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 inadvertantly 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.