Chapter VIII
LONG-TERM CARE SERVICES
INTRODUCTION AND CHAPTER SCOPE

"Long-term care" is a planning concept that encourages focus on a very broad range of services required by various constituent groups who have aggregate special needs. Such needs may be attributable to one or more of the following conditions: aging; chronic illness; a physical disability; or a developmental disability. The total population in need of long-term care services may be the fastest growing of all "target populations" interacting with the health system. The fundamental reasons are the lengthening life span of individuals, including persons with special needs attributable to one or more disabilities; and the vulnerability of family support structures in an industrialized, mobile, self-reliant society. The long-term care concept encompasses efforts to identify, categorize and organize a continuum of services which will respond to the multiple needs of an extremely diverse population.

Critical to the discussion of long-term care is an understanding of the nature of disability and chronic illness. Chronic conditions differ from acute illnesses in that they are usually not curable in the classic sense and require management over a long period of time. "These conditions may be experienced at any age as recurrent or persistent symptoms, illness, disabilities or impairments of a physical or mental nature. Chronic conditions may be defined to include at least those for which there is no known cure as well as those which last for prolonged periods, e.g., three months or more."

Examples of major chronic conditions are arthritis, rheumatism, stroke, heart disease, high blood pressure, cancer, diabetes, asthma, bronchitis, orthopedic and neurological abnormalities, visual and hearing impairments, chronic brain syndrome and alcoholism.

Functional limitations rather than diagnostic categories define the nature of disability. While disability is frequently equated with separate and specific physical or mental impairments, wide ranges of functional abilities exist among persons with the same or similar diagnostic categories. The interaction of the individual with the environment and family or community support systems is an important determining factor, as is the individual's own conception of disability. Long-term care services are aimed at those whose disability and environmental circumstances create a need for long-term assistance.

The characteristics of chronic illness and disability have consequences for the development of an ideal system of care. These have been described as follows:

463
since chronic disease and disability are long-term, continuity of care is essential

since their course is uncertain and frequent fluctuations occur, differing levels of care may be required within a relatively short time, ranging from intensive hospital care, skilled nursing services, custodial care or home health services, to periodic physician office visits

since chronic disease often involves subjectively experienced discomfort, pain, disability and restricted activity, measures of relief may be required which run counter to narrowly conceived ideas of what is "medically necessary," or "cost effective"

chronic diseases tend to multiply themselves, a single chronic condition often leading to multiple chronic conditions

chronic conditions are disproportionately intrusive into the lives of patients and their families

chronic conditions require a wide variety of ancillary services if they are to be properly cared for: social services; counseling; education; and training, in addition to basic medical services

chronic illness and disabilities are expensive; the long-term, complex and multiple nature of many chronic illnesses, and the need for a variety of ancillary services, make the direct costs of chronic illness care substantial; the indirect costs are high due to lost work opportunity and restriction of activity.

These characteristics require an organization of services which provides for repeated interaction, continuous management, extraordinary sensitivity to client perceptions, a respect for their civil rights and reimbursement schemes which foster appropriate living arrangements as well as allow for mobility.

Recognizing that long-term care public policy should promote a diverse and integrated society, develop and maintain a competent citizenry and to the maximum extent possible, make a return on the investment of public resources made in pursuit of social goals, appropriate policies are needed which:

- develop a systematic organization and sustained coordination of needed services

- allow individuals, whose functional capacity may be impaired, access to those resources and services which will assist them in achieving and maintaining a maximum level of health and well-being

- encourage and foster the development of a continuum of services which relate to the level of need rather than solely upon the choice of living arrangements

- promote an optimal balance between costs, effectiveness and satisfaction.
DEFINITIONS AND SCOPE OF SERVICES

Long-term care (LTC) is defined as services designed to provide preventive, diagnostic, therapeutic, rehabilitative, supportive (maintenance) and case management services for individuals of all age groups who have chronic physical and/or mental functional impairment requiring care by another individual. Included are social as well as strictly medical and nursing services, with the goal of promoting an optimum level of physical, social and psychological functioning.

Of particular importance for long-term care are the rehabilitative, supportive (or maintenance) and case management services, defined as follows:

- **Habilitation and rehabilitation services** "restore the ill or disabled individual and assist the developmentally disabled individual, to achieve the fullest physical, mental, emotional, social, vocational and economic usefulness of which the individual is capable," or prevent deterioration.

The full spectrum of such services includes: medical rehabilitation; physical, occupational and speech therapy; various assistive devices and services; social and psychological services; vocational activity and educational assistance; and residential care. These services may be appropriately provided in any setting. (The reference to medical rehabilitation refers to those limited aspects of individual rehabilitation services which are delivered through skilled nursing facilities, intermediate care facilities, home health agencies or by private practice therapists. A discussion of intensive medical rehabilitation care is provided in the "Acute Rehabilitation" section of the Diagnosis and Treatment Chapter.)

While many of the same services and treatment modalities are utilized in both habilitation and rehabilitation, they may be differentiated. "Habilitation services" are designed to assist persons handicapped from birth or early childhood to develop a variety of skills needed for activities of daily living at home and in the community. "Rehabilitation services" are primarily designed to restore persons with catastrophic or chronic disabilities to normal or near normal functional levels in the shortest possible time, with a goal of gainful employment implicit in many programs.

- **Support Services** include services provided to individuals with chronic physical and/or mental ill health conditions at home, in the community and in residential settings, in order to prevent or slow the process of deterioration, as well as
services to assist in daily living. Such services are not strictly medical, but are designed to improve self-help skills, keep persons in touch with reality and enable them to maintain the maximum level of well-being possible.

- **Assessment and Case Management Services** include patient assessment, development of care plans, placement and referral and monitoring for quality and appropriateness of placement. These services are essential to assure continuity and an appropriate mix of services as the course of illness or disability fluctuates.

Long-term care services are provided in a variety of settings, many of which include a living arrangement function:

- the home
- group homes, residential care facilities and other assisted living arrangements
- nursing homes offering either skilled nursing or intermediate care
- multilevel facilities
- specialized care facilities
- general acute care hospitals
- hospices
- senior citizen centers
- day care centers
- physicians' offices
- outpatient clinics.

Though skilled nursing and intermediate care facilities have been the dominant alternative setting to the home, there has been a recent shift in the attention of policy makers towards developing the full continuum of long-term care services. This has resulted in the creation of programs and services which, in addition to institutional care, can also serve as appropriate alternatives to the home when such need arises. Community support type programs and services, including those focusing on alternative living arrangements, have attempted to stress independence, community integration and the development and maintenance of a maximum level of well-being for individuals with special needs.

This chapter discusses long-term care services provided in the following manner:

- "community support systems," i.e., other types of alternatives to the home other than institutional services
Major Issues

- "nursing care facilities," i.e., skilled nursing facilities and intermediate care facilities
- "alternative living arrangements," i.e., specifically residential care facilities, assisted living arrangements and independent living programs.

This chapter also addresses the range of services and issues related to such services, required by persons with special developmental needs. This is done as a separate section due to the explicit legal mandates for planning and provision of services for this recognized constituent group.

(Services for persons with mental health and substance abuse problems are described in Chapters IX and X respectively.)

Health Systems Plan Highlights

The demand for all levels of long-term care is growing due to an increase in the aging population, improved medical technology and better and faster treatment of persons with severe injury and/or disability. The great variety of issues in long-term care services will require major attention from planning agencies and State government. Separate and multiple services and funding arrangements and the patients' needs for continuity when shifting from one level of care to another calls for a comprehensive, organized system of long-term care responsive to the different needs of the individual client over time.

Even though nursing home bed shortages exist in some areas of the State, HSA's concerns center around other issues:

- increased utilization and expansion of alternative services
- appropriate levels of care from which to choose from
- financing and reimbursement in relation to level of care
- quality of nursing care and training of personnel
- need for the development of a model to plan for long-term care patients which would link all appropriate levels and settings of care.

MAJOR ISSUES IN LONG-TERM CARE

A long-term care planning focus facilitates discussion of several issues which appear and reappear in analyses of many long-term care services and settings. The frequency of their appearance raises such issues to a policy level, and their resolution would have profound consequences for every long-term care service. Five such issues will be considered here.
They are:

- development of the long-term care service continuum
- development of a client centered assessment and case management mechanism to coordinate entry into the long-term care system, to ensure appropriate services within its many "levels" and to oversee the quality of care
- development of a funding mechanism appropriate to the long-term care service continuum concept
- development of a balanced system for assuring quality long-term care services
- improvement of the planning capability for long-term care, to effect a comprehensive approach in dealing with issues of both a short- and long-term nature.

Issue #1: Development of the Long-Term Care Services Continuum

The historic social response to long-term care needs is currently undergoing many changes. The increasing at risk population presents a major challenge to society's capacity to provide those services within present policy mandates and fiscal resources. The development of the long-term care services continuum represents an approach which is gaining increased attention and acceptance among policy makers as a viable response.

Development of the service continuum requires an appropriate focus on the major technical areas of long-term care such as case management, funding mechanisms, quality assurance and a comprehensive and coordinated framework for planning. These issues must be addressed in order to realize the public policy goal of eliminating inappropriate institutional care — now an overriding priority of the federal and State governments, professionals in the field and consumer groups.

Channeling resources toward the development of the service continuum does not necessarily mean replacing those services provided in health care facilities (SNFs and ICFs) with community support services. Rather, it indicates that a priority is being placed on developing, strengthening and increasing the use of community support services and other types of alternative living arrangements. The fact that an overwhelming proportion of our population in need of long-term care assistance and services continue to reside in their own home requires that the service delivery system represents available alternatives to the home and the family support system rather than simply institutional care.
The overall intent of having a continuum is therefore to assure the availability of needed resources from which the consumer can freely choose according to their needs. Such assurances in the face of countervailing financial incentives will necessitate resources costing money and requiring imagination and coordination.

**Issue #2: Development of Client Centered Case Management**

Developing the continuum requires new mechanisms to "track" clients through the range of long-term care services. The whereabouts of a person within institutional settings is always known, as are (in theory) the services available and used. Those long-term care service recipients able to remain outside of health care facilities should also have access to services which provide "management support." Support of this nature would facilitate access to services such as physicians who will accept Medicare and Medi-Cal clients, dental care which is responsive to the special needs of elderly or disabled persons, supervision of Life Care Contracts and those provided by persons and organizations with bilingual capability, just to name a few. The great variety of services and lack of knowledge concerning their availability, quality or appropriate use create a serious need for client centered "case management" service.

If remaining in the home setting as long as possible is a major therapeutic goal, a service must be available which assesses each individual's specific needs and coordinates a program to meet those needs. The difficulty of finding appropriate alternative living arrangements in the long-term care system, and the access barriers to services such arrangements may induce, further emphasize the need for case management.

For the present, the precise form this service should take is less significant than commitment to its development. Policy questions regarding where case management services should be located (i.e., PSROs, local departments of Social Services or newly created organizations) and the degree and nature of control (i.e., statewide or local) should be the focus of continuing research and experimentation. There are two programs in the State which provide a potential model: the Regional Centers for the Developmentally Disabled and the Multi-purpose Senior Service projects. More recently, the Department of Social Services has drafted a proposal regarding a placement program for adult clients. The many individuals who continue to fall outside of programs such as these should also have access to similar types of case management services. Critical to the development of these services are those design elements which accommodate change. Proper case management necessitates having the capability of appropriately meeting new, and possibly unforeseen, needs due to changes in the level of dysfunction and/or health condition of clients.

It should be noted that this "case management" function in long-term care is analogous to one of the characteristics of primary care in Chapter VI ("the matching of patient needs to available resources . . . screening, referral, coordination, liaison . . ."). Despite the
obvious similarity, the linkages between primary care and case management for LTC have not been explored. This is a fragmentation problem that will eventually need to be faced. The role of the physician in long-term case management is an issue which needs to be explored further.

**Issue #3: Appropriate Funding Mechanisms**

Long-term care is plagued by fragmented funding sources, limitations on kinds and duration of care and arbitrary eligibility categories which may not only be wasteful, but also limit access to services and the growth of a more rational system. The growth of alternatives within the continuum, the development of mechanisms for appropriate case management and incentives for quality care all depend on a more rational funding and reimbursement system. The challenge is to develop that mechanism.

Fee-for-service payment for long-term care, modeled on the financing pattern for acute, physician centered care, creates virtually intolerable fragmentation and gaps when used for chronic care. Capitation is often mentioned, but the application of capitation to lifelong, highly individualized, unpredictably changing needs has yet to be tested. Assuming that an amount "per capita" could be established, there is the question of who should get it: the client, the family (if there is one), the "case management" entity, the direct provider, etc. Other possibilities include some form of "credit" account or voucher. At a minimum, financing appropriate to the variety and duration of long-term care needs must be applicable to both the health and the social/living needs of clients, that are inextricably intertwined.

At the heart of these options is the fundamental distinction between the social and medical models for long-term care and the critical policy question of eminent domain. "The issue of predominance between the medical and social models for long-term care is not merely a battle for bureaucratic supremacy between two actions of government; it is a fundamental clash of beliefs in the style of life to be pursued and the appropriate manner of its pursuit. It involves questions of both ends and means — the goals and expectations generated by different perspectives and the paths deemed most approachable to reach them."6

**Issue #4: Quality Assurance**

State concern for quality of care represents another issue which must be addressed in the development of the service continuum. "The issue of quality has attracted increasing attention with the advent of the merging view of health care as a social right, an increase in consumer sophistication, the recognition that health care is a limited national resource, and the need that costs be controlled."7
Quality has been defined in terms of either structure, process or outcome of care. Structure of care focuses upon criteria which are supposed to represent a measure of good care and the degree to which that criteria is met, e.g., licensing regulations. Process of care looks at identified client needs and then determines the degree to which the client received appropriate services, e.g., utilization reviews. Outcome of care attempts to specify expected and desired outcomes of care and assistance and then evaluates the actual delivery of services in relationship to the resulting impact on the client. While the latter approach is currently not well delineated, it probably represents the most effective means of assessing quality of care because of its requirements for measurable criteria that can be used to evaluate clients over time as well as through the multitude of long-term care services.

A system for assuring quality of care needs to have an appropriate balance of staff development, expertise and continuous training, necessary regulations which are not contradictory or duplicative, effective monitoring and assessment programs and data acquisition and analysis capabilities which produce timely and relevant information. The nature of that balance will largely be influenced by how the social and medical models of long-term care are integrated. More importantly though, quality assurance mechanisms should be designed to insure that provided services effectively contribute to the achievement and maintenance of well-being for all service recipients.

**Issue #5: Improvement of Planning for Long-Term Care**

The current profusion of various planning methods and assumptions used in estimating long-term care resource requirements presents another challenge to the development of the service continuum. This multiplicity is merely indicative of the dispersed nature of authority and planning responsibility for long-term care services among such State entities as: The Office of Statewide Health Planning and Development; the Department of Health Services, Social Services, Rehabilitation, Developmental Services and Aging; the Council on Developmental Disabilities and the Commission on Aging. In addition, local counterparts to these State entities have widely differing sets of mandates and levels of authority.

Current planning approaches mandated for HSP development, for example, fragment long-term care services along both facility (skilled nursing) and service (rehabilitation) lines. Current health planning resource projection methods deal only with beds and with allegedly separate (skilled, intermediate) kinds of beds. Many agencies develop resource estimates on a programatic basis or as a result of the budgetary approval process or both. Current data available for long-term care planning are meager at best, and more often inappropriate or absent altogether.

