise restrictions on RCFE medication practices while at the same time safeguarding consumer protections.

The elderly are a population that is already at risk for over-medication and incorrect usage of medication. But a system that requires event-by-event phone calls to physicians for permission to provide residents with over-the-counter cough medicine and aspirin seems to serve no-one's best interests.

Recommendation 4-E: The Governor and the Legislature should couple a strengthened process for protecting residents from unwarranted evictions with the creation of a limited probation period when a resident can be asked to move without cause.

While residents should be protected from summarily being forced from a facility, RCFEs also should have tools at their disposal to ensure that residents can live together comfortably.

Recommendation 4-F: The Governor and the Legislature should request that the federal government restructure its health information collection process to include specific data on residential care facility residents.

The federal government should be encouraged to use the Census process to collect data on people who live in different types of out-of-home arrangements. In addition, the federal government's American Housing Survey suffers from the problem of lumping together everyone who lives with more than five unrelated people (including college dorms and half-way houses) rather than examining information by specific categories.

Conclusion

Conclusion

There is little mystery about what an effective, consumer-preferred long-term care system would look like. For years, if not decades, advocates have described a continuum of care that would provide freedom of choice and the least-restrictive type of assistance as a person moves from independence to assisted living to total dependence. A variety of barriers have kept such a system from evolving:

- **Conceptual:** The health care system is designed to diagnose, treat and sometimes cure acute illnesses. Long-term care for chronic illnesses has always been an add-on function to health systems. In a country that is youth-focused and that has reached no consensus about universal health care, there has been scant discussion about how best to meet the needs of people who need long-term care.
- **Structural:** Programs and funding streams are spread across three levels of government -- federal, state and local. While the State has statutes and a federally required State Plan on Aging that should provide focus for a long-term care system, the State's efforts are fragmented across multiple departments. There is neither the bureaucratic leadership nor the policy-making will to institute broad-scale reform.
- **Funding:** In an era of limited resources, policy makers at both the federal and state levels are fearful of creating new programs or making new commitments to meet people's needs. Many worry that attempting to provide government assistance in this area will lead to families abandoning their involvement in the care for

elderly relatives. Policies that hold the potential for curbing high-cost government support inevitably save funds in future years or in some other program's budget, so fiscal imperatives create little pressure for reform. As a result, any change is limited in scope and incremental in effect.

Many on the front lines of advocacy would argue that reform is vitally needed today because thousands of Californians live impaired lives and deteriorate prematurely to the point of institutionalization. Adding weight to their push for change is the State's demographic destiny: The population of elderly people needing assistance is expected to soar as the Baby Boomer generation ages and medical advances continue to stave off diseases that once were a death sentence.

This report lays out a series of recommendations for policy makers that will reshape the State's long-term care approach. The key recommendations are:

- Overhauling the State's structure for overseeing long-term care services so there is a single voice and point of leadership.
- Recasting policies that favor institutionalization so that home- and community-based care are broadened and supported by government actions.
- Addressing long-identified problems that are specific to the skilled nursing facility and residential care facility industries.

The Little Hoover Commission recognizes that many of the ideas advanced in this report are not ground-breaking. But the Commission believes the timing of this report -- which synthesizes the best-practices trends across the nation -- should enhance the opportunities for reform. The State has already taken good-faith steps toward a home- and community-based ethic of long-term care by creating an integrated services pilot project for five areas of the state and revising the Older Californians Act. The State can continue down this path by providing the oversight structure and leadership to nurture these initial steps.

Appendices



APPENDIX A
Witnesses Appearing At
Little Hoover Commission Long-Term Care Public Hearings

February 28, 1996
Sacramento

Richard K. Matros
California Association of Health Facilities

Daniel Polakoff
Gray Panthers

Dr. Dennis Stone
California Association of Medical Directors

Carol Widemon
Department of Social Services

Pat McGinnis
California Advocates for Nursing Home Reform

A. Alan Post
Former Legislative Analyst

Derrell Kelch
California Association of Homes and Services for the Aging

September 25, 1996
Sacramento

Ray Mastalish
California Commission on Aging

Lynn Friss Feinberg
Family Caregiver Alliance

Carol Widemon
Department of Social Services

Benson Nadell
San Francisco Ombudsman Program

Fred Miller
Department of Aging

Sue Hodges
Alameda County Public Authority

Brenda Klutz
Department of Health Services

Hale Zukas
World Institute on Disabilities

Marilyn Ditty
State Long-Term Care Advisory Committee

Mark Beckwith
ADAPT

Toby Kaplowitz
Public Interest Center for Long-Term Care

Lauri Evans
Butte Long-Term Care Network

Judy Boothby
California Dental Hygienists Association

Deborah Doctor
Alameda County Public Authority

APPENDIX B
Little Hoover Commission Long-Term Care Advisory Committee

A. Alan Post
Former Legislative Analyst

Diane Cooper
The Peg Taylor Center

John Anderson
California Senior Assemblyman

Sheree Crum
California Association of Health Facilities

Dixon Arnett, Director
Department of Aging

Rebecca Dowd
Resources for Independent Living

Carol Bell
Department of Aging

Jennifer Hendrick
California Association of Health Facilities

Elizabeth Boardman
California Association for Adult Day
Services

David Howard
AARP

Judy Boothby
Dental Hygienists

John Daniel
American Association of Retired
Persons/Sacramento

Teri Boughton
Assemblyman Martin Gallegos

Bonnie Darwin
California Healthcare Association

Rocky Burks, Executive Director
Independent Living Services of Northern
California

Ramona Davies
No. California Presbyterian Homes, Inc.