Problems such as these are indicative of the need for a comprehensive framework which can provide a coordinated approach to long-term care. This framework should be capable of addressing both short and long range issues.
Short range issues would be those which involve questions regarding resource planning methodologies, reimbursement levels within the current systems, or minor changes in licensing regulations. Longer range issues would be those that have been just discussed within this section of the Plan, namely the service continuum, case management, funding mechanisms, quality assurance and planning coordination. Addressing these issues in a coordinated approach must entail a consideration of concerns such as State control versus local control, trade-offs among various options and alternatives and current shortages and duplication of resources, to name a few.
POLICY RECOMMENDATIONS FOR LONG-TERM CARE

Long-Term-1: STATE FUNDS, SERVICES, AND PROGRAMS SHOULD SHIFT AWAY FROM AN INAPPROPRIATE RELIANCE ON NURSING HOME AND OTHER FACILITY PLACEMENT (INCLUDING STATE INSTITUTIONS) AND TOWARD DEVELOPMENT AND USE OF THE FULL CONTINUUM OF SERVICES AND LIVING ARRANGEMENTS WHICH PROVIDE ADDITIONAL ALTERNATIVES FOR THOSE PERSONS IN NEED OF LONG-TERM CARE ASSISTANCE.

This is consistent with the contemporary thinking of professional groups and the expressed wishes of the client groups.

Long-Term-2: APPROPRIATE FINANCIAL INCENTIVES SHOULD BE DEVELOPED WHICH ENCOURAGE OF PRIVATE INVESTMENT RESOURCES TO BE DIRECTED TOWARD DEVELOPMENT OF HOME HEALTH, IN-HOME SUPPORTIVE SERVICES, DAY CARE, OPTIONAL RESIDENTIAL LIVING ARRANGEMENTS AND HOSPICE CARE.

Incentives toward the investment of private financial resources would complement the State's effort in developing the full continuum of long-term care services.

Long-Term-3: THE STATE SHOULD ENCOURAGE DEVELOPMENT OF A STATEWIDE, BUT LOCALLY BASED, ASSESSMENT AND CASE MANAGEMENT SYSTEM WHICH WOULD PROVIDE MULTIDISCIPLINARY ASSESSMENT, COUNSELING, REFERRAL, FOLLOW-UP SERVICES, AND ADVOCACY TO MAKE THESE SERVICES AVAILABLE TO ALL PERSONS REQUIRING LONG TERM CARE.

The vital linkage function case management services provides is essential to the development of the service continuum if self-determination and accessibility are to be valued characteristics of long-term care. As with many other long-term care services, the State must play a lead role if this service is to be available to all who need it.
Long-Term-4: AN APPROPRIATE SYSTEM FOR FINANCING A CONTINUUM OF LONG-TERM CARE SERVICES IN CALIFORNIA SHOULD BE DEVELOPED AND IMPLEMENTED.

The need for changing financing and reimbursement mechanisms for long-term care is crucial to the development of the service continuum. This new system should reflect an approach which policy makers determine provides an appropriate balance of cost, effectiveness and satisfaction.

Long-Term-5: AN EFFECTIVE SYSTEM FOR ASSURING QUALITY IN LONG-TERM CARE SERVICES SHOULD BE RESEARCHED, DEVELOPED AND IMPLEMENTED ON A COORDINATED BASIS.

Mechanisms which provide such assurances are essential if the service continuum is to assist those persons with special needs in achieving an optimal level in the quality of life.

Long-Term-6: RESPONSIBILITY FOR LONG-TERM CARE SERVICES PLANNING SHOULD ULTIMATELY BE A COORDINATED EFFORT INVOLVING THE OSHPD, DHS, DSS, DOA AND OTHER APPROPRIATE STATE GOVERNMENT DEPARTMENTS, AGENCIES AND ADVISORY GROUPS ALONG WITH OTHER INTERESTED PARTIES.

Comprehensive planning and policy analysis is inhibited by multiple jurisdictions. Given its mandate to develop a State Health Plan, the OSHPD should improve its coordination activities so as to provide an effective forum for comprehensively assessing and recommending appropriate policies related to the provision of long-term care.

Long-Term-7: A STATEWIDE SYSTEM SHOULD BE DESIGNED, FUNDED, AND IMPLEMENTED IN COOPERATION WITH OTHER STATE AND LOCAL AGENCIES TO COLLECT DATA ON LONG-TERM CARE WHICH WOULD BE CONSISTENT WITH THE LONG-TERM CARE DATA SET BEING DEVELOPED ON THE NATIONAL LEVEL.

Poor data yields poor planning.
Long-Term-8: THE OSHPD, IN COOPERATION WITH APPROPRIATE ENTITIES, SHOULD CONTINUE TO RESEARCH AND DEVELOP RESOURCE PROJECTION METHODOLOGIES FOR LONG-TERM CARE SERVICES THAT TAKE INTO ACCOUNT THE RANGE OF SERVICES AS WELL AS THOSE AGREED UPON ASSUMPTIONS CONCERNING THEIR FUTURE ORGANIZATION.

The ability to translate aggregate needs of persons at-risk or in need of assistance into resource requirements must transcend the exclusive focus upon beds. The degree of success in this effort will have a direct impact on successful development of the full continuum of long-term care services.
COMMUNITY SUPPORT SYSTEM

DEFINITIONS AND SCOPE OF SERVICES

Community support systems are integrated sets of services designed to foster, maintain and encourage full social and physical integration and well-being on a generic and special service basis. Essential to the objective of preventing an increase in dependency and disability, these services should be provided, in the least restrictive setting. Services vary from minor personal care, homemaker services in normal housing or respite care, to more structured ambulatory settings providing nursing, rehabilitative services and personal care on a regular basis.

Home health and in-home supportive services are a set of health and health related services for individuals of all ages and their families provided in the home, singly or in combinations, for the purpose of promoting, maintaining or restoring health, activity, or independence, or minimizing the effects of illness and disability. Services appropriate to the needs of the individual patient and family are planned, coordinated and made available by an agency/institution, or a unit of an agency/institution, organized for the delivery of health care and supportive services through the use of employed staff, contractual arrangements or a combination of administrative patterns. Services included are shown in Figure VIII-1. Skilled and professional home health services, such as nursing care or therapy, are provided on an intermittent basis, usually through a home health agency. Support services are usually furnished by family, friends, community organizations or a separately employed homemaker/chore worker.

Figure VIII-1

IN-HOME HEALTH SERVICES: SCOPE

<table>
<thead>
<tr>
<th>Health Related Services</th>
<th>Support Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory therapy</td>
<td>Barber/cosmetology</td>
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<tr>
<td>Speech therapy</td>
<td>Handyman</td>
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<tr>
<td>Medical social service</td>
<td>Heavy cleaning</td>
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<tr>
<td>Nutrition counseling</td>
<td>Legal and protective</td>
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<tr>
<td>Medical equipment and supplies</td>
<td>Pastoral</td>
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<tr>
<td>Audiology</td>
<td>Recreational</td>
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<tr>
<td>Nursing (RN/PHN/LPN)</td>
<td>Translation</td>
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<tr>
<td>Physician visits</td>
<td>Laundry</td>
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<tr>
<td>Home Health Aides</td>
<td>Personal escort</td>
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<tr>
<td>Occupational therapy</td>
<td>Home crafts</td>
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<tr>
<td>Physical therapy</td>
<td>Sitter</td>
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<tr>
<td>Podiatry</td>
<td>Shopping</td>
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<tr>
<td>Prescription drugs</td>
<td>Book and gift</td>
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<td></td>
<td>Information and referral</td>
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<tr>
<td></td>
<td>Telephone reassurance</td>
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<td></td>
<td>Friendly visitors</td>
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<td></td>
<td>Meals</td>
</tr>
<tr>
<td></td>
<td>Transportation</td>
</tr>
<tr>
<td></td>
<td>Homemaker-housekeeper</td>
</tr>
</tbody>
</table>

476
Day Care Services include the following services:

- for elderly persons: (a) adult day health care is "an organized day program of therapeutic, social and health activities and services provided to persons 55 years or older or other adults with functional impairments, either physical or mental, for the purpose of restoring or maintaining optimal capacity for self-care"; (b) adult day care programs provide supportive services and care to functionally impaired older people and prevent early institutionalization by providing social interaction, reality orientation and adequate nutrition.

- for persons who have disabilities: (a) workshop services are community based programs of less than 24 hours/day designed for adults who are unable to participate in competitive employment due to the nature of their disability. They include vocational and rehabilitation counseling, work training and vocational evaluation to assist handicapped persons to achieve and maintain competitive employment if possible, or extended sheltered employment if needed; (b) work activities center is a workshop or physically separated department of a workshop whose major purpose is to provide long-term personal and social development in a work environment with inconsequential productive capacity in order to evaluate and improve their rehabilitation potential; (c) activity Center is a center providing services which develop personal independent living skills; promote social adjustment to home/community living situations and provide life enriching and satisfying experiences; (d) centers for the blind and deaf provide services such as communication skills, mobility and orientation and activities of daily living.

Hospice is a program which provides palliative and supportive care for terminally ill patients in the latter stages of their disease and for their families. Such care can be provided either at home or in an inpatient setting. The patient and the family are the primary unit of care with emphasis on physical, psychological, social and spiritual needs. Hospice care is available 24 hours a day, 7 days a week by a coordinated interdisciplinary team and extends to families through the bereavement period. The interdisciplinary team includes but is not limited to a medical director, nurses, lay and professional volunteers and clergy. Accurate and current health records are maintained for every patient and family receiving hospice services, the hospice program is autonomous and centrally administered.

Assessment and Case management means assessment of the person's needs, development of a care plan, assistance with appropriate entry into the long-term care system and
functioning as the patient/client's advocate to coordinate the delivery of necessary services. Periodic evaluation of the client and monitoring of the care provided are also included. In many instances, agencies which provide these functions also pay for or purchase services on behalf of their clients, e.g., Crippled Children Services (in California, now the California Children's Service) and Regional Centers for persons with developmental needs, etc.

BACKGROUND

Relationship to Health Status

The value of community support services is that they facilitate a continuance of lifestyle which people find personally desirable. While research evaluations of services provided in the community compared to those provided in institutions having generally been hampered by inconsistencies in defining outcomes and expectations, it has been shown that:

- virtually all older and most disabled persons are protective of their status as independent, autonomous, self-sufficient individuals and wish to live in the freedom and privacy of their own dwellings
- the decision to enter an institutional environment is often accompanied by emotional responses related to loss of independence, the relinquishing lifelong possessions, a severing of community ties, as well as a possible prelude to death
- the array of services provided in institutions for the severely disabled is usually in excess of those required by as many as 10 to 40 percent of their populations and this over-servicing results in premature dependence and loss of personal integrity.11 (Such over-servicing may be attributed to certain requirements either for participation in reimbursement programs or facility licensure.)
- deterioration of patients can be linked directly to institutionalization and prolonged bed rest.12

National Trends

Disappointment with institutional, medically oriented long-term care financed by Medicare and Medicaid has stimulated strong interest, by professional groups, consumer groups and government in other alternatives besides institutional care. Both national legislation and professional activities have begun to focus on the need for services and treatment philosophies that promote the independence, dignity and self-sufficiency for persons with chronic illness or disability.

A similar change of direction animates the fields of rehabilitation/habilitation in which the principles of normalization and deinstitutionalization have become predominant aims.
There has been a shift in rehabilitation from veterans to civilians; from a State/federal vocational rehabilitation system with emphasis on job training and placement to vocational rehabilitation which includes medical services; from services to only the vocationally handicapped to services for even the most severely handicapped individuals, including those with developmental service needs. Workers Compensation legislation, which provides financial assistance to persons injured on the job still includes, however, certain disincentives for individuals to return to their highest levels of recovery.

Community support services are confronted by issues and concerns typical of long-term care generally: inadequate funding, extreme fragmentation, lack of coordination, narrow definitions of eligible people, people falling between the cracks of programs and funding sources, and an increase of proprietary (as compared to the historical nonprofit) agencies supported by government contracts. Some examples:

- Out of an estimated 5-10 million persons in the nation in need of long-term care, fewer than 300,000 are receiving home care services.
- Reimbursement for home health services usually is not available under insurance plans, including Medicare and Medicaid, except following release from an inpatient facility, and narrow interpretation of these requirements often reduces benefits for these services.
- Expenditures for home care services come to no more than 1 percent of both Medicare and Medicaid budgets.
- Present federal policy limits expenditures under Title XX to $2.5 billion and these expenditures must also cover other mandated social services.
- States vary in their use of Medicaid for homemaker services: New York includes this benefit under Medicaid, California does not.
- The proprietaries appear to be particularly active in the provision of homemaker/home health aide services, especially through Title XX contracts.

Despite problems, many types of community support services are currently in their expansion phase. Employment opportunities for persons who have a disability, through the use of day care services, was recognized in federal legislation in 1965. Since 1973 (Vocational Rehabilitation Act) this has been expanded to accommodate persons with "severe disabilities," including those with mental retardation (53 percent of today's caseload). Rehabilitation/habilitation services are, as of 1978 (P.L. 95-602), to be made available to all persons with disability needs, regardless of their employment potential. Adult day care, established in England for two decades and sporadically available in the U.S. under voluntary auspices has, since 1976, been funded through the
Older Americans Act. Medicare and Medicaid are also authorized, since 1972, to fund "demonstration" projects for this service as a substitute for nursing home placement. Provision of congregate housing for low and middle income disabled persons and elderly is now being implemented in public housing and under Department of Housing and Urban Development Section 202 and Section 8 programs, which call for specially designed housing offering a number of site basic services.

Hospices are typical of the growing interest and rapid growth in community support systems. Based on a British model, the first American hospice was developed in Connecticut in 1974, followed by approximately 80 around the country by 1978. Another 30 to 40 hospice organizations are reportedly making plans to establish programs and 80 to 90 are beginning to consider them. DHEW and the National Cancer Institute are interested in this movement and are providing funds to support construction, program development and evaluation. For example, DHEW is conducting a two year demonstration project involving 26 hospices nationwide in which the Medicaid and Medicare limits on reimbursement for custodial care and use of pain controlling drugs at home for the dying patients is waived.

Given their growing number and disparate eligibility requirements, appropriate use of community support systems virtually requires a "coordinating" service, or centralized case management, to guide clients and families into, through and occasionally out of, these systems. Although a felt need, case management services remain to be defined as to location, form, financing and accountability. One model is the function as performed by the California Children's Service. Another option is the county "brokerage" concept, currently being explored by the Riverside County Health Department in California. This would involve participation in DHEW's grant program to establish a Long-Term Care Channeling Demonstration Project. This project would be designed to test the extent to which a local structure is able to manage, coordinate and arrange provision of in-home community based and institutional long-term care services in order to assure that people who need long-term care receive the appropriate types and levels of services in the least restrictive setting and in the most cost effective manner.

Finally, the need for data and adequate planning methods relating to community support systems is reaching crisis proportions. Recognizing this, the National Center for Health Statistics and the Technical Consultant Panel on Long-Term Care of the U.S. National Committee on Vital Health Statistics are developing a minimum basic data set for long-term care.

National Policy

The federal government appears committed to the development of the full range of long-term care services. The extension of civil rights to the handicapped by Section 504 of the Federal Rehabilitation Act of 1974, for which regulations were recently formulated, awards to persons with handicapping conditions the right to the same services as those available to the public, or, where necessary, adequate alternative services.
Among the consequences are new design requirements for access to buses, airplanes and buildings. Titles XIX and XX of the Social Security Act provide, respectively, basic living expense support at home or in a residential care facility; services to maintain self-support at home or in a residential care facility; and services to maintain self-support, prevent dependency and avoid institutional placement. The Older Americans Act (1965) supports, among other things, the "multipurpose senior center," which may provide some "health" services.

California Trends

California community support systems fully reflect the diversity of the national scene and include some nationally known examples, including On Lok Senior Health Center (San Francisco), Hospice of Marin (San Rafael) and Center for Independent Living (Berkeley). Toward the end of 1979 it was reported there were approximately 70 programs in the State which were either giving some phase of hospice care or were in preparatory stages prior to presenting hospice services. The State supports active home health services through the Medi-Cal program administered by the Department of Health Services and In-Home Supportive Services (IHSS), which is administered by the Department of Social Services programs. The picture typical of these services -- multiple funding, uneven quality, growth of proprieties and uncoordinated State jurisdictions -- applies here as well. IHSS is growing prodigiously: from $96 million (federal and State) in 1975-1976 to a State budget alone of over $249 million (proposed) in 1980-1981.

California Policy

The State of California generally recognizes the value of noninstitutional services, but at the same time, maintains an enormous commitment to State facilities for persons with a mental illness or a developmental disability. As for older persons, funding and licensure of home health agencies has been in existence since the 1960s, and expenditures for In-Home Supportive Services are expected to continue to grow in recognition of an increase of case load and prevailing minimum wage rate. The State has recognized adult day health care as a licensable and Medi-Cal eligible service (in nonprofit facilities only) since 1977 (AB 1611). The State under AB 998 has established pilot projects for multipurpose senior services -- an attempt to provide continuity of care and optimum access to resources.

In 1978, the Legislature adopted AB 1586 which required the Department of Health Services to conduct at least two hospice pilot projects to establish regulations and levels of reimbursement for Medi-Cal recipients and to evaluate hospice care. Additionally, the Department is to report to the Legislature conclusions and recommendations concerning hospice care on at least the following issues:

- whether Medi-Cal reimbursement should be made available and, if so, recommended rates and regulations
• an assessment of the quality and cost-effectiveness of the use of lay person volunteers, hospice versus traditional care, and institutional versus in-home hospice care

• an assessment of the current and projected demand for hospice care including the need for construction of hospice facilities and/or use of existing facilities.

ANALYSIS OF DEMAND AND SUPPLY

Although common sense and demographic trends imply an increasing "need" for community support system services, analysis of demand for these services is hazardous. This is because demand for them is first a function of demand for the larger set of long-term care services and second, demand for any particular set of services in the total spectrum depends on policies and philosophies regarding appropriate settings and kinds of care, the kind and amount of financing available and knowledge concerning the available alternatives on the part of professionals, the general public and consumers. Demand here is, perhaps more obviously than elsewhere in the health system created by available resources rather than measurable according to population or utilization criteria.

Lacking a comprehensive methodology for estimating demand for long-term care* estimates for community support systems can begin with some crude and perhaps, self-evident guidelines:

• demand cannot be based on past utilization because availability has been limited or absent

• demand cannot be based entirely on prevalence of chronic illness or disability because the diagnostic or descriptive category does not indicate severity or care required

• at a minimum, some unknown proportion of the elderly, the chronically ill and the disabled will need community support systems

For a discussion of supply see Figures VIII-2 through VIII-6.

* See Long-Term Major Issue #5.
Figure VIII-2

HOME HEALTH AGENCIES

| Number: | in 1975, 122 home health agencies; rural areas tend to lack |
| People served: | in 1975, 93,000; potential target population, 1976 = 165,000 to 600,000 |
| Where: | 90 percent of services at home, 10 percent in other settings |
| Type services: | majority nursing, homemakers/aides second, occupational and speech therapists 12.5 percent of total (1973) |
| Financing: | Medicare, Medi-Cal, private |
| Financial barriers: | stringent Medicare requirements; Medi-Cal requires that rehab services be tied to skilled nursing services; limited private insurance coverage; a major problem |
| Cost: | under Medi-Cal, $100/month/recipient |
| Quality: | monitoring is State responsibility and quality is uneven |
FIGURE VIII-3

IN-HOME SUPPORTIVE SERVICES

Number: administered by 58 counties; services are provided by persons employed by the recipient, a contract agency, or by the county; approximately 15 contracts are with proprietary agencies and three with nonprofit agencies

People served: 71,000 (1977), of which 92.3 percent are recipients of SSI/SSP and 7.7 percent are fee eligibles. Potential State target population is 690,000+

Type services: domestic and related services, heavy cleaning, nonmedical personal care, assistance with travel, yard hazard abatement, protective supervision, paramedical services, and teaching and demonstration

Financing: Title XX, State General Fund

Financial barriers: little private insurance; fee schedule imposes significant financial obligation on recipients who do not receive welfare; personal property limitations

Cost: approximately $177/month per recipient (1977)

Quality: due to unique nature of most IHSS recipients, defining quality and specifying appropriate standards is difficult and involves a number of concerns with respect to necessity, relevancy and cost. Currently, Statewide efforts to minimize fraud, abuse, and inadequate service delivery involve the following: implementation of Statewide regulations regarding IHSS (eligibility, needs assessment and service delivery requirements); authorization for first line supervision by counties (although utilized to differing degrees throughout the State) and use of a standardized Statewide system for authorizing and making payments to individual service providers
ADULT DAY HEALTH CARE (ELDERLY) (AS OF JULY 1977)

Number: in December 1978, 11 centers in 4 counties; 10 counties have approved "county plans for adult day health centers"*

People served: average 387 per month (66 percent Medi-Cal)

Type services: social, psychological, therapeutic, medical

Financing: Medi-Cal since 1977; private

Financial barriers: no Medicare

Cost: $25/day/person, which includes all services for an 8-hour period; usual attendance is 3 time/week

Quality: surveys indicate high quality, lower rates of institutionalization, and high recipient satisfaction21

* AB 1611 requires establishment of county adult day health center councils and plans before centers can be licensed and covered by Medi-Cal.
Figure VIII-5

WORKSHOPS AND DAY ACTIVITY CENTERS (DISABLED) (July 1977)

Number: 322 known agencies, of which 283 self-classified as follows:

- 56 multiple program workshops
- 54 work activity center programs
- 32 single program workshops
- 27 rehabilitation center (medical) programs
- 22 activity center programs only
- 6 services to the blind
- 7 other vocational and developmental programs
- 13 other medically related programs
- 66 recovery home or other residential rehabilitative programs

People served: 26,000 (1976) total; 15,000 average; potential target population = 122,000; of those served, 67 percent = mentally retarded, 16 percent = emotional disabilities, 16 percent = physical disabilities

Type services: vocational and rehabilitation counseling work training, independent living skills training, social adjustment, sheltered employment.

Financing: for workshops

- 43 percent, Dept. of Rehab.
- 22 percent, Regional Centers
- 9 percent, public schools
- 7 percent, county
- 4 percent, mental health agencies

for activity centers:

- 15 percent, Dept. of Rehab.
- 47 percent, Regional Centers
- 11 percent, mental health agencies
- 8 percent, public schools

Financial barriers: fragmentation of sources; less than 40 percent are paid from above sources; gainful employment potential as an eligibility requirement for workshops (recently eliminated to accommodate deinstitutionalization of State hospitals)

Cost: $3,000/year average

Quality: voluntary accreditation required by the Department of Rehabilitation
CASE MANAGEMENT SERVICES

Number: virtually nonexistent, except for:

California Children's Services (CCS) for disabled children to age 21 and others over 21 with cystic fibrosis, hemophilia, and sickle-cell anemia

Department of Rehabilitation for its clients (max. 18 months)

personal physician (no permanent community referral/team care networks)

Regional Centers for Developmental Services (see Developmental Services Section)

20 Independent Living Centers

4 Multipurpose Senior Services Projects (pilot projects for coordination of services to elderly)
ANALYSIS OF ISSUES

All the long-term care issues discussed are relevant to community support systems. Aspects of particular importance are highlighted here, with accompanying service-specific recommendations. In addition, one issue specific to hospices is also identified. Issues include:

- inadequate supply
- fragmentation, lack of continuity of care
- comparison of costs
- appropriate regulation
- duplication of planning responsibility
- future of hospice care.

Issue #1: Inadequate Supply

Increasing the supply of community based services involves two major concerns: the purpose or role of alternatives and cost implications of increasing their supply.

The inadequate levels of availability of community based services is related to the multiple and sometimes confusing concepts of "alternatives." Indeed, specific proposals often evoke considerable debate as to whether it is meant to represent a preventive, substitutive or institutional alternative. Since continuous debates of this nature only serve to inhibit the growth of community based services, and thus the development of the full continuum, it is important that the State develop a policy consensus as to the role of alternatives. The nature of this consensus would be evident by the types of social and economic incentives which are developed for making available and utilizing such services.

The basic resource for increasing the availability of community support services is increased funding using appropriate reimbursement mechanisms and criteria. Scarcity and concern of public resources used for meeting human needs require a careful analysis of the program, as well as the fiscal consequences of expansion. For example, simply increasing the income eligibility for IHSS services, within current statutory and regulatory mandates, may have raised a number of issues each of which needs to be studied in more detail. Questions regarding changes in how earned and unearned income are to be treated, revisions in the criteria regarding the status of personal property holdings, and having
appropriate and incentives for attracting new providers of service are among those which would need to be examined. Consideration of whether the priority is to reach more client or to increase the services to existing clients would be critical to such an analysis. Finally, the income eligibility factor should be evaluated with respect to its impact on the provision of long-term care.

Fundamental changes in long-term care financing need to be undertaken not only at the State level but more importantly at the national level. Debate will be lengthy and new forms will probably not be instituted in the near future. The State should study this matter and be prepared to lobby for what it considers most appropriate to California's needs. In the absence of comprehensive federal legislation, California should move in the direction of identifying and removing technical barriers to increasing the availability of community support services, pooling existing federal and State funds and increasing funding where appropriate.

Issue #2: Fragmentation, Lack of Continuity of Care

Community support systems are currently fragmented, uncoordinated and client movement among various organizations and settings is difficult. Many State and federal agencies administer a multitude of categorical programs focusing on different services and/or specific groups of patients or clients and organized around particular types of funding. Usually no one agency is capable of supplying a range of services sufficiently diversified and flexible to meet the needs of the population at risk. No structure exists to ensure that the variety of resources are used in a consistent, comprehensive manner to effectively address the needs of those not eligible for Regional Center, Department of Rehabilitation, California Children's Services or Area Agency on Aging services.

Continuity requires a designated local agency with administrative responsibility for linking different services. Alternatives include:

- nonprofit community long-term care centers in each county or community to evaluate and certify need for services and offer these services directly or through arrangement with providers, similar to the Regional Centers model, or the multipurpose senior service projects being established; to maintain a continuous relationship with their clients; to be funded through a comprehensive program of long-term care benefits or through decategorization of funds and a variety of waivers of specific requirements of Medicare and Medi-Cal programs

- community long-term care centers on a prepaid basis; On Lok Senior Health Services in San Francisco is developing such a pilot program

- a State administered long-term care system which would provide entry, initial needs assessment and case management for patients receiving federal or State
funding; could be based on the existing system of field offices; would require changes in present law to permit greater flexibility and integration of services; or the development of a new funding mechanism at the federal level.

Improved information and referral programs at the county level would be helpful in disseminating information but would not provide the assessment and case management function.

**Issue #3: Comparison of Costs**

While providing community support services may be viewed as a desirable social policy it is less clear, and perhaps hazardous, to argue such services per se are cheaper. Exclusive reliance upon this argument is clearly inconsistent with one of the fundamental interests of the long-term care delivery systems of maximizing the return on the investment of public resources. This inappropriate focus further jeopardizes the already difficult task of directing resources towards the development of this segment of the service continuum.

A recent study concluded by the National Center for Health Services Research,\(^2^3\) which focused on the cost and use of homemaker and day care services as a substitute for other Medicare provided services, reported that contrary to earlier findings, day care services for the elderly may not be cost effective or prevent nursing home care. The model of day care evaluated in the study was admittedly oriented towards the health model (the other type being a social services model which the authors indicated similar study is needed). Also the author cautioned against generalizing their findings to a "real life" setting because of the unique characteristics of this study which limited its external validity. Such limitations apply to any study of a service not yet developed and in wide use. More importantly though, the general findings of the study further begs the resolution of two other related policy issues, namely, the function of "alternatives" and accepted measures of "cost-effectiveness." First, the phenomenon of using alternatives in addition to rather than in place of nursing home services, which occurred in the study, points out the previously mentioned need to clarify the intent or purpose of having alternatives. Are they meant to be substitutes for existing services or additional options from which to choose from? Secondly, more sensitive parameters of cost-effectiveness need to be identified. The fact that the aggregate dollar amount is comparatively more or less for a particular set of services should not be the sole criterion of determining desirable level of care. Rather long-term cost estimates should be related to a set of appropriate and expected outcomes of care.
Issue #4: Appropriate Regulation

There are risks associated with stimulating rapid expansion of services and implementing major program changes:

- agencies and programs can, with no regard for geographical distribution, develop estimates of the population at risk, utilization patterns and the capabilities of existing agencies to meet demands
- overuse of services can occur
- quality of care can suffer
- a dearth of qualified staff may result.

Community support services, like other types of services require appropriate mechanisms to minimize the adverse impacts of such risks. The debate around the increasing use of regulations involves concerns related to necessity, clarity and consistency. The suggestion that it may be more difficult to regulate a system of services which by design is less centralized and has less control over those elements which affect the lives of clients would seem to indicate that simply applying institutional health service regulations to community supports per se is not only inappropriate but possibly a waste of public resources.

Issue #5: Duplicated Planning

Numerous State and local agencies with overlapping concerns are engaged in planning for community based, long-term care services. The Department on Aging prepares an annual plan which includes funding home delivered meals, renovation of buildings for Multipurpose Senior Services, Adult Day Health Centers, information and referral systems, transportation services, ombudsman and other programs related to long-term care and support services for the elderly. The Department of Social Services prepares a comprehensive Annual Services Program Plan which includes plans and funding for In-Home Supportive Services. The Adult Day Health Program sets up planning councils in each county which plan for services independently of the overall health planning carried out by the HSAs.

Available data are not comparable and current collection procedures are uncoordinated and inappropriate for planning.

Issue #6: The Future of Hospice Care

The future growth and development of hospice care will undoubtedly be affected by State and federal policy decisions regarding three areas of current debate:
• the degree to which hospice care is integrated with the existing health and human care system

• the scope of service, including those support types which are essential to the hospice philosophy, which should be reimbursed through public and/or private sources

• the extent and nature of the standards and criteria of care which need to be developed to provide an effective framework for hospice operations.