Beth Capell
CNA

Mattie Sawyers Davis, LCSW
City of Oakland

Eric Carlson
Bet Tzedek

Patricia de Cos
California Research Bureau

Michelle Castro
California State Council of Service
Employees

Margaret DeBow, Deputy Director
Department of Health Services

Gloria Cavanaugh, Executive Director
American Society on Aging

Gerry Desmond
Desmond & Desmond

Mary Charles
Older Women's League

Inge Dietrich

Marilyn Ditty
State Long-Term Care Advisory Committee

Don Clark
Sacramento County Mental Health Board

Deborah Doctor
Public Authority for IHSS

Lesley Clement
Attorney at Law

Barney Donnelly, Commissioner
Adult and Aging Commission

Kathleen Dorosz
Elder Abuse Prevention

William Duclus, President
California Seniors Coalition

Jim Eli and Joel Goldman
California Assisted Living Facilities
Association

Dr. Marian and Stanley Faustman
Older Women's League & Congress of CA
Seniors

Carol Freels, Chief, Long Term Care &
Special Projects
Department of Health Services

Lynn Friss Feinberg
California Caregiver Resource Centers
System, Family Caregiver Alliance

Calvin Groeneweg, R.N.

Joe Hafkenschiel
California Association of Health Services at
Home

Douglas Harris
North Coast Opportunities, Inc.

Jim Harrison, Commissioner
Adult and Aging Commission

Mark Heaney
National Homecare Systems

Phyllis Heath
State Long-Term Care Ombudsman

Senator Henry Mello
Senate Subcommittee on Aging

Carole Herman
Foundation Aiding the Elderly

Elizabeth Hill
Legislative Analyst

Anne Hinton
Multipurpose Senior Services Program Site
Directors Association

Jack Horak
Triple A Council of California

Sue Hodges
Alameda County Public Authority

Kim Hughes, California Office
National Council on Aging

Michael Humphrey
Community Resource for Independence

Vic Ioppolo
Senior Legislature

Fahari Jeffers
United Domestic Workers of America

Vicky Jones, Director of Social Services
Twin Palms Care Center

Toby Kaplowitz, Deputy Director
Public Interest Center for Long Term Care

John Kehoe, Executive Director
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Derrell Kelch
California Association of Homes and
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Dorothy Kellner

Kathleen Kelly, Executive Director
Family Caregiver Alliance Inc.

Elisabeth Kersten
Senate Office of Research

Ruth Kletzing, President
California Chapter, Older Women's League

Nancy B. Knutsen

Ken Kruser
Addus Health Care

Francis Labaco
ACLU

Martha Lipka

Patricia Longo
Commission on Aging

Martha Lopez, Deputy Director
Community Care Licensing, DSS

Patricia Lorne
Senior Care Network (HMH)

Eldon Luce
San Mateo County In-Home Supportive
Services

Gary Marshall

Ray Mastalish, Chairman
California Commission on Aging

John McCune, Vice Chair
California Commission on Aging

Pat McGinnis
California Advocates for Nursing Home
Reform

Pamala McGovern, Executive Director
Orange County Council on Aging

Gerald McIntyre
National Senior Citizens Law Center

Kay Merrill, Director
Sacramento County Adult and Aging
Commission

Tara Mesick
Assemblyman Wally Knox

Jeanine Meyer Rodriguez
SEIU

Lydia Missaelides
California Association for Adult Day
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Martha Moehler
National Committee to Preserve Social
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Irma Weissenberg, Chair
Linkages Site Directors Association

Katherine Murphy

Benson Nadell, Program Manager
California Long-Term Care Ombudsmen

Ron Nelson, President
California Association of Residential Care
Homes

Robert Newcomer
University of California, SF- Institute for
Health and Aging

Vivian Plank
Retired Public Employees Association of
California

Daniel Polakoff
Gray Panthers

Bob Polvinale
CA-RES, Inc.

Dawn Myers Purkey
Area 4 Agency on Aging

Sharon Raynor
Aaron Read & Associates

Charles Ridgell, Vice President
SEIU Local 250

Carol Risley, Executive Director
Organization of Area Boards on
Developmental Disabilities

Jacqueline Riss, RN
Care Home Health

Ted Ruhig
California Coalition of Seniors

Tony Sauer, California Federation of
Independent Living Centers

Steve Schmoll
Director, Santa Clara County Council on
Aging

Tanner Silva
Community Resources for Independence

Charles Skoien Jr.
Community Residential Care Association of
California

Perri Sloane, MSG, MPA
Jewish Family Service of Los Angeles

Betty Soennichsen
California Senior Legislature

Ila Swan

Assemblyman Tom Bordonaro
Assembly Committee on Human Services

Lisa Trask
UC Davis Geriatrics

Burns Vick, Jr.

Lois Wellington, President
Congress of California Seniors

Daniel Wessel

Carol Widemon, Deputy Director
Department of Social Services

Mark Wiesel, President
Greater L. A. Chapter, Huntington's Disease
Society

Terri Williams, MSG
Watts Health Foundation, Inc.

Veronica Woodards
Lively Pines

Kathleen Zegalia

Endnotes

Endnotes

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LITTLE HOOVER COMMISSION FACT SHEET

The Little Hoover Commission, formally known as the Milton Marks "Little Hoover" Commission on California State Government Organization and Economy, is an independent state oversight agency that was created in 1962. The Commission's mission is to investigate state government operations and -- through reports, and recommendations and legislative proposals -- promote efficiency, economy and improved service.

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