Programatic concerns regarding the necessity for new facilities, the nature and levels of public reimbursement and the scope of program accreditation, including appropriate training of personnel, should be the focus of such policy determination.
POLICY RECOMMENDATIONS FOR COMMUNITY SUPPORT SYSTEMS

Long-Term-9: THE HEALTH AND WELFARE AGENCY SHOULD WORK TO ELIMINATE BARRIERS TO THE USE OF EXISTING ALTERNATIVE, COMMUNITY SUPPORT SYSTEMS, INCLUDING:

- REVISION OF MEDICARE AND MEDICAID TO CREATE UNIFORM HOME HEALTH BENEFITS; RELAX RESTRICTIONS THAT PERMIT ONLY SKILLED NURSING SERVICES IN CERTAIN SITUATIONS; PERMIT NONMEDICAL PERSONAL CARE AND SUPPORT SERVICES TO THE CHRONICALLY ILL AND DISABLED AT HOME; AND INCLUDE DAY HEALTH CARE AND HOSPICE CARE

- INCLUSION OF HOME HEALTH CARE AND OTHER IN-HOME SUPPORTIVE SERVICES IN PRIVATE INSURANCE COVERAGE

- APPLICATION OF FUNDS POOLING CONCEPT FOUND IN MULTIPURPOSE SENIOR SERVICES PROJECTS, TO DEVELOP AN INTEGRATED REIMBURSEMENT SYSTEM WHICH WOULD TIE THE PAYMENT FOR SERVICES TO AN ASSESSMENT AND CASE MANAGEMENT SYSTEM.

- ANALYSIS AND RECOMMENDATIONS REGARDING THE IHHS NEEDS MIDDLE INCOME PRIVATE DAY PATIENTS NOT CURRENTLY ELIGIBLE FOR TITLE XX ASSISTANCE.

Pending federal action on long-term care financing, some beneficial "patchwork" and indepth analysis can be done at the State level.

Long-Term-10: THE DEPARTMENT OF HEALTH SERVICES SHOULD TEST THE FEASIBILITY AND COST-EFFECTIVENESS OF PROVIDING PERSONAL CARE SERVICES UNDER THE MEDI-CAL PROGRAM (TITLE XIX) IN LIEU OF IN-HOME SUPPORTIVE SERVICES PROGRAM (TITLE XX).

Under the mandate of AB 124, the Department of Health Services will conduct pilot projects to provide personal care services to disabled and elderly persons that include an examination of the effects of fragmentation and coordination of these services.
Attention will focus on alternative means of service provision, as well as identifying those factors essential to defining and measuring "cost effectiveness".

**Long-Term-11**: THE DEPARTMENT OF REHABILITATION SHOULD ADVOCATE AND PLAN FOR INCREASED APPROPRIATIONS UNDER P.L. 95-602 TO PROVIDE FOR COMPREHENSIVE REHABILITATION CENTERS AND EXPANDED COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING, SHELTERED WORKSHOPS AND ACTIVITY CENTERS.

Only a small proportion of disabled persons can receive services under current appropriations.

**Long-Term-12**: THE HEALTH AND WELFARE AGENCY SHOULD DOCUMENT THE IMPACT OF FUNDING COMMUNITY ALTERNATIVES ON STATE EXPENDITURES AND THE HEALTH STATUS OF BENEFICIARIES OVER THE NEXT FIVE YEARS.

Funds for community support systems may be an addition to or a replacement for current expenditures. Their impact should be studied and justified by all agency departments.

**Long-Term-13**: THE STATE SHOULD ADVOCATE THAT CONGRESS ELIMINATE TITLE XX EXPENDITURE CEILINGS AND INCREASE TITLE XX FUNDING FOR IN-HOME SUPPORTIVE SERVICES.

Title XX funds are central to improved access to alternative, community services.

**Long-Term-14**: THE DEPARTMENT OF SOCIAL SERVICES SHOULD CONSIDER THE USE OF TITLE XX FUNDS FOR TRAINING AND SUPERVISION OF CERTAIN CATEGORIES OF IN-HOME WORKERS.

This would improve the quality of care by increasing knowledge about the special needs of elderly and disabled persons.

**Long-Term-15**: THE OSHPD SHOULD ENCOURAGE AND PROMOTE ESTABLISHMENT OF MECHANISMS FOR COORDINATING THE PLANNING FUNCTIONS OF ALL AGENCIES WITH PROGRAMS IN LONG-TERM CARE TO ENSURE CONTINUITY AND CONSISTENCY.
If long-term care is to be a "continuum" of services and patients are to move freely from one point to another depending on their needs, planning must be better integrated.

**Long-Term-16:** THE STATE SHOULD ENCOURAGE AND PROMOTE THE DEVELOPMENT OF HOSPICE CARE CONSISTENT WITH POLICY DETERMINATIONS PERTAINING TO: AN APPROPRIATE RELATIONSHIP TO THE HEALTH CARE SYSTEM; ADEQUATE REIMBURSEMENT; AND NECESSARY STANDARDS AND CRITERIA.

State recognition of and financial support for hospice care is necessary to assure its availability and accessibility.

**Long-Term-17:** ADDITIONAL STUDIES RELATING TO THE NEED FOR CONSTRUCTION OF HOSPICE FACILITIES AND/OR USE OF EXISTING FACILITIES SHOULD INCLUDE AN ASSESSMENT OF THE ECONOMIC AND FINANCIAL IMPACTS ON THE PROVISION OF CARE.

The results of the current pilot project studies may only address this issue on a general basis. Further research of this issue should be supported if it will provide viable information relating to policy and reimbursement issues.
NURSING CARE FACILITIES: SKILLED AND INTERMEDIATE CARE

DEFINITIONS AND SCOPE OF SERVICES

Nursing care facilities comprise that portion of the long-term care continuum which provide 24-hour inpatient service, including medical and nursing supervision.

**Skilled Nursing Facility (SNF):** Licensing regulations of the Department of Health Services define a skilled nursing facility as a health facility or a distinct part of a hospital which provides skilled nursing care and supportive care to patients whose primary needs are for availability of skilled nursing care on an extended basis. It provides 24-hour inpatient care, and as a minimum, includes medical, nursing, dietary, pharmaceutical services and an activity program. The facility must have effective arrangements, confirmed in writing, through which services required by the patients, but not regularly provided within the facility, can be obtained promptly when needed. Skilled nursing facilities may be freestanding or a part of a hospital.

**Intermediate Care Facility (ICF):** Licensing regulations of the Department of Health Services define an intermediate care facility as a health facility, or a distinct part of a hospital or skilled nursing facility, which provides in-patient care to patients who have need for skilled nursing supervision and need supportive care, but who do not require continuous nursing care.

These two categories of facilities may be further differentiated by the inclusion of special programs designed to meet the special needs of persons with developmental disabilities or mental disorders. The requirements for these services are found in Chapters 3 and 4, Division 5, of Title 22, California Administrative Code.

BACKGROUND

**Relationship to Health Status**

Institutional care is required for long-term care patients who require skilled nursing on an extended basis or supervision on a 24-hour basis. Nursing care facilities also provide places for convalescence for those needing the sophisticated resources of a hospital. With adequate rehabilitative resources, many other long-term care patients can be rehabilitated enough to live at home. For those who must remain in an institutional setting, care can be provided in as homelike a setting as possible while preventing deterioration of health as long as possible. However, present legislation relating to long-term care fosters institutional placement rather than services in a less restrictive environment.
National Trends

The enactment of Medicare and Medicaid dramatically increased the availability of public financial assistance for nursing home care and subsequently caused a major increase in the number of nursing home beds. From 1967 to 1973, the number of nursing home beds in the U.S. doubled. The 1977 National Nursing Home Survey estimates that some 18,300 nursing homes had a total of 1,383,600 beds and served 1,248,400 residents.

These two programs, through their financial incentives for nursing home care, have caused such care to become the principal setting for delivery of long-term care services to the elderly. Of all residents in nursing homes in 1974, 90 percent were 65 and older. The use of nursing homes has also increased as utilization review in acute hospitals forced earlier discharges.

Increasing use and national inflation have caused federal expenditures in this area to increase rapidly. Expenditures for nursing homes, while accounting for only 7.6 percent of health care spending in 1976, have grown at a rate of 21 percent a year since the enactment of Medicare and Medicaid, compared to 16 percent per year for the previous ten years. Estimates from the Congressional Budget Office indicate that based on present law and funding patterns, the number of persons in SNFs and ICFs will grow from 1.3 million in 1976 to 2.5 million in 1985 a 92 percent increase, if no changes in law or funding patterns occur.

Escalating use of long-term care is causing great concern that persons in need of such services be placed at the most appropriate level of care, including institutional, protected residential and independent living arrangements. At the core of this trend is the assumption by some national researchers that many elderly persons are currently at inappropriate levels of care, generally higher than their needs require. In an effort to measure existing placement status and determine future needs, many groups have developed placement classification systems which attempt to consider the totality of a person's needs -- social and personal as well as medical and nursing. Numerous studies have documented inappropriate placement, ranging up to 50 percent and more, of persons in institutional care, primarily due to lack of adequate alternatives.

National attention has long been focused on the quality of care in nursing facilities. The U.S. Senate Subcommittee on Long Term Care identified such problems as patient abuse, substandard physical characteristics, poor medication control and inadequate professional nursing availability, while the U.S. Office of Nursing Home Affairs identified prevalent failures as:

- governing bodies not meeting obligations
- patient care policies lacking professional input
Concern for cost, quality and inappropriate placement has stimulated widespread attention to noninstitutional forms of long-term care and a host of new federal and State activities.

National Policy

As noted above, national policy has changed direction over the last ten years. The intent of Medicare and Medicaid was to facilitate access to institutional care, i.e., nursing home services, for the elderly. The result was rapid growth in the industry accompanied by problems such as those cited above by the U.S. Senate Subcommittee on Long-Term Care. In reaction, legislation and fund allocations have begun to shift toward outpatient and in-home services. The Older Americans Act of 1965, amended throughout the 1970s, has expanded the mandate for the Administration on Aging, broadened research and program activities and created State and area councils. The Office of Nursing Home Affairs is now a focal point for long-term care and aging within the Public Health Service. The National Institute on Aging was established in 1974 and there has been a marked increase in programs throughout the various governmental agencies oriented toward aging. From 1971 to 1975, the research appropriations for aging and long-term care within DHEW increased three and one-half times. Through its Special Committee on Aging, the U.S. Senate has been one of the most active participants in this policy changing process.

California Trends

In California, the growth in nursing home facilities has paralleled that of the U.S. While it appears, nationwide, that a much larger proportion of facilities and beds are certified for intermediate care (45 percent of those certified in 1976), the extent of this variance may partially be due to differences in licensure and reimbursement policies. In California, there were about 3,339 ICF beds and 108,000 SNF beds in 1977.

The population 65 and over, the heaviest user of nursing homes, is increasing and becoming more evenly distributed. In 1970, the elderly made up 9.0 percent of the State's population, while in the central cities they were 10.1 percent of the total residents. In 1970, there were six counties with 14 percent or more elderly, and ten such counties in 1977. It is estimated that by 1984 there will be 12. These shifts in population distribution indicate an increasing number of older persons in the less populous rural areas — areas where health care is already apt to be too far for easy access by residents.

Under amendments to the California Health Facilities Disclosure Act, the California Health Facilities Commission is responsible for the development and implementation of an
accounting and reporting system for long-term care facilities. Nursing homes were required to file financial reports according to new accounting procedures after January 1, 1977. Information from these reports will enable the State to develop reimbursement rates in a rational manner.

A draft report of costs in California Long-Term Care Facilities\textsuperscript{37} showed the following:

- during 1974, 1975 and 1976 overall costs increased from $570.2 million to $736.5 million
- over 60 percent of the facilities are concentrated in the urban areas of the State (HSAs 4, 5, 11, 13 and 14) which account for nearly 70 percent of the total expenditures
- annual statewide increases have averaged 13.6 percent since 1974. Certain individual counties show smaller increases in aggregate facility costs than the State total, but ten HSAs show high increases in one or both of the last two years. These increases may be attributed to changes in government regulations, additions or deletions in the number of facilities operating in a given period, or utilization changes
- the highest and lowest cost per capita for 1976 in the HSA groupings occurred in East Bay HSA (Area 5), $41.12, and Ventura/Santa Barbara HSA (Area 10), $23.83, respectively. County cost per capita for 1976 ranged from a high of $58.19 in Modoc County, to a low of $14.89 in Tuolumne County
- per capita expenses had an average annual increase of 12 percent since 1974, and has generally increased proportionately to total expenditures.

California Policy

Nursing home care has been a long-standing public policy issue for the State. Medi-Cal financing is continually alleged by the industry to be too low, while the quality of care in some facilities is continually deemed by the State to be unacceptable. The resulting confrontation has produced a great deal of regulation and not very much improvement. The State is beginning to develop other types of long-term care services in response to this and other findings relating to either unnecessary use or inappropriate settings for the delivery of skilled nursing services. Yet substantial investment of public resources for the institutional models of long-term care remains.

The advent of such commitments has been paralleled by the creation of various State programs to oversee particular aspects in the provision of these services. Programs for certifying institutional providers, conducting utilization reviews, controlling fraudulent
and abusive actions, reviewing the need for and desirability of additional institutional health services, and collecting facility cost data are among those which are mandated by current State policy.

ANALYSIS OF DEMAND AND SUPPLY

Analysis of Demand

As with community support systems, the demand for SNF and ICF services is a portion of the total demand for long-term care services. Here again, neither total nor proportion is known.

However, since changes in use and investment in new SNF and ICF facilities require State approval under certificate of need, a proxy measure of demand "need" is used. In the past, resource requirements have been determined simply by projecting past utilization to future population projections and converting this figure to a specified amount of beds through the use of a desired level of occupancy for long-term care facilities. Most HSAs have attempted to mitigate some of the major shortcomings of this method through the use of State approved alternative methods and rates. The result is that the Statewide Health Facilities and Services Plan has projected a need for over 112,000 skilled nursing care and 7,800 intermediate care beds by 1985. Based on 1977 inventories this will require an additional 4,200+ SNF and 3,660+ ICF beds, respectively, statewide.

More recently though, the OSHPD, in conjunction with HSAs, has revised its method for determining resource requirements. Historical utilization is now more appropriately used as a starting point by targeting an "initial" future utilization projection. HSAs, in response to local needs and circumstances, are then able to adjust this projection. Both internal and external forces affecting the health system such as changes in population characteristics, information from PSROs and Medical/Social Review Teams regarding inappropriate utilization, changes in reimbursement or discharge policies are but a few examples of factors HSAs can consider. An estimate of resource requirement (beds) needed to meet the desired level of utilization is then made using a method which selects an appropriate occupancy rate as a function of an acceptable waiting time.

This represents the most comprehensive change in the way long-term care bed need estimates are determined in California since the inception of the demand based formula. This new approach not only recognizes program differences within skilled nursing and intermediate care beds, it also allows HSAs to account for problems such as lack of access to existing beds by Medi-Cal patients, serious differences in quality among facilities in the same service area and inappropriate placement.
Some facts about the population using SNFs are available:

- for FY 1976-77, there were 14 skilled nursing patients for every 1 intermediate care patient; this compares to the national ratio for the same group of patients in 1974 of approximately 1 to 1.41

- 10 to 20 percent of the population in skilled nursing facilities are convalescent; i.e., primary diagnosis of recent cardiovascular accident, or complications from a fracture; these patients have a high degree of rehabilitation potential and usually have a length of stay of less than three months.42

- other patients in the skilled nursing facilities, 80 to 90 percent at any one time, are long-term care chronic disease individuals, i.e., chronic brain syndrome or disorders of the circulatory condition; their primary need is for personal care and supervision on a daily basis; the average length of stay is two to three years.43

Analysis of Supply

Average SNF capacity in 1977 (latest data) was 90 percent. In only 1 out of 14 HSAs was the State standard of 95 percent occupancy reached, while 10 out of 14 reached 90 to 94 percent and the other 3 between 85 and 90 percent. Given the current pattern of utilization, the SNFs are reaching capacity. An ICF utilization analysis indicates that only one HSA has an annual occupancy of 95 percent or higher. Only three HSAs have annual occupancy rates of between 90 and 94 percent. The remaining HSAs indicate an occupancy range of between 65 and 89 percent.44 The low utilization and supply of ICF beds is directly related to the current low Medi-Cal reimbursement.

Intermediate care beds are not currently available in most areas of the State and almost all HSPs have recommended the expansion of these facilities and services.

ANALYSIS OF ISSUES

Again, most of the major long-term issues are applicable to nursing care facilities. The form these issues take in the nursing home setting creates the following "service-specific" issues:

- appropriate placement
- quality of care
- cost
- resource growth.
One critical nursing care issue which cuts across these four is that of:

- access for indigent clients.

**Issue #1: Appropriate Placement**

SNFs and ICFS have an essential role in the spectrum of long-term care; however, there is an over reliance on these institutions. Reasons for inappropriate use include lack of family and/or community based alternatives, financing incentives that favor institutional care (or require it before other services can be used), and possibly some measure of "Roemer's Law" (bed use expands to fill available beds). A growing body of evidence suggest that were adequate alternatives available many people who are currently being institutionalized could be cared for without utilizing nursing homes.45.

At the same time, it cannot be forgotten that some patients will always require institutional care. One such group includes the extremely elderly, the chronically and severely disabled and people with serious behavioral problems. Another group is made up of postacute patients who no longer require 24-hour hospital care but who do require 24-hour nursing care and usually some significant rehabilitation: the classical "Extended Care" patient. Many such patients, currently in acute care hospital beds, are finding it increasingly difficult to be placed in a less expensive and more appropriate "extended care/subacute" type of setting. In the drive to correct the abuses of institutional placement, the needs of certain people for communal environments offering health care services cannot be overlooked.

Two basic responses to the general problem of inappropriate placement are possible. One is to encourage flexible levels of care within institutions such that inpatients can receive services at suitable levels and intensities, changing as patient condition changes but not requiring transfer to another source of care. Many multilevel institutions currently offer this type of comprehensive service, usually at a premium price and often requiring a "life care contract." The other is to develop case management capability to see the home-based patient through a network of different services, the appropriate mix at a given time to be tailored to the current situation. In fact, both options are necessary if the patient is to be treated properly.

The Department of Health Services already has the ability to revise its Medi-Cal reimbursement policies and rates in order to assure the acute care hospitals that they will be adequately compensated while they are actively seeking placement of patients in skilled nursing facilities. The problem of "difficult-to-place" acute hospital patients and total care skilled nursing facility patients, i.e., "heavy care," may also necessitate pilot programs whereby the Department could designate and appropriately reimburse underutilized general acute care beds as extended care/subacute beds. Permanent conversion of licensed general acute care beds may eventually be necessary so that such pilot projects would not result in a net increase in areas currently demonstrating excess bed capacity.
**Issue #2: Quality of Care**

Two problems with personnel continue to pose barriers to high quality care in SNFs and ICFs: inadequate physician care and poorly trained, underpaid nursing personnel.

While it is very difficult to evaluate the quality of physician services in nursing homes, there is mounting evidence of problems with physician care. While many physicians have a serious commitment to providing continuing care for patients they have been seeing for years even after those patients are institutionalized, they are reluctant to pick up new nursing home patients whom they have never seen before. Economic reasons proposed to explain why physicians avoid SNF/ICF patients are that special trips to nursing homes are inconvenient, time consuming and not reimbursed at adequate levels.

Thus, one very basic problem is simply the difficulty of locating a doctor willing to make regular visits to those patients. A recent study found that among the physicians studied, only 14 percent provided care to patients in SNFs and ICFs and only 6 percent of those serving such facilities were involved in more than 2 of them. Reasons for this include reimbursement disincentives (see Chapter III, Policy Issues #2 and #3) and lack of knowledge of or exposure to gerontological medical care. The results are well known: incomplete records, inappropriate orders, and high level of postadmissions, iatrogenic problems (see Chapter III, Policy Issue #1). While private patients may not experience difficulties with physician care, the problem is acute for the 70+ percent on Medi-Cal.

The working conditions and salaries of all nursing home personnel also have a bearing on the quality of care. Aides as well as nurses are underpaid compared with their colleagues in acute and State hospitals. Despite recent legislation certifying nurses aides and raising their salaries slightly, the average salaries for all workers (not just nurses aides) in SNFs and ICFs are still substantially lower than salaries in general acute and State hospitals. Administrators report they are unable to pay better wages or hire additional staff due to low rates of Medi-Cal reimbursement. Consequently, nursing homes have difficulty hiring and retaining experienced, motivated staff.

The federal requirement for long-term care facilities to have a medical director, if implemented effectively, could contribute to an improvement of the quality of the medical care patients receive. Requiring certification of nursing assistants may also upgrade and enhance the self-image of personnel in SNFs. If programs such as these continue with adequate funding an improvement in the quality of care may be possible.
Issue #3: Cost

Cost reforms in paying for institutional care are virtually inseparable from the need for deinstitutionalization and appropriate placement. If patients were properly located in the system, and if reimbursement were case based, both the willingness and resources to improve reimbursement might increase.

Nevertheless, it may be repeated: reimbursement of reasonable costs under Medicare and Medi-Cal is a longstanding issue for the industry. Expiration of the Medicare benefit and the per diem Medi-Cal payment are continually cited as the origin of a multitude of problems, including lack of access for Medi-Cal patients (see Issue #5), poor quality of care, and "institutional treatment."

The inflation engendered over the last ten years by cost-based reimbursement in hospitals is the primary obstacle to instituting cost-based reimbursement in nursing homes. This precedent, plus current rates of inflation in per diem reimbursement and the impact of Proposition 13, make cost based reimbursement under Medi-Cal a very remote possibility.

More recently, the Department of Health Services submitted proposed amendments to the State's Medicaid plan for DHEW consideration which would establish annual prospective rates for reimbursement for skilled nursing and intermediate care services. Payment rates would be established for various classes of providers on the basis of the following criteria: levels of care (SNF or ICF); the number of beds (1-59, 60-299, and 300+); except for ICF-DD which would be 1-59, 60-99, 100-299 and 300+ to recognize programmatic differences); and specified geographical locations (1. San Francisco, Marin Alameda/Contra Costa, Santa Clara and San Mateo counties, 2. Los Angeles County and 3. All other counties) for freestanding SNF and ICF bed sizes of 1-59 and 60-299 (the 300+ facilities, distinct parts of acute care facilities and ICF-DD facilities are excluded from this last criteria). The proposal also provides procedures and criteria for adjusting the rates primarily to reflect changing conditions of the economy. The proposal's sensitivity to the changing status of the economy and its intent of creating a reimbursement mechanism to support the 300+ bed facilities holds much appeal. However, concerns for general cost containment in the health care area, the possible adverse affects on small facilities, existing interest in other alternative criteria and procedures for establishing such rates all may affect the final outcome of DHS's proposal.

Issue #4: Resource Growth

Future resource growth of this part of the long-term continuum must be disaggregated into a short range and long range perspective.
The short range perspective relates to those concerns involving the development of SNF and ICF resources which have been locally determined and subsequently approved by the State. This approval is represented by the Statewide Health Facilities and Services Plan, 1980-1985 and is intended to serve a number of specific purposes including:

- the provision of a summary of the supply and distribution of existing California health facility and service resources
- the projection of health facility and service resources required in California by 1985
- the implementation of State health planning policies by providing one of the bases for State and local certificate of need decision making.

The strategies of conversion and consolidation are two of the most widely discussed options for putting additional needed beds into service. While they are motivated by health planning's interest in cost containment, their implementation is stymied by those very same interests. Indeed, appropriate mechanisms and incentives which address such factors as existing and future investment, along with existing and desired physical environmental characteristics of facilities, must be developed which are consistent with the policies of cost containment.

The long range concerns for resources growth relate to the appropriate implementation of those new methods for estimating needed resources which were described previously. These new methods allow adjustments in the projected future rate of utilization based on factors which are local in nature. Clear identification and documentation of such factors, will be largely dependent upon the information and data which the HSAs, and ultimately the State, has access to. Current and expected information about long-term care in health facilities are gathered through annual reports to OSHPD, financial reports to the California Health Facilities Commission, utilization reviews of medical social review teams of Department of Health Services and PSROs. While improvement in data from these sources will promote better planning they alone may not be sufficient to provide the specific policies and identification of needed resources to sufficiently follow through with the commitment of developing the full continuum of long-term care services.

Issue #5: Access for Indigent Clients

In many parts of California, patients whose care is reimbursed by the public needing extensive nursing care, have considerable difficulty in gaining access to skilled nursing facilities (SNFs). Limitations reflect both a lack of beds and restricted access to existing beds due to source of payment.

The problem of inadequate access for indigents to skilled nursing facilities is a compound problem, with few statewide data to pinpoint its dimensions. The problem is complicated
because of major differences between geographic regions. For example, 6 percent of the SNFs in the State had no Medi-Cal patient days in 1977–78, but in San Francisco this figure was 29 percent. Unnecessary hospital costs for persons who need only SNF care are estimated to be over $10 million per year for Medi-Cal and over $17 million per year for Medicare. In a few places, particularly the Bay Area, many clients have to be placed at a considerable distance from home. Around the State, the greatest difficulty in placing clients occurs when heavy nursing care is needed. The major urban areas have county skilled nursing facilities which serve as a last resort for this type of patient. Because county facility costs are at least double what Medi-Cal pays for SNF care, the facilities are a financial burden on county government. A further result of the shortage of SNF beds is that some patients receive poor quality care since competition has been reduced. With little competition, inferior homes continue to operate and some persons receive inappropriate care at home because they cannot gain access to a nursing home. Finally, the current situation is unfair to those facilities that accept public pay clients, to private pay clients who are subsidizing public pay clients, and to the public pay patients themselves whose health is threatened simply because of the source of reimbursement for their care.

The unavailability and lack of access to nursing homes for public pay patients has a complex set of causes. Historically, government policies have resulted in a nationwide excess of demand over supply of nursing home beds. In a sense, this scarcity has been a conscious choice, a tolerable consequence of keeping costs down. In another sense, the scarcity results from failure to develop alternative methods of long-term care and reliance on fee-for-service and operator choice in an otherwise controlled market. The effects of those health planning policies, which fostered an inadequate need assessment formula and unreasonably high occupancy level requirements, also have contributed to a shortage of beds overall and an operator preference for private pay clients. Throughout the nation, but especially in California, there is a shortage of intermediate care facility beds, fostering inappropriate use of SNF beds for patients needing a lower level of care. High financing and operating costs and a flat rate reimbursement system pegged to median costs also reduce availability of beds and put a premium on private pay patients who allow operators to make a profit. Finally, in major urban areas the threat to county operated nursing homes posed by Proposition 13 cutbacks and the flat rate reimbursement system ignores the special role these facilities play in serving the sickest and least wanted patients.

Solutions for alleviating the shortage of beds for public pay clients have been proposed, both those of a long run nature as well as those meeting the current crisis. Many of these are encompassed within this Plan’s discussion of long-term care issues relating to the development of other alternatives within the service continuum, changes in the reimbursement system, and altering the supply of beds. A fourth general approach, which was the focus of a recent paper from the Assembly Office of Research, is for the State to more directly influence operator decisions concerning patient admissions.
This tactic would focus on two current State programs: certificate of need and licensing. Specifically, it was suggested that the necessary statutory basis be created to make more explicit the authority to require a specification of the percentage of Medi-Cal recipients that each new facility would serve. The paper concluded that it made sense to apply access requirements during the certificate of need process because:

- the certificate of need is in essence a special license to meet health needs in a given area. If the needs are for public pay beds, then the "license" should reflect this fact
- since the determination that Medi-Cal patients must be accepted, and in what proportion, is made prior to an entrepreneur's final decisions to go ahead with the project, the requirements cannot in any way be construed to be confiscatory
- the certificate of need process is intended to consider public social value related to the issues of equity. The licensing process is a less appropriate method for achieving these kinds of social values.

With respect to regulating access through licensing, it was proposed that California follow the New Jersey approach of adopting a regulation that requires SNFs to accept a "reasonable proportion" of Medicaid patients as a condition of licensure. In practice this has been construed to mean 10 percent or more. Though such an approach is considered technically possible, it was felt that it would have minimal impact on the problems of access and availability if done in isolation from other measures designed to increase the bed supply and address the needs of heavy care patients. The paper concluded that it would be more appropriate to attempt to implement a combination of other reimbursement and planning measures before further pursuing an access requirement as a condition of license.

The approach of regulating access raises a number of questions which warrant further discussion and deliberation. Concerns regarding the impact on multilevel facility programs, the types of authority and resources necessary for implementation and the potential for effectively alleviating the problem of access for indigent clients are a few of the questions to be considered.
POLICY RECOMMENDATIONS FOR SKILLED NURSING FACILITIES

**Long-Term-18**: THE POTENTIAL EFFECTIVENESS OF CASE MANAGEMENT SERVICES SHOULD BE ANALYZED AND, IF DEMONSTRATED, SUCH SERVICES SHOULD BE MADE AVAILABLE TO ALL RESIDENTS OF SNFS AND ICFs IN ORDER TO ASSURE ACCESS AND APPROPRIATE USE OF THE FULL RANGE OF LONG-TERM CARE SERVICES.

Consistent with recommendation LTC-3 residents of SNFs and ICFs should not be denied access to other long-term care services simply due their current setting. Linkages to other levels of services and living arrangements are critical to the appropriate use of institutional care.

**Long-Term-19**: THE OSHPD AND THE DEPARTMENT OF HEALTH SERVICES SHOULD JOINTLY UNDERTAKE A PROGRAM TO IDENTIFY ACUTE BEDS SUITABLE FOR RECLASSIFICATION AS ICF BEDS — THE FORMER FOR THE HARD TO PLACE AND POSTACUTE PATIENT AND THE LATTER FOR THE BED PATIENTS NOT REQUIRING SNF LEVEL CARE—AND THAT BOTH WORK TO ENSURE REIMBURSEMENT ADEQUATE FOR THESE LEVELS OF CARE.

Since both agencies have an interest in using existing bed capacity in the most appropriate manner necessary, authority and resources for such an undertaking should be developed. It should be noted the Long-Term Care Task Force of DHS is currently studying the feasibility of developing standards for Extended Care Facilities or other needed levels of care. Such an approach may require new authority and additional resources for implementation.

**Long-Term-20**: THE LEGISLATURE, THE DEPARTMENT OF HEALTH SERVICES AND OTHER STATE AGENCIES SHOULD TAKE NECESSARY STEPS TO ENCOURAGE FULL USE OF NURSE PRACTITIONERS AND PHYSICIAN ASSISTANTS IN SNFS AND ICFs AND TO REMOVE ANY BARRIERS TO THEIR PRACTICE AND FOR APPROPRIATE MEDI-CAL AND MEDICARE REIMBURSEMENT IN THESE FACILITIES.

The expanded use of PAs and NPs to provide medical services to LTC patients who, for one reason or another, have not had the full interest and attention of physicians is a "natural." Under existing practice laws, working under protocols in collaborative arrangements with physicians, they can provide much needed services. However, reimbursement modes need to be clear and any remaining inhibitory facility regulations should be modified.

Even adequate fee-for-service reimbursement may not secure necessary physician supervision of SNF/ICF patients. A task force of DHS is currently studying this issue with respect to concerns for quality and cost containment.


Poorly paid employees in nursing care facilities have become virtually synonymous with poor quality care. If some use declines as community resources become available, in theory, funds would be freed to improve wage scales.

Long-Term-23: DEPARTMENT OF HEALTH SERVICES SHOULD ELIMINATE THOSE SNF/ICF REGULATIONS THAT DISCOURAGE A HOMELIKE ATMOSPHERE AND DO NOT SIGNIFICANTLY CONTRIBUTE TO QUALITY OF CARE.

Unnecessary regulation is often cited as one factor contributing to the adverse effects associated with institutional care.

Long-Term-24: THE NURSING FACILITY INDUSTRY, THE UNIVERSITY OF CALIFORNIA HEALTH PROFESSIONS SCHOOLS AND THE STATE UNIVERSITY HEALTH PROFESSIONS DEPARTMENTS DEVELOP A COORDINATED PROGRAM TO ENABLE ROTATION OF HEALTH PROFESSIONS STUDENTS AND RESIDENTS THROUGH LONG TERM CARE SETTINGS, BOTH INSTITUTIONAL AND COMMUNITY BASED, ESPECIALLY RESIDENTS IN INTERNAL MEDICINE, FAMILY PRACTICE, GYNECOLOGY, ORTHOPEDICS AND PSYCHIATRY.

All health professionals — physicians, nurses, dentists, pharmacists, etc. — will be dealing increasingly with elderly and disabled people as the population ages. All should be acquainted with the medical problems and full spectrum of service resources for these groups.
Long-Term-25: THE POLICY OF HSAS AND THE OSHPD STRIVING TO ALLEVIATE EXISTING SNF AND ICF BED SHORTAGES AND DEMONSTRATED LOCAL ACCESS PROBLEMS THROUGH CONVERSION OF ACUTE (TO SNF) AND SNF (TO ICF) BEDS NEEDS TO BE COMPLEMENTED WITH APPROPRIATE FINANCIAL INCENTIVES AND INDUCEMENTS.

Creating those financial mechanisms which will make this approach feasible, and therefore appealing to providers of institutional care, should be given high priority.

Long-Term-26: THE LINKAGES AND COORDINATION WITH OTHER ALTERNATIVES WITHIN THE LONG-TERM CARE SERVICES CONTINUUM SHOULD BE CONSIDERED IN CERTIFICATE OF NEED REVIEWS INVOLVING A CHANGE IN THE SUPPLY OF NURSING HOME BEDS.

Opportunities for developing those linkages among the various services and settings need to be pursued so as to achieve a reasonable balance among such options.

Long-Term-27: THE OSHPD AND DEPARTMENT OF HEALTH SERVICES SHOULD COORDINATE ACTIVITIES IN REVIEWING LEVELS OF CARE UTILIZATION, CURRENT PLACEMENT CRITERIA AND OPTIMAL PLACEMENT CRITERIA FOR PURPOSES OF DEVELOPING THOSE RESOURCES NECESSARY FOR THE FULL RANGE OF LONG-TERM CARE SERVICES.

A policy commitment to appropriate use of institutional care will require the joint sharing of ideas and information among those agencies which have program mandates relating to long-term institutional health facilities.

Long-Term 28: FACILITATING ACCESS TO LONG-TERM INSTITUTIONAL HEALTH FACILITIES FOR INDIGENT PERSONS SHOULD BE ADDRESSED BY THE LEGISLATURE.

Policy direction for alleviating this problem is needed so that agencies responsible for planning, licensure and reimbursement can take appropriate and coordinative action. The strategy of regulating access either through the certificate of need review process or as a condition of licensure needs careful consideration with timely input from interested parties.
DEFINITIONS AND SCOPE OF SERVICES

Alternative Living Arrangements represents those services that enable persons with long-term care service needs in maintaining suitable residential arrangements in the community. Specific programs discussed within this context are residential care, assisted living arrangement programs and independent living programs.

Residential Care is that part of the continuum of long-term care that provides "twenty-four hour nonmedical care to persons in need of personal services, protection, supervision, assistance, guidance, or training essential for sustaining the activities of daily living or for the protection of the individual."49

Residential care facilities (RCFs) are classified as small family homes (serving six or fewer clients); foster family homes (serving six or fewer foster children); large family homes (serving seven to twelve children up to age 18 or seven to fifteen adults); group homes for children and adults; and social rehabilitation facilities (serving exoffenders and persons being rehabilitated from alcohol and drug addictions). RCFs serving six or fewer persons can be located in any area zoned for single family dwellings.

Assisted Living Arrangement Programs, often referred to as "congregate housing" or "assisted residential living," provide an environment that enable persons who would have difficulty living independently to avoid or delay confinement in institutions. Congregate housing is viewed as another type of alternative living arrangement between independent living and institutional care. Services may include meals, housekeeping, health, personal hygiene and transportation, or simply apartments with access to special services for disabled persons. "Assisted residential living" is one of the levels of care often found in multilevel long-term care facilities which offer differing levels of care.

Independent Living Programs are nonprofit community based programs providing a comprehensive range of services which enable physically disabled people to live in their own private residences and participate in a variety of independent life styles.

BACKGROUND

Purposes served by RCFs are temporary care and long-term nonmedical care. Target groups are persons with developmental disabilities, mental disorders, physical handicaps, the elderly, unwed mothers, children who are under juvenile
court jurisdiction, dependent children, persons being rehabilitated from alcohol and drug addictions; and persons on parole. According to State licensing statistics for March 1976, one-third of all residential facility clients in State licensed facilities were over 65.

While RCFs do not provide medical services for their clients, they do offer social and support services which both assist in the healing process and allow the appropriate level of care for those who no longer use the more sophisticated services of a medical facility, yet who cannot live independently.

The variety of groups served by RCFs is also reflected in the number of funding sources for residential care: Supplemental Security Income/State Supplemental Program; funds earmarked for persons with mental disorders and developmental disabilities; Regional Centers, county governments, Veterans Administration, and private sources. Many State and local agencies become involved in placement of clients into RCFs: probation departments, welfare departments, State Department of Social Services, Regional Centers, mental health departments, Veterans Administration, and private individuals and agencies.

Relationship to Health Status

No data available.

California Trends

Little is known about the growth of residential care in California. Approximately 6,400 facilities with 100,000 beds are currently licensed by the State; there is limited information available for those facilities licensed by 48 counties under contract with the State Department of Social Services. SSI/SSP paid for residential care for about 18,000 recipients in 1976-77. Recent statistics indicate that there are approximately 21,000 RCFs serving adults and children.

Residential care is largely an unmanaged system in which there has been a severe lack of communication and coordination. The State Department of Social Services, authorized by State legislation to perform licensing, issues licenses without consulting local governments, program personnel, and State placement agencies. It is possible for a licensee who operates a substandard facility to be forced by the local community to close the facility, and while awaiting the lengthy residential care license revocation process, to move to another county and open another facility. The State Department of Social Services is taking action to resolve this problem through legislative proposals which would give the department the authority to deny an application based on previous or current administrative actions taken against the applicant.
California Policy

In general, the focus of most State legislation has been the treatment of persons with developmental disabilities, mental disorders and physical handicaps.

As an impetus for the development and regulation of community care facilities (including residential care facilities), the State legislature has passed bills establishing licensure and overriding restrictive local zoning ordinances. The Community Care Facilities Act of 1973 provides for licensure of RCFs, special permits for facilities offering specialized services, training for licensure personnel and facilities staffs, needs assessment plan for all clients and a rate system for State purchased services. In its 1978 session, the Legislature acted to override restrictive local zoning ordinances for those residential facilities serving six or fewer clients, to prevent over concentration of RCFs, to implement community living continuums throughout the State for developmentally disabled persons and to provide separate licensure standards for facilities serving the elderly.

Health System Plan Highlights

The 1978 HSPs make few references to RCFs, except in the context of encouraging the development of continuums of community care and the need for deinstitutionalization of persons who no longer need sophisticated hospital and nursing home services. There are also recommendations that persons being rehabilitated from substance abuse be referred to residential care rather than be treated only for medical complications.

ANALYSIS OF DEMAND AND SUPPLY

Analysis of Demand

The level of demand is impossible to estimate at this time, given the lack of data about residential care.

Analysis of Supply

A complete inventory of residential facilities in California is not available; such an inventory is necessary for understanding and analyzing supply. However, some data on assisted living arrangements in California is available. In 1978, 2,000 subsidies for housing assistance were made available to eligible persons with disabilities by the federal Department of Housing and Urban Development at a cost of $20 million.
ANALYSIS OF ISSUES

Issue #1: Uncoordinated and Inadequate State Oversight

The Community Care Facilities Act of 1973 is the legislation which authorizes the licensing of RCFs, its provisions pertain primarily to persons with developmental disabilities, mental disorders and physical handicaps. The State Department of Social Services is in the process of developing licensing regulations which specifically address the needs of Department of Developmental Services (DDS) clients. The critical factor is separating and clarifying placement agency responsibilities (in this case DDS) from licensing agency responsibilities. The Department of Social Services anticipates developing similar regulations to serve clients from other placement agencies (e.g., Department of Mental Health). Regulations for RCFs serving the elderly are also in the process of being developed.

RCFs are now licensed by both county welfare departments and the State Department of Social Services. In some counties, neither is aware of facilities licensed by the other. The Community Care Licensing Division (CCLD), Department of Social Services, does not currently coordinate and communicate with local welfare departments, local governments, or local placement agencies before issuing licenses. Although Section 1520.5 of the Health and Safety Code requires licensing agencies to notify city or county planning authorities of new applications for facilities in their respective areas, the Department of Social Services authority to impact local governments on such issues as zoning and use permits is limited. Also, State licensing personnel and those in counties with State contracts for licensing RCFs have not coordinated their efforts and have not been uniformly trained to administer State licensing regulations. The Department of Social Services is correcting this situation with an Operations Evaluation Section which is responsible for monitoring and standardizing county licensing procedures. The Department has also provided training to State and county licensing staff in 1978-80 and plans similar training efforts in the future.

Licensing has thus far served primarily as a gateway into the system; there has been inadequate followup and few license revocations. Facing a license revocation process which lasts from six months to two years, the Community Care Licensing Division has moved to shorten this time by establishing a Client Protection Services Branch to coordinate and facilitate legal actions.

Little is known about the quality of care in RCFs; no one group is responsible for developing quality standards, monitoring quality, and assuring follow-up care. There is no assigned responsibility for monitoring quality of care received by clients in RCFs and there is no legislative requirement that licensing and placement be coordinated. The roles and responsibilities of placement and licensing agencies are not clearly defined, resulting
in confusion among licensers, licensees, local governments, community residents and facilities residents. In order to clarify this issue, the Community Care Licensing Division has taken the initiative to define its role and responsibility as separate from those of placement agencies. As part of this effort, the CCLD is addressing the issue of "quality of care" as it applies to licensing community care facilities.

While the Community Care Facilities Act would seem to give the Department of Social Services the responsibility for overseeing the residential care program, the authority is not totally clear. Program agencies generally prefer that the licensing agency not also become involved in monitoring programs, even though their not doing so leaves a void in the system.

While responsibility has not been assigned for overall monitoring of quality of care, some program agencies and advocacy groups do so for either the specialized groups which they serve or for their member facilities. This situation does not assure that all facilities and clients are served.

Issue #2: Lack of Data for Planning or Monitoring

The general lack of ongoing and timely information regarding residential care on a statewide basis continues to hamper effective planning and resource development.

Data regarding numbers, types, locations and utilizations of RCFs are not available for all RCFs. The State Department of Social Services does collect data about the number of licensed beds, number of violations, and number and location of facilities licensed directly by the State; however, similar information about all county licensed facilities is not available, although the Department of Social Services is making an effort to secure statewide participation.

It is known that availability of RCFs varies throughout California. Some communities seem to have an excess of facilities, while others have none. The 1975 Santa Clara County Pilot Study, for example, documented that between 26 and 40 percent of the mentally disordered and developmentally disabled residents of RCFs had resided in a county other than Santa Clara prior to entering residential care, for reasons of both nonavailability of facilities in other counties and communities and restrictive local zoning ordinances and practices. Though out-of-county placement is an indicator of inadequate supply and uneven distribution, the extent of this problem is not known.

Issue #3: Cost

There is no relationship between the rate of payment to a RCF and the quality of care and services provided. Reimbursement rates vary from approximately $300 to over $1,000 per month. Sometimes two different agencies reimburse different amounts for the same
service within the same facility. The differentiation is probably related to the number and the sophistication of services required; however, the assumption is not documented.

There is no uniform method for determining reimbursement for basic and supplemental services. In the area of developmental services, Regional Centers have determined basic rates and fee schedules for supplemental services. The recently passed Senate Concurrent Resolution 22 requests that a study be done of the rate setting procedures for community care facilities established by various State and local public agencies and that subsequent recommendations are made to provide greater equity and parity in the rate setting process.

**Issue #4: Increasing the Availability of Assisted Living Arrangement Programs**

As previously stated, the overall supply of assisted living arrangements in California is not well documented. However, such housing is often a necessary complement to day care services for the elderly and persons with disabilities. Such housing also facilitates integration of these groups into mainstream community life. It is clear that the State Department of Housing and Community Development should continue its emphasis on expanding alternative housing opportunities for these groups. However, continued federal assistance is an absolute requirement.

**Issue #5: Independent Living Programs**

One of the most innovative methods of service delivery for long-term care service is through Independent Living Programs (ILPs). Such programs (e.g., Center for Independent Living, Berkeley and Community Service Center for the Disabled, Inc., San Diego) are designed to assist those nonmentally impaired persons with severe physical disabilities achieve a lifestyle which fosters greater mobility, opportunities and independence.

Successful independent living programs have shared a number of common developmental characteristics: effective interaction with a college community; maintenance of a private, nonprofit status; client control, specifically the persons who are, themselves, severely disabled; the use of effective coalitions of various disability groups and a nonresidential approach. This latter characteristic merits specific attention as it is perhaps the dominant feature which distinguishes such programs from more traditional methods of service delivery.

"California's severely disabled members of independent living organizations do not depend on being provided special group living facilities, even though this might be one alternative to offer when good accessible housing is scarce. They have entitlement through various public aid programs to the means they need to arrange their own living situations. They need only the help of basic services such as consumer advocacy, housing survey and
referral service and help with attendants to exercise this entitlement. Some advantages which ILPs cite as accruing from the nonresidential approach are that: (1) conflicting interests of being both tenant advocates and landlords are avoided; (2) burdens and chores of property management do not tie up program energies which might go toward ILP services and advocacy; (3) ILPs, which already provide a great deal of the social, political and worklife for many members, remain less of a total environment for them than if they lacked their own separate residences.\(^{30}\)

Independent living programs, besides serving as one potential source for needed support services (counseling, advocacy, specialized assistance, etc.), act as a clearinghouse for information regarding other agencies, both public and private, which provide similar or other types of services. ILPs also provide peer group support, a vital element in enabling disabled individuals to acquire the initial motivation and then the ability to sustain functional independence. In ILPs, individual differences in one's capacity for self-sufficiency can be realistically taken into account when attempting to appropriately balance the needs for dependence as well as independence.
POLICY RECOMMENDATIONS FOR ALTERNATIVE LIVING ARRANGEMENTS

**Long-Term-29:** AVAILABILITY OF, AND PLACEMENT OF DEPENDENT PERSONS IN RCFS SHOULD BE A LOWER PRIORITY FOR THE STATE THAN INCREASING AND IMPROVING NONINSITUTIONAL LONG-TERM CARE RESOURCES.

A RCF, no matter how small, is an "institutional" setting. While necessary for some persons, and often unavailable for them, this type of care is nevertheless less desirable for the target groups than community support systems that encourage and underwrite independence. It is recognized, however, that an RCF as an institutional setting, is preferable to a State facility.

**Long-Term-30:** PLANNING FOR RESIDENTIAL CARE FACILITIES SHOULD INCLUDE OSHPD PLAYING A COORDINATING ROLE IN DATA COLLECTION, ISSUE ANALYSIS AND POLICY SETTING REQUIREMENTS.

Residential care homes serve the same population groups — those with disabilities and handicaps and the elderly — as long-term care services now within the health system. Current State oversight is inadequate for planning purposes, or for linking RCFs to other long-term care resources. There needs to be increased coordination of health planning policy among the various State agencies who have mandated responsibilities related to residential care facilities.

**Long-Term-31:** CALIFORNIA HEALTH SYSTEM ENTITIES, INCLUDING HSAS, STATE AGENCIES AND CONSUMER AND PROVIDER GROUPS, SHOULD COLLECTIVELY URGE THE FEDERAL DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT (HUD) TO STRENGTHEN ITS PROGRAM OF ALTERNATIVE HOUSING FOR THE ELDERLY AND DISABLED.

It should be a matter of policy that HUD be urged by a single voice in California to channel its limited resources in this manner. Assuming that HUD itself has many and conflicting priorities, the health implications of its many alternative living arrangements should be clearly understood.
Long-Term-32: THE DEPARTMENT OF HOUSING AND COMMUNITY DEVELOPMENT SHOULD CONTINUE ITS EMPHASIS ON EXPANDING ALTERNATIVE HOUSING OPPORTUNITIES FOR ELDERLY AND DISABLED PERSONS.

Acceptable housing is the first step toward preventing inappropriate institutional care.

Long-Term-33: THE STATE AND FEDERAL GOVERNMENT SHOULD BE ENCOURAGED TO INCREASE THE FUNDS AVAILABLE FOR INDEPENDENT LIVING PROGRAMS.

It is clearly evident that programs such as these which allow people to live in their own private residences contribute greatly to the well-being and overall health of persons with special disability needs. Thus, programs which provide an integrated approach to meeting the specialized needs of individuals warrants the continued and expanding support of government, as well as private citizens and foundations.
DEFINITIONS AND SCOPE OF SERVICES

One of the major target groups for long-term care services has been severely developmentally and multiply disabled children and adults. The population considered developmentally disabled (DD) exhibits a broad spectrum of disabilities, and governmental agencies which provide services to the developmentally disabled have continually broadened the definitions of those to be included. From pertaining exclusively to the mentally retarded, the present definition recognized in California law is:

"a disability which originates before an individual attains 18, continues, or can be expected to continue, indefinitely and constitutes a substantial handicap for such individual ... This term shall include mental retardation, cerebral palsy, epilepsy and autism. It shall also include handicapping conditions that are solely physical in nature."51

Recent federal legislation (P.L. 95-602, 1978) has also changed the definition of "developmental disability" so that it is oriented toward a person's functional limitations or capacities rather than toward inclusion in a diagnostic category. It also extends the age limit to 22 for the required manifestation of the disability. The federal definition is as follows:

"The term developmental disability means a severe chronic disability of a person which:

A. is attributable to a mental or physical impairment or combination of mental and physical impairments;

B. is manifested before such person attains age twenty-two;

C. is likely to continue indefinitely;

D. results in substantial functional limitations in three or more of the following areas of major life activity: i. self-care; ii. receptive and expressive language; iii. learning; iv. mobility; v. self-direction; vi. capacity for independent living; vii. economic self-sufficiency; and

E. reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated."
Studies are to be instituted by the federal government to analyze the impact of this changed definition on the numbers of developmentally disabled and the services required.

The services required for the developmentally disabled under the category of "long-term care" are found in all the settings described earlier in this chapter, from State hospitals, skilled and intermediate levels of nursing home care, residential care programs, community based and home programs. Services include medical and nursing care, habilitation and rehabilitation services, maintenance care, and case management services. Additional services utilized include education, vocational rehabilitation, day activity and sheltered workshops.

Finally, it should be remembered when making decisions regarding persons with developmental disabilities, of foremost importance is the "Bill of Rights for Persons with Developmental Disabilities;"

The right to prevention, early diagnosis and proper care. The right to a barrier-free environment and accessible transportation. The right to an appropriate public education. The right to necessary assistance, given in a way that promotes independence. The right to income for a lifestyle comparable to the able-bodied. The right to a choice of lifestyles and residential alternatives. The right to training and employment as qualified. The right to petition social institutions for just and humane treatment. The right to self-esteem.

BACKGROUND

During the past decade, it has been increasingly recognized that disabled individuals should have access to a variety of services in order to secure the most effective and acceptable means of reducing functional limitations related to developmental disabilities. In the past, the main service network for those who were substantially handicapped among the developmentally disabled was the network of large residential facilities or State hospitals. Today, mechanisms are being developed for assessing the individual's needs and selecting the particular array of resources most suited to him/her. Federal and State policies are aimed at deinstitutionalization and provision of services in the community. The principle of normalization has become the predominant aim in planning for services in this field. This means reliance on general human service systems serving all people, rather than the creation of specialized ones. Among the mechanisms being developed to assess individual needs are the following:
AB 3274 (Chapter 12 of Division 4.5 of the Welfare and Institutions Code), signed into law by Governor Brown in September 1978, permits the Director of the Department of Developmental Services (DDS) to appoint one or more Living Arrangement Agencies (LAAs) to design, organize, and provide comprehensive networks of residential services on a regional basis. The legislation thus lays the basis for ensuring the provision of community services even if an LAA must create the services needed by a consumer. It also provides a statutory basis for ensuring the provision of community based residential services. One million dollars was appropriated in the 1979 legislative session to permit the initial implementation of this bill. A report prepared for the State Council on Developmental Disabilities recommends utilizing the impetus of AB 3274 for adjusting the existing California service system to assure greater availability of quality and integrative living arrangements, including the personal homes of individuals.

Deinstitutionalization/Normalization: In keeping with current clinical and legal concepts of optimal residential treatment environments, it is the policy of the State to reduce reliance on large public and private institutional residential care facilities. The first steps required to implement this are assessment of the need for community residential care beds and development of small community residential programs (e.g., small ICF/DD and CCF) as placement alternatives to deflect potential State hospital admissions and provide appropriate placement resource for current State hospital residents. The Department of Developmental Services is currently involved in both of these tasks. Part of this effort has culminated in recent legislative proposals to provide a separate type of health facility designated as a "small intermediate care facility/developmentally disabled habilitative." The nature of developmental disabilities and our present ability to overcome them, implies that many persons with developmental needs will require some form of lifelong health and/or supervisory care. It is the policy of the State to provide this care in the least restrictive, most normal environment possible consistent with the care needs of the individual. The principle of normalization has become the predominant aim in planning for services in this field. The principle requires reliance on community based, general human service systems serving all people, rather than relegation of the DD to centralized self-contained, relatively isolated residential environments.

Relationship to Health Status

Development disabilities are from a variety of causes, many of which are preventable. These include:
• in utero abnormalities associated with drug, alcohol, and other substance abuse by pregnant women, and with nutritional deficiencies experienced by the pregnant woman; rubella and other diseases that damage the fetus
• various "high-risk" problems encountered during birth
• suboptimal intrapartum obstetrical care; and childhood accidents and poisoning (e.g., lead poisoning).

Other causes include genetic abnormalities (many of which can now be detected through amniocentesis, with a resulting choice concerning abortion) and the as yet unknown (in the United States) consequences of exposure to radiation hazards from a variety of sources. It is estimated that birth handicaps affect about one out of every 12 families in the State, and that half of these are avoidable. Prevention of these defects would eliminate unmeasureable hardships for handicapped persons and would significantly decrease the population in need of long-term care services. (See issue section of "Reproductive Services" in Chapter VII.)

Once a developmental disability exists, some form of lifelong health and/or supervisory care is usually needed, such care often meaning sheer survival for the affected person. To that extent, services for persons with developmental service needs are "effective."

Besides reinforcing and supporting the civil rights of persons with developmental service needs, the policy of deinstitutionalization is one which has been shown to be a great benefit.

A particular and critical problem relative to health status is that of the availability of corrective medical or dental services. Often it is difficult to secure the most basic and primary kinds of health services for persons with developmental disabilities. The lack of physicians or dentists who have the appropriate skills and training relative to developmental disabilities is at the center of this problem.

**National and California Trends and Policies**

A network of comprehensive, lifelong, supportive services is being developed for persons with developmental service needs under several major pieces of legislation at the federal and State level. The Developmental Disabilities Assistance and Bill of Rights Act (P.L. 94-103) provides funds and resources for the State to provide a broad comprehensive service network. The Act provides authorization of funding for planning, provision of direct services, training, development of new services, and assurance that the rights of developmentally disabled persons are protected and that services are provided for maximum personal development. The November 1978 amendments to this law, changed the definition of developmental disability as noted above and placed emphasis on four
Developmental Services

Priority services: case management, child development, alternative community living arrangements and nonvocational social development services.

At the State level the Lanterman Developmental Disabilities Services Act provides for the State machinery to carry out the services required for this target group. Subsequent legislation, AB 3274 (1978) and SB 354 (1979), has required additional activities by the Department of Developmental Services in addressing the need for and expansion of community services. The State Council on Developmental Disabilities is responsible for overall State planning and is the specified agency through which federal funds are distributed within the State. Thirteen Area Boards on Developmental Disabilities coordinate programs, encourage the development of needed services, monitor all publicly funded agencies providing services and provide the State Council with information, priorities, goals and objectives for inclusion in the State Plan for Developmental Disabilities Services. These Boards are not currently contiguous with the California HSAs.

In addition to legislation, the federal government (DHEW) has issued "Guidelines and Instructions for Developing and Preparing the Comprehensive State Plan for the Developmental Disabilities Program as amended by Public Law 94-103." The regulations cover services, persons to be served, standards, the general manner in which a State shall determine priorities, and general standards of construction and equipment. Other federal regulations pertain to intermediate care and skilled nursing care services. A new classification of beds, intermediate care facility/developmentally disabled (ICF/DD), has been defined and State regulations for this classification have been developed. These beds are covered by CON requirements. Additional regulations specifically designed to meet the program and living environment concepts of the small (15 beds or less) ICF/DD will be developed as necessary.

Other regulations that pertain to the Regional Centers and Area Boards are in Division 25 of the Health and Safety Code of California. Regulations and procedures concerning admissions, readmissions, and releases from State Hospitals are found in the Health and Safety Code and the Welfare and Institutions Code of California.

As noted above, Workshops and Work Activity Centers are accredited by the Department of Rehabilitation Facilities.

Standards for services for developmentally disabled persons have been developed by the Accreditation Council for services for mentally retarded and other developmentally disabled persons.

ANALYSIS OF DEMAND AND SUPPLY

Analysis of Demand

California's Plan for Developmental Disabilities Services for Fiscal Year 1980, using the federal definition, estimated that there are nearly 360,000 persons with developmental
service needs within the State. This estimate was disaggregated into age groups for those persons residing in both institutional and noninstitutional settings as shown in Figure VIII-7.

The fact that the total of these estimates are greater than 327,915 indicates that persons often have more than one functional limitation or disability.

All developmentally disabled persons need medical, dental and other special treatment services. Services such as education, health promotion and prevention are also required. Transportation services are also needed for many in this population group, to be able to utilize community services. In short, persons, regardless of their level of impairment, need access to services in a manner consistent with the principles of normalization.

Analysis of Supply

A vast complex of public and private agencies form a developmental services network within California. State agencies include the Department of Developmental Services, Education, Vocational Rehabilitation, and Social Services. A description of the components of this service network follows.

Regional Centers: Twenty-one developmental disability Regional Centers are located throughout the State, with locations based on population density. These Centers provide the primary contact point between the community and State services and agencies, and the persons with developmental service needs. The Department of Developmental Services contracts with nonprofit community agencies for the operation of the centers. The size of Regional Centers varies and the resources available in the areas they serve vary. Some Centers are in regions where extensive generic service systems exist to serve developmentally disabled persons. Comparisons between, or evaluations of, these Centers is, therefore, difficult.

These Centers provide some services directly, including:

- information and referral
- medical/psychological diagnosis
- counseling
- placement/case management
- hospital discharge placement
- court ordered evaluation
- guardianship
FIGURE VIII-7

ESTIMATED NUMBER OF DEVELOPMENTALLY DISABLED PERSONS IN CALIFORNIA

<table>
<thead>
<tr>
<th>SETTING</th>
<th>AGE GROUPS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
</tr>
<tr>
<td>Statewide Total</td>
<td>359,854</td>
</tr>
<tr>
<td>Institutional</td>
<td>31,939</td>
</tr>
<tr>
<td>Non-Institutional</td>
<td>327,915</td>
</tr>
</tbody>
</table>

(Totals may not balance due to rounding and methods of estimation.)

Of those residing within a non-institutionalized setting, the Plan also estimated the number of persons having a functional disability in one of the seven areas of major life activity which is specified by the federal definition:

FUNCTIONAL DISABILITY (AGE GROUP)  POPULATION ESTIMATE

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Self Care (18 - 64)</td>
<td>50,805</td>
</tr>
<tr>
<td>Receptive &amp; Expressive Language (3 - 64)</td>
<td>178,721</td>
</tr>
<tr>
<td>Learning (3 - 64)</td>
<td>293,896</td>
</tr>
<tr>
<td>Mobility (18 - 64)</td>
<td>45,160</td>
</tr>
<tr>
<td>Self-Direction (3 - 64)</td>
<td>99,289</td>
</tr>
<tr>
<td>Capacity for Independent Living (18 - 64)</td>
<td>251,203</td>
</tr>
<tr>
<td>Economic Sufficiency (18 - 64)</td>
<td>208,865</td>
</tr>
</tbody>
</table>
Developmental Services

- consultation to agencies and private facilities
- community education.

The Centers also purchase services on a contractual basis from qualified community persons and programs if they are not available to their clients through generic services in the community. These services include:

- foster home care
- private institutional care and treatment
- respite care
- preschool training programs
- workshop and activity programs
- medical/dental
- psychological therapy
- psychiatric evaluation
- physical and occupational therapy
- speech therapy
- home health
- homemaker
- recreational
- transportation.

The Regional Centers evaluate all clients, but carry in their permanent caseloads only those who are identified as substantially handicapped. An increasing number of developmentally disabled persons are being served by Regional Centers. From a total of over 42,000 who received services in Fiscal Year 1976/77, the total is expected to reach over 73,000 in 1980/81. 58

The funding of Regional Centers, which purchase services for the developmentally disabled clients, has an enormous impact on the extent of community services available. Total expenditures for FY 1978/79 were over $122 million. The proposed budget for FY 1980/81 is nearly $161 million for an increased client load. Regional Centers provided services to 64,625 developmentally disabled persons in FY 1978/79 at an average per capita cost of $1,915.59
Basic Living and Care Services: Basic living and care arrangements include a variety of residential care settings in the community.

Nursing Care Facilities: Facilities with special programs for the developmentally disabled were set in motion when the federal government passed legislation establishing Medicaid supported ICFs for the mentally retarded. These focused not only on meeting medical and social need in a normalized living situation but on active treatment directed toward upgrading the resident's functional level. There are an inadequate number of these facilities to meet the needs for these patients. Special rates were provided to nursing homes to encourage the development of these special services for the developmentally disabled but the restrictions on the numbers that must be served within a facility and the additional amount paid have not provided sufficient incentives to develop the level of services required. In 1977-78, Medi-Cal provided funding for care to 2,600 persons with developmental disabilities in SNFs and to 200 in ICFs. The 28 facilities licensed as SNF and ICF range in size from 30 to 172 beds; the average size is 99 beds.

Quality issues in these facilities, while similar to those found in all nursing care facilities, are complicated by the need for special training.

Small Residential Model ICF/DD: As is indicated above, the development of ICF/DD facilities in California has tended to follow the model of large institutional private nursing homes. An alternative ICF/DD model is available. The small residential model ICF/DD is characteristically different in the following ways:

- size capacity of 15 or fewer residents (and now possibly less than 6)
- physical environment/appearance similar to normal residential single family dwellings located in residential neighborhoods
- program — in compliance with federal ICF/MR requirements, the program must emphasize habilitative services designed to maximize developmental skills, independent functioning and capacity for self-care rather than the more traditional nursing services of an ICF.

The development and implementation of a small ICF/DD program is a key service component for those individuals who require continued health related residential care and have the legally defined right to receive such care in the least restrictive most normal environment possible.

Changes in existing State regulations to ICF/DD (e.g., licensing, construction, Medi-Cal, certificate of need, etc.) must be made to make this concept feasible and insure conformity to program intent.

Residential Care: Approximately 16,000 persons with developmental disabilities reside in residential care facilities. The quantity and quality of residential care facilities is reported as deficient in most Area Board Plans. The availability of an adequate number of residential care facilities has centered on the need for an adequate rate of
reimbursement, as well as staff competence, for these services. Client/need related rates have been instituted. However, the adequacy of the rates is still debated and the effect on the supply is unknown because of the lack of information on the number and utilization of residential care facilities. The Department of Developmental Services in cooperation with Regional Centers is assessing community care resources and will lead in the development of sufficient community care resources to meet the developmental disability population need.

Issues regarding accessibility have begun to be dealt with in State legislation regarding changes in local zoning laws to encourage more reasonable distribution within communities.

Independent Living Settings and Group Residences: Such settings and residences which provide a minimal level of personal care and supervision are not uniformly available throughout California. The Department of Developmental Services and some Regional Centers are developing and implementing these programs as a key part of overall efforts to provide appropriate services in the least restrictive environment possible.

Workshops, Day Program and Sheltered Employment: The supply of these programs was discussed above. They are generally considered insufficient, and/or inappropriate, to meet the demand. An increased supply of workshop and activity center slots should soon be available based on the new program instituted through the State Department of Rehabilitation to provide sheltered workshops and activity programs for developmentally disabled persons. However, the $2.5 million allocated will not meet the need for all who require these services (approximately 800 to 1,000 clients can be served under this program). Significant reduction in State hospital population will create a corresponding increase in demand for those services in the community.

Personal Care Support Services: In-home supportive services, such as homemakers and attendants, were discussed above.

Respite Services: A special problem for the person cared for in his or her own home or in a small family care home is the need for respite services to allow the family/caretaker relief for short periods of time. Attaining these services is a high priority area for most sections of the State, since there are not sufficient personnel, facilities and services available. A stable source of funding to support these services is not available. Regional Centers will purchase respite care when necessary in board and care homes.

State Hospitals: There are nine State hospital programs which provide State managed care, treatment and life maintenance services at the request of the Regional Centers. The State hospital population decreased from 13,000 in 1963-64 to about 9,000 in 1969 and moved upward to 10,200 in 1975. Since June 1977, the reported in-hospital population count made at the end of each fiscal year has been steadily decreasing from 9,585 to an estimated 8,552 for June 1980.
During the last few years, the composition of the State hospital inpatient population has shifted. Whereas in 1960, 65 percent were labeled as profoundly and severely disabled, in 1975 these groups constituted 80 percent of the population. This trend is a consequence of successful efforts by the Regional Centers and the State to place hospital residents and deflect new admissions into community placement. It also reflects the current lack of communities capable of absorbing and providing adequate care for the most severely disabled and/or those individuals with severe behavior problems.

The Department of Developmental Services is currently reassessing State hospital admissions policies and assessing the number and types of community placement alternatives necessary to further reduce hospital utilization. The legislature (AB 354, 1979) has required the department to address both of the aforementioned issues in required planning to reduce hospital utilization to 5,500 beds by alternative target dates of July 1982 and July 1985.

Complicating the State hospital situation is the requirement to bring the State hospitals into conformity with the State and federal requirements on staffing and fire and safety codes. The State has allocated $95 million to bring these institutions into compliance with fire and safety codes. It is estimated that, with the remodeling, there will be places for 8,000 residents in the State hospital system in 1982. There is no definite plan at present concerning whether all hospitals will remain open.

The operating cost of State hospitals for the current fiscal year (FY 1979) is $231,615,360 or an average of $25,703 per client. The proposed budget (FY 1980) is $233,445,487 or $27,050 per client annually.

Case Management and Coordination: In addition to the case management functions carried out under the Regional Centers, the Continuing Care Services Section of the State Department of Developmental Services provided case management and protective social services to 10,969 developmentally disabled persons in FY 1979/80. Expenditures estimates for the current and proposed budget years are:

<table>
<thead>
<tr>
<th>Year</th>
<th>Budget</th>
</tr>
</thead>
<tbody>
<tr>
<td>FY 1979/80</td>
<td>$10,421,040 (estimated)</td>
</tr>
<tr>
<td>FY 1980/81</td>
<td>$11,343,595 (proposed)</td>
</tr>
</tbody>
</table>

Education/Habilitation Services: Yet another subset of services consists of habilitation services for children provided in conjunction with other health services (hospitals) and community children/education services. The State Department of Education and the various county and local school boards are now required under P.L. 94-142 to provide education to all developmentally disabled within the regular school system (from ages 3 to 21). Development Centers for the Handicapped, mandatory under federal law (P.L. 94-142), provide therapy services to handicapped children in the schools through a joint effort of the California Children's Services Program, the State Department of Education,
and the county school systems. The program seeks to provide physical, occupational, speech, and other therapy in conjunction with the more traditional aspects of public education in the public school setting. These services are available without charge and without regard to family financial status. While enrollment in the Development Centers has grown from 32 in 1962 to over 4,820 in 1977, limitation of local property taxes may inhibit their growth.

**ANALYSIS OF ISSUES**

While all the major issues have relevance to developmental services, the poignancy of individual problems among the target population makes these issues seem particularly pressing. Proposition 13 costs are already forcing service cutbacks that appear to make deinstitutionalization with its corresponding need to increase community resources more difficult and reinstitutionalization more attractive to financially pressed local agencies. All the more important, therefore, is the need to spend money on prevention to minimize future incidence of developmental disability.

The major issues discussed below are: prevention; the future of the State hospitals; quality; and coordination of planning.

**Issue #1: Prevention**

The occurrence of developmental disabilities is related to birth defects caused by childhood accidents, drug, alcohol, and toxic substances, genetic disorders, high risk conditions in women and infants, lead poisoning, metabolic disorders, nutritional deficiencies and rubella and other infectious diseases. Prevention of these defects would eliminate unmeasurable hardships for handicapped persons and would significantly lower the amount of long-term care services required by persons with developmental disabilities.

State policy alternatives are to continue to provide the current and increasing level of remedial programs and supportive services to persons with developmental disabilities with low amounts earmarked for preventing birth defects and handicaps, or it can increase prevention activities. Though this may require short run increases in funding, it would decrease costs for long-term care in the long run. (For additional discussion see Chapters V and VI.)

**Issue #2: Deinstitutionalization/Community Resource Development**

The goal of reduced reliance on State hospital utilization concept requires a commitment to develop adequate alternative community resources for persons in need of developmental services. The acceptance of the goal of deinstitutionalization occurred in
an environment of continuous public impact into policies related to State hospitals through legislative processes, statewide advisory boards and relatives of hospital residents, etc. Implementing such policies to affect the fiscal resources needed for community based services is now the focus of such involvement.

Issue #3: Quality

There is widespread agreement that beside the overall lack of alternatives, quality of care in out-of-home facilities providing services to developmentally disabled persons is hampered by the lack of personnel with training and understanding of the problems of serving this group.

Methods of approaching this problem include:

- establishment of qualifications and certification for family care operators and personnel in community care facilities
- funding adequate to pay competitive salaries to trained staff
- requiring licensed and certified personnel to take a specified portion of their continuing education requirement in courses directly related to the area in which they are working (developmental disabilities; aging)
- recent efforts have focused on programs designed to evaluate the quality of services to individuals with development service needs, e.g., "A Normalization and Development Instrument."

Issue #4: Coordination of Planning

Current planning responsibilities relating to developmental services involve the State Developmental Disabilities Council, Department of Developmental Disabilities, the OSHPD, the Area Boards, and the HSAs. The HSAs and the OSHPD are responsible for planning for nursing care facilities and other alternative long-term care facilities. The Area Boards and the State Developmental Disabilities Council are also concerned about residential facilities such as SNFs, ICFs, and RCFs available to developmentally disabled clients, as well as the broad range of community programs which provide habilitation and rehabilitation services and maintenance care. Recommendations of these groups should not conflict or be unnecessarily duplicative.
POLICY RECOMMENDATIONS FOR DEVELOPMENTAL SERVICES

Long-Term-34: THAT THE CORNERSTONE OF STATE POLICY CONCERNING CARE OF DEVELOPMENTALLY DISABLED PERSONS BE THE PREVENTION OF DISABILITY ATTRIBUTABLE TO PREVENTABLE BIRTH DEFECTS.

Active public and interdepartmental support for development of new and innovative approaches for providing developmental services is necessary.

Long-Term-35: THE LEGISLATIVE PROGRAM PROPOSED TO IMPLEMENT THIS POLICY SHOULD BE ACTIVELY SUPPORTED BY THE OSHPD AND THE HSAs.

Consistent with Chapter III and Chapter VI.

Long-Term-36: THE DEPARTMENT OF DEVELOPMENTAL SERVICES, IN CLOSE COOPERATION WITH THE DEPARTMENT OF HEALTH SERVICES, DEPARTMENT OF SOCIAL SERVICES AND OSHPD SHOULD TAKE ACTIVE MEASURES TO DEVELOP APPROPRIATE RESIDENTIAL AND NONRESIDENTIAL COMMUNITY RESOURCES. THESE MEASURES INCLUDE MAKING APPROPRIATE CHANGES IN THE REGULATORY ENVIRONMENTS IN WHICH COMMUNITY RESOURCES OPERATE TO ENCOURAGE THEIR DEVELOPMENT, WHILE CONTINUING TO ASSURE ADEQUATE PROTECTION OF THE RECIPIENTS OF SERVICES.

Active public and interdepartmental support for the development of new and innovative approaches (e.g., small ICF/DD) for providing developmental services is necessary to insure successful implementation.

Long-Term-37: AN INTERAGENCY BODY TO DEVELOP TRAINING SPECIFICATIONS AND CERTIFICATION CRITERIA FOR INDIVIDUALS WORKING WITH DEVELOPMENTALLY DISABLED PERSONS SHOULD BE INITIATED BY THE HEALTH AND WELFARE AGENCY.

The efforts to focus coordination on this specific issue will involve not only several departments within the Health and Welfare Agency but also departments in other agencies.
Long-Term-38: THE DEPARTMENT OF CONSUMER AFFAIRS AND THE OSHPD IN CONJUNCTION WITH THE DEPARTMENTS OF DEVELOPMENTAL SERVICES, SOCIAL SERVICES AND HEALTH SERVICES SHOULD ESTABLISH APPROPRIATE QUALIFICATIONS AND CERTIFICATION FOR PERSONNEL IN HEALTH CARE FACILITIES AND COMMUNITY CARE FACILITIES CARING FOR PERSONS WITH DEVELOPMENTAL NEEDS AND THAT EXISTING LICENSING AND/OR CERTIFICATION STANDARDS OF THE REGISTERED NURSES, LVNS, AND OTHERS BE REVIEWED REGARDING THEIR RELEVANCE TO THE DEVELOPMENTAL SERVICE NEEDS.

Assuring the availability of appropriately trained personnel will not only improve the quality of services provided but also contribute to the social integration and personal independence for persons with special developmental needs.

Long-Term-39: THE OSHPD, SHCC, DEPARTMENT OF DEVELOPMENTAL DISABILITIES AND THE STATE DEVELOPMENTAL DISABILITIES COUNCIL SHOULD ESTABLISH COMPREHENSIVE GUIDELINES FOR MUTUAL WORKING RELATIONSHIPS, INCLUDING VOLUNTEER LINKAGES, PLAN DEVELOPMENT INPUT, ISSUE TASK FORCES AND DATA COLLECTION.

Coordinating responsibility for planning and implementation among not only State level agencies but also local HSAs, Area Boards and Regional Centers, in planning that is especially important in light of the size of the service system for persons with developmental service needs.
NOTES


3. C. Galloway, "Philosophical and Service Design Implications of the Department of Finance Report, 'A Review of Sheltered Workshops and Rehabilitation Programs (Phase II),'" prepared for the Director of the Department of Rehabilitation, April 25, 1979, pp. 1-2.


9. Chapter 10, Division 5, Title 22 of the California Administrative Code.


24. Section 72095, Chapter 3, Division 5, Title 22 of the California Administrative Code.

25. Section 73051, Chapter 4, Division 5, Title 22 of the California Administrative Code.


34. *Nursing Home Care in the U.S.: Failure in Public Policy*, Subcommittee on Long-Term Care of the Special Committee on Aging, U.S. Senate, 1975.


39. Ibid., pp. 94, 121-140.


43. Ibid.


46. Total Medi-Cal Costs for SNFs increased 31.5 percent from Fiscal Year 1976-77 to Fiscal Year 1977-78, of which one half (53 percent) was due to increased cost/recipient. Cost per recipient increased 15.5 percent over the same period. Center for Health Statistics, Medi-Cal: Monthly Management Report, State of California Health and Welfare Agency, Department of Health Services, September 1978, p. 22.

47. Advisory Health Council, op. cit.


49. Section 80005, Chapter 1, Division 6, Title 22 of the California Administrative Code.


51. Section 4512, Chapter 1, Division 4.5, California Welfare and Institutions Code.


538


59. Ibid., p. HW 69-70.


61. Ibid., pp. HW 69, 72